

University of the Witwatersrand

Johannesburg



**Department of Occupational Therapy**

**SENSORY PROCESSING IN WOMEN DIAGNOSED WITH  
GENITO-PELVIC PAIN/PENETRATION DISORDER**

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

Johannesburg

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## DECLARATION

### Student's contribution to article(s) and agreement of co-author

I, Elsie Susanna Labuschagne, student number 1800496, declare that this dissertation, titled SENSORY PROCESSING IN WOMEN DIAGNOSED WITH GENITO-PELVIC PAIN/PENETRATION DISORDER, is my own work and that any assistance obtained has been only in the form of professional guidance and supervision. No part of this research report has previously been submitted to any other research institution of higher learning or university. Where someone else's work was used, due acknowledgment has been given and references have been made accordingly to the requirements of Faculty of Health Sciences at Wits University. I claim complete responsibility for the conclusions drawn in this research study.



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31 March 2020

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## ABSTRACT

**Introduction:** The role of sexual functioning is often ignored in occupational therapy and literature regarding sensory integration and processing and female sexual dysfunction is virtually non-existent. Current multi-disciplinary intervention approaches for female sexual dysfunction do not include occupational therapy and intervention may be rendered ineffective, or actually worsen the condition if the person has sensory processing dysfunction (SPD).

**Aim:** The study objectives were to describe the sensory processing patterns of women diagnosed with genito-pelvic pain/penetration disorder (GPPPD), to explore the level of anxiety when both GPPPD and SPD are present and to investigate participants' experience of participating in a sensory-based home program (SBHP).

**Methods:** A descriptive two-phased study design was used. Phase one consisted of a quantitative, cross sectional nonexperimental descriptive study, using the Adolescent/Adult Sensory History (ASH) and Hospital Anxiety and Depression Scales (HADS) to obtain data from purposive sampling. Phase two consisted of an exploratory qualitative study involving participants who were identified with SPD in Phase one. They participated in a SBHP and their experience thereof were established during semi-structured interviews.

**Results:** Phase one: Quantitative descriptive analyses indicated that the majority (79.5%; n=35) of participants presented with SPD requiring further investigation and/or intervention for SPD. Phase two: Two themes emerged from the qualitative data: "Changes experienced after participating in a SBHP"; and "Coping strategies employed by women with SPD & GPPPD".

The study identified SPD as an alternative factor in female sexual dysfunction, specifically GPPPD. Participants found a SBHP, catering to specific needs/personalities beneficial as a non-invasive, non-pharmacological intervention approach for women who suffer from both SPD and GPPPD. The study further emphasises the role of the occupational therapist in sexuality.

Ethical clearance was obtained from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand with clearance certificate number: M170829 (Appendix A).

## PLAGIARISM DECLARATION

### PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

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31 March 2020

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**Date**

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## AGREEMENT BY CO-AUTHOR



By signing this declaration, the co-authors listed below agree to the use of the article/s by the student as part of her dissertation.

### **Article 1: Title: Sensory processing patters of women diagnosed with genito-pelvic pain/penetration disorder: A research proposal.**

Labuschagne E, van Niekerk M. Sensory processing of women diagnosed with genito-pelvic pain/penetration disorder: a research proposal. *BMC Research Notes*. 2019;12(1):577. <https://doi.org/10.1186/s13104-019-4612-6>.



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## PUBLICATIONS & PRESENTATIONS

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  - o **Title:** Sensory processing dysfunction and genito-pelvic pain/penetration disorder: women share their experiences of participating in a sensory-based home program

## TABLE OF CONTENTS

Declaration.....	ii
Abstract.....	iii
Plagiarism Declaration .....	iv
Acknowledgements .....	v
Agreement by Co-author.....	vi
Publications & Presentations .....	viii
Table of Contents.....	ix
List of Figures .....	xii
List of Tables.....	xiii
List of Appendices.....	xiv
Definitions .....	xv
List of Abbreviations.....	xvii
<b>Chapter 1. Introduction .....</b>	<b>1</b>
Introduction .....	1
Outline of the Dissertation.....	3
<b>Chapter 2. Literature Review .....</b>	<b>4</b>
Introduction .....	4
Sensory Integration.....	5
Terminology Related to Sensory Processing Difficulties.....	5
Sensory Systems.....	9
Neurophysiological Aspects Related to Sensory Processing Dysfunction .....	11
Impact of Sensory Processing Dysfunction.....	12
Sensory Processing Dysfunction and Pain .....	13
Interventions Related to Sensory Processing Dysfunction .....	13
Sexual Dysfunction/Genito-Pelvic Pain/Penetration Disorder .....	15

History of Sexual Pain Disorders .....	15
Genito-Pelvic Pain/Penetration Disorder Interventions .....	16
Anxiety .....	17
Description of Anxiety .....	17
Theory and Brain Mechanisms .....	17
Anxiety and Sensory Processing Dysfunction.....	18
Interventions for Anxiety .....	18
Conclusion .....	19
<b>Chapter 3. Paper 1 .....</b>	<b>20</b>
Introduction to Paper 1 .....	20
Paper 1: Sensory Processing of Women Diagnosed with Genito-Pelvic Pain/Penetration Disorder: A Research Proposal.....	20
<b>Chapter 4. Paper 2.....</b>	<b>28</b>
Introduction to Paper 2.....	28
Paper 2: Sensory Processing Dysfunction in Women With Genito-Pelvic Pain/Penetration Disorder .....	29
<b>Chapter 5. Paper 3.....</b>	<b>74</b>
Introduction to Paper 3.....	74
Paper 3: Sensory Processing Dysfunction and Genito-Pelvic Pain/Penetration Disorder: Women share their Experiences of Participating in a Sensory-Based Home Program .....	76
<b>Chapter 6. Integrating Chapter .....</b>	<b>128</b>
Context of the Study.....	129
Methodology .....	129
Phase One.....	129
Phase Two.....	132
Ethical Considerations .....	134
Key Findings of the Study .....	136

Objective 1: Describe the Sensory Processing Patterns of Women Diagnosed with GPPPD .....	136
Objective 2: Describe the Presence of Anxiety when both SPD and GPPPD are present .....	137
Objective 3: Describe Participants' Experiences of Participating in a Sensory-Based Home Program .....	139
<b>Chapter 7. Conclusion .....</b>	<b>148</b>
Limitations.....	149
Implications of the Study .....	150
Future Research .....	151
<b>Reference List for Chapters 1, 2, 4, 6 &amp; 7 .....</b>	<b>152</b>
<b>Appendices .....</b>	<b>180</b>

## LIST OF FIGURES

### List of figures (excluding Papers 1, 2 & 3)

#### CHAPTER 2

---

Figure 2.1	Sensory Processing: behavioural responses and neurological thresholds.....	6
Figure 2.2	Sensory Processing Disorder: diagnostic groups and subtypes...	7
Figure 2.3	Aspects evaluated by ASH.....	8

#### CHAPTER 6

---

Figure 6.1	Possible link between interoception, SPD, GPPPD & Anxiety.....	138
------------	--	-----

### List of figures Chapters 3, 4 & 5 (published paper and manuscripts)<sup>1</sup>

#### CHAPTER 4

---

Figure 1	Aspects evaluated by ASH.....	39
Figure 2	Total scores on ASH.....	44
Figure 3	Anxiety scores on the HADS-A.....	48

---

<sup>1</sup> Figures in Papers 1, 2 & 3 numbered according to Journal guidelines.

## LIST OF TABLES

### List of tables (excluding Papers 1, 2 & 3)

---

Table 6.1	Papers and the study components/objectives they cover.....	128
Table 6.2	Summary of theme and categories: Theme three.....	141

### List of tables Chapters 3, 4 & 5 (published paper and manuscripts)<sup>2</sup>

#### CHAPTER 3

---

Table 1	Sensory Processing Disorder: Diagnostic Groups and subtypes.....	22
---------	--	----

#### CHAPTER 4

---

Table 1	Sexual dysfunction diagnosis, treatment received and additional diagnosis.....	42
Table 2	Pain experiences currently and prior to treatment.....	43
Table 3	ASH's combined scores (mild & definite scores) for sensory section, sensory modulation, sensory discrimination, functional problems and motor/social areas, including sub-scores (ranked from most to least involved) for each sensory modality.....	45
Table 4	ASH-A: responses obtaining a score of '3'.....	49

#### CHAPTER 5

---

Table I	Parameters of trustworthiness.....	87
Table II	Summary of theme and categories.....	90

---

<sup>2</sup> Tables in Papers 1, 2 & 3 numbered according to Journal guidelines.

## LIST OF APPENDICES

- Appendix A : Human Research Ethics Committee (Medical): Clearance certificate
- Appendix B : Plagiarism Report
- Appendix C : Paper 1 - Cover letter & Consent
- Appendix D : Paper 1 - Sensory Processing Information Leaflet
- Appendix E : Paper 1 - Demographic Questionnaire
- Appendix F : Paper 1 - Adult/Adolescent Sensory History: Self-Report Questionnaire - sample pages
- Appendix G : Paper 1 - Adult/Adolescent Sensory History: Report Form
- Appendix H : Paper 1 - Hospital Anxiety and Depression Scale (HADS)
- Appendix I : Paper 1 - Copyright BioMed Central: BMC Research Notes
- Appendix J : Paper 2 - Poster Presentation: WFOT Congress, May 2019
- Appendix K : Paper 2 – Archives of Sexual Behaviour: Submission guidelines
- Appendix L : Paper 3 - First author's journal/notes
- Appendix M : Paper 3 - SAJOT: Guidelines for publishing
- Appendix N : Chapter 6 - List of semi-structured interview prompts
- Appendix O : Chapter 5 - Sample of e-mail & individualised report sent to participants

## DEFINITIONS

Ayres Sensory Integration	A theoretical framework that describes how the nervous system processes and integrate sensory information for use in adaptive behaviour <sup>1-3</sup> .
Dyspareunia	Recurrent or persistent genital pain associated with sexual intercourse <sup>4</sup> .
Dyspraxia	Dyspraxia is an impaired ability to conceive of, plan, sequence, or execute novel actions <sup>5</sup> .
Gravitational Insecurity	Excessive emotional reactions in response to changes in movement or head position <sup>6</sup> .
"Hard-to-reach"	A term used to describe those sub-groups of the population that may be difficult to reach or involve in research or public health programmes <sup>7</sup> .
Postural Disorder	Postural disorder is difficulty stabilizing the body during movement or at rest to meet the demands of the environment or of a given motor task <sup>5</sup> .
Postural -Ocular skills	The ability to demonstrate adequate and functional postural control, and to coordinate that control with the oculo-motor system <sup>8</sup> .
Praxis/Motor coordination	The ability to generate ideas for motor actions, sequence and organize motor responses, and make adaptive responses to environmental demands <sup>8</sup> .
Quality of life	"individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" <sup>9</sup> p.1570.
Sensory Discrimination	The ability to identify the salient qualities of sensory stimuli and process the information effectively for use, especially for postural-ocular and praxis skills <sup>8</sup> .

Sensory Integration	The neurological process that organizes sensation from one's own body and from the environment and makes it possible to use the body effectively within the environment <sup>10</sup> (p 11).
Sensory Integration Theory	Sensory integration theory is used to explain behaviour, plan intervention, and predict how behaviour will change through intervention <sup>11</sup> .
Sensory Integrative Dysfunction	An irregularity or disorder in brain function that makes it difficult to integrate sensory input <sup>12</sup> .
Sensory modulation	The ability to determine the relevance of sensory stimuli and adapt one's nervous system responses to make an appropriate response <sup>8</sup> .
Sensory modulation disorder	Difficulty responding to sensory input with behaviour that is graded relative to the degree, nature, or intensity of the sensory information <sup>5</sup> .
Sensory seeking	Crave an unusual amount or type of sensory input and seem to have an insatiable desire for sensation <sup>5</sup> .
Sensory over-responsivity	Respond to sensation faster, with more intensity, or for a longer duration than those with typical sensory responsivity <sup>5</sup> .
Sensory processing	The method and manner of sensation detection and transmission through the central nervous system <sup>12</sup> .
Sensory processing disorder	Clinical condition referring to individuals with atypical responses to sensory stimulation <sup>13</sup> .
Sensory under-responsivity	Disregard, or do not respond to, sensory stimuli in environment <sup>5</sup> .
Tactile defensiveness	The tendency to react negatively and emotionally to touch sensations. A specific type of sensory integrative dysfunction in which tactile sensations cause excessive emotional reactions, hyperactivity, or other behavioural problems <sup>12</sup> .
Vaginismus	Defined as recurrent or persistent involuntary spasm of the musculature of the outer third of the vagina that interferes with sexual intercourse <sup>4</sup> .

## LIST OF ABBREVIATIONS

ADL	:	Activities of daily living
AI	:	Aggressive/Impulsive
ANS	:	Autonomic Nervous System
Anx	:	Anxious
ASH	:	Adult/ Adolescent History
ASI®	:	Ayres Sensory Integration (Trademark)
ATP	:	Atypical Pain Response
Aud	:	Auditory
Car	:	Difficulties driving a car
DSM	:	Diagnostic and Statistical Manual of Mental Disorders
FM	:	Fine motor
FSPD	:	Female sexual pain disorders
GABA	:	Gamma-aminobutyric acid
GAS	:	Goal attainment scaling
GI	:	Gravitational Insecurity
GPPPD	:	Genito-pelvic pain/penetration disorder
HADS	:	Hospital anxiety and Depression Scale
HADS-A	:	Hospital Anxiety and Depression Scale's for Anxiety
HCP	:	Healthcare professionals
HREC	:	Human Research Ethics Committee at the University of the Witwatersrand
Hyg	:	Tactile-related Hygiene

IT	:	Imposed touch
JPMR	:	Jacobson progressive muscle relaxation
MC	:	Motor Coordination
MDT	:	Multi-disciplinary treatment
Mov	:	Seeks Movement
MP	:	Motor Planning
MRT	:	Muscle relaxation therapy
OM	:	Oculo-Motor
OMP	:	Oral Motor Planning
OT	:	Occupational therapy
OT/SI	:	Occupational therapy using a sensory integrative approach
PC	:	Postural control
PMR	:	Progressive muscle relaxation
PRT	:	Progressive relaxation technique
Prop	:	Proprioception
PsNS	:	parasympathetic nervous system
QoL	:	Quality of life
QRI	:	Qualitative research interview
REDCAP	:	Research electronic data capture
S/E	:	Social/Emotional
SBHP	:	Sensory-based home program
SBMD	:	Sensory based motor disorder
SD	:	Sensory Discrimination

SDD	:	Sensory discrimination disorder
Seq	:	Sequencing
SI	:	Sensory integration
SIBI	:	Sensory integration based interventions
SID	:	Sensory integration dysfunction
SM	:	Sensory modulation
SMD	:	Sensory modulation disorder
SNS	:	Sympathetic nervous system
SOR	:	Sensory over-responsivity
SPD	:	Sensory processing dysfunction
SS	:	Sensory seeking
SUR	:	Sensory under-responsivity
T&S	:	Tactile & Smell
Tac	:	Tactile
TB	:	Therapeutic brushing
Tou	:	Seek Touch
Vest	:	Vestibular
VSP	:	Visual Spatial Processing
WD	:	Withdrawn/Depressed
WM	:	White matter
WTP	:	Wilbarger Therapressure Program
Wtr	:	Discomfort with Water

# CHAPTER 1. INTRODUCTION

---

## INTRODUCTION

Women who have been diagnosed with genito-pelvic pain/penetration disorder (GPPPD) often experience sexual and psychological difficulties, as well as significant relationship impairments<sup>14–17</sup>. Genito-pelvic pain/penetration disorder requires a holistic (bio-psychosocial) and multi-professional approach<sup>18</sup>.

In occupational therapy, sexuality is categorised as part of the performance of activities of daily living as well as the fulfilment of various roles<sup>19</sup>. Dysfunction in this performance area is therefore of concern to occupational therapists, as it may affect a client's well-being<sup>20</sup> and mental health<sup>21,22</sup>. Nonetheless, the role of sexuality in a client's well-being is often ignored in occupational therapy (OT)<sup>23,24</sup>. Marsh, in a blog as early as 2011, suggested that sensory processing dysfunction (SPD) may have a potential effect on sexual intimacy that should be addressed to optimally manage sexual dysfunction<sup>25</sup>.

The terms SPD and sensory integration dysfunction (SID) have been used in studies to describe persons who experience difficulties related to registration, integration and organisation of sensory input<sup>5,13</sup>. Both SID and SPD will be used during the literature review, as both terms are used in the literature. A section of the literature review will be dedicated to clarify terminology. However, for the purposes of this study SPD<sup>8</sup> will be the primary term used in the discussion section of the papers which form part of this dissertation, for uniformity sake, since this is the terminology used by the Adolescent/Adult Sensory History (ASH) assessment, used to collect data in Phase one.

Sensory processing dysfunction (SPD) has been investigated quite extensively, especially in the paediatric population<sup>6,12,26–30</sup>, but in recent years, the focus has moved to adults, as it was found that SPD is present throughout a person's life<sup>31–36</sup>, impacting significantly on a person's activities of daily living, including intimacy<sup>37</sup>, interpersonal relationships<sup>33</sup> and mental health<sup>38–40</sup>.

GPPPD and SPD have been researched quite extensively as separate entities, but literature linking these conditions could not be sourced. Both SPD and GPPPD have been associated with mental health conditions especially anxiety<sup>21,41</sup>, and women are often referred to healthcare professionals (HCPs) due to these co-morbid psychological conditions.

Additionally, the presence of pain is central to both GPPPD and SPD<sup>35,42,43</sup>, and evidence suggest that sensory integration (SI) based interventions assist with pain management<sup>36</sup>. Thus, there is a need for research into SPD and female sexual pain disorders, because occupational therapy (OT) is not included in the current best evidence intervention protocols to address female sexual pain conditions<sup>18,44,45</sup>. Non-invasive, non-pharmacological occupational therapy using a sensory integrative approach (OT/SI)<sup>46</sup> intervention could be a valuable addition to the current multi-disciplinary approach.

Thus, the aim of the study is to describe the sensory processing of women diagnosed with GPPPD and to explore the presence of anxiety when both SPD and GPPPD are present.

The objectives of the study are:

- To describe the sensory processing patterns of women diagnosed with GPPPD.
- To explore the presence of anxiety in women when both SPD and GPPPD are present.
- To describe their experiences of participating in a sensory-based home program (SBHP).

The following chapter provides literature review regarding SPD, its impact and related interventions, GPPPD and its impact together with current interventions. This will be followed by literature regarding anxiety, its links with SPD and GPPPD, as well as interventions.

## OUTLINE OF THE DISSERTATION

This dissertation follows the publication format and the chapters will not necessarily follow a traditional outline.

Chapter 1: Introduction, explaining the purpose of the study, and highlights the problem the study attempts to address.

Chapter 2: Non-systematic literature review, which briefly explores the following themes: sensory integration and processing, genito-pelvic pain penetration disorder and anxiety.

Chapter 3: Paper 1: First publication,<sup>47</sup> which replaces the traditional methodology chapter.

Chapter 4: Paper 2: Draft paper describing the results of the first phase of the study.

Chapter 5: Paper 3: Draft paper describing the results of the second phase of the study.

Chapter 6: An integrating chapter, which contains a brief, critical review of the methodology, as well as a discussion of the two draft papers in view of the objectives of the study

Chapter 7: Conclusion.

## CHAPTER 2. LITERATURE REVIEW

---

### INTRODUCTION

This chapter highlights existing knowledge about SI and sexual dysfunction, specifically GPPPD. A discussion of anxiety, and its role related to SPD and GPPPD, will conclude the literature review. The relevant literature was obtained by accessing various databases, which included EBSCOHost, ClinicalKey, Cochrane Library, Google Scholar, ProQuest Central, PubMed, SAGE Journals Online, ScienceDirect, Springer, SCOPUS, Taylor & Francis Journals and Wiley Online Library.

Books, individual journals, websites and grey literature such as Clinician's guide for implementing Ayres Sensory Integration<sup>3</sup>, Sensory Integration and the Child<sup>12</sup>, Interoception<sup>48</sup>, OT Practice ([www.aota.org/Publications-News/otp.aspx](http://www.aota.org/Publications-News/otp.aspx)), Cosmopolitan ([www.cosmopolitan.com](http://www.cosmopolitan.com)), and Masters dissertations were accessed. The bibliographies of relevant articles were also searched.

Keywords for the non-systematic literature search included: 'sensory integration', 'adult sensory', 'sensory processing', 'sensory processing dysfunction/disorder' OR 'SPD', 'sensory integration dysfunction' OR 'SID', 'Adolescent/Adult Sensory History' OR 'ASH', 'Jean Ayres', 'Sensory Profile', 'atypical sensory processing', 'sensory modulation', 'sensory discrimination', 'sensory overload', 'sensory shutdown', 'impact of sensory processing', 'defensiveness', 'intervention/treatment sensory processing', 'intervention/treatment sensory', 'brushing protocol', 'Wilbarger', 'therapeutic brushing', 'mindfulness', 'sensory diet', 'sensory home program', 'sensory integration/processing sexual pain', 'sensory processing pain', 'interoception', 'neurological sensory processing', 'female sexual pain', 'aetiology sexual pain', 'genito-pelvic pain/penetration disorder' OR 'GPPPD', 'vaginismus', 'dyspareunia', 'treatment/intervention female sexual pain', 'impact sexual pain', 'partner sexual pain', 'anxiety' OR 'anxiousness', 'intervention/treatment anxiety', 'sensory processing female sexual pain anxiety'.

## **SENSORY INTEGRATION**

In this section, the different terminology in the SI field will be unpacked. Thereafter, sensory systems will be discussed, followed by a brief description of the neuroscience, the impact of SPD on quality of life as well as a brief look at pain and SPD. Intervention options related to SPD, including sensory diets and environmental adaptations will also be discussed.

### **Terminology related to sensory processing difficulties**

Jean Ayres pioneered the concept of SI and identified individuals with atypical responses related to processing and integration of information obtained from the different sensory systems, namely tactile, visual, proprioceptive, vestibular, auditory, gustatory and olfactory<sup>12,30,49,50</sup>. The concept of Ayres Sensory Integration® (ASI®) was registered as a trademark to refer to sensory integration aligned with Ayres' original concepts/theory of practice<sup>1,51,52</sup>. Ayres SI is based on the concepts that SI is fundamental to learning and behaviour (promoting neuroplasticity), and that meaningful experiences presented as 'just-right-challenges' promote adaptive responses and active engagement with the environment<sup>3</sup>. The term sensory integration disorder/dysfunction has been used to describe persons with atypical responses to sensory stimuli<sup>13</sup>.

The theory of SI has evolved over the years, however it lacks uniformity regarding the use of terminology<sup>5,46,53–56</sup>. In addition to ASI®, other frameworks/models related to sensory integration/processing difficulties<sup>57,58</sup> have been described in the literature. Two of these frameworks/models, namely Dunns' model of sensory processing, and sensory processing disorder with its proposed subtypes, will be discussed briefly.

### ***Dunn's model of sensory processing***

According to Dunn's model of sensory processing<sup>59,60</sup> there are four sensory processing categories.

These categories are defined according to a person's neurological threshold and response strategy, as described in Figure 2.1 below:

BEHAVIOURAL RESPONSE CONTINUUM			
Neurological threshold continuum		<i>Passive response in ACCORDANCE to threshold</i>	<i>Active response to COUNTERACT threshold</i>
	<b>HIGH</b>	<b>Poor registration</b> of sensory stimuli	<b>Sensation Seeking</b> pattern
	<b>LOW</b>	<b>Sensory sensitivity</b> to sensory stimuli	<b>Sensation-avoiding</b> pattern (i.e. actively limiting any form of sensory stimulation)

**Figure 2.1 Sensory Processing: behavioural responses and neurological thresholds** Adapted from: (Dunn 1997: page 24)<sup>60</sup>

Persons with a high neurological threshold can either display passive responses due to a poor registration of sensory stimuli or active responses like sensory seeking in attempt to counter the high neurological threshold. People with a low neurological threshold may display passive responses due to sensory sensitivity, whilst limiting sensory input by actively avoiding sensory input<sup>59,60</sup>.

Acting on these thresholds, people develop certain behavioural and emotional responses<sup>33</sup> as a regulatory measure, resulting in sensory modulation and adaptive behaviour<sup>61</sup>.

Sensory modulation (SM), as a separate category, emerged between 1991<sup>62</sup> and 2002<sup>11</sup>. Dunn's research has led to the development of the Sensory Profile<sup>56</sup> which is still widely used<sup>63</sup>, especially when referring to coping strategies used by persons with sensory modulation disorder (SMD)<sup>64</sup>.

### ***Sensory Processing Disorder***

Another framework which has been used to describe persons with difficulty grading and/or regulating responses to sensory stimulation refers to Sensory processing disorder<sup>5,13</sup> and consists of three diagnostic groups each with its respective sub-groups. The diagnostic groups include sensory modulation disorder (SMD), sensory discrimination disorder (SDD) and sensory based motor disorder (SBMD), as can be seen in Figure 2.2 below.

Diagnostic groups:	Sensory modulation disorder (SMD),	Sensory discrimination disorder (SDD)	Sensory based motor disorder (SBMD)
<b>Subtypes</b>	Sensory over-responsivity (SOR)	– Visual	Postural disorder
	Sensory under-responsivity (SUR)	– Auditory	Dyspraxia
	Sensory seeking/craving (SS)	– Tactile – Vestibular – Proprioception – Taste/Smell	

**Figure 2.2 Sensory Processing Disorder: diagnostic groups and subtypes**

From: (Labuschagne E. Van Niekerk M. 2019: page 2)<sup>47</sup>

Sensory modulation disorder consists of three subtypes, namely SOR, SUR and SS. Individuals with SOR experience non-painful sensations as abnormally irritating, unpleasant or painful. They respond too much, for too long and they also respond to stimuli that are weak<sup>13,65</sup>. Sensory over-responsivity (SOR) is also associated with inadequate inhibition of irrelevant sensory stimuli<sup>66</sup>. In contrast, sensory under-responsivity (SUR) refers to a lack of awareness or reduced sensitivity to sensory stimuli that most people would notice. People with SUR also need more intense stimulation before registering sensory input<sup>13</sup>. Where SUR and SOR relates to how people respond to stimuli, SS is a tendency to seek/engage in behaviours that generate sensations that are more intense and/or frequent when compared to the general population<sup>65</sup>.

The second diagnostic group, SDD, can be present in any of the seven sensory systems and refers to the difficulty interpreting the intensity, duration, spatial and temporal elements of sensory stimuli<sup>13</sup>.

Sensory motor based disorder (SMBD), the third diagnostic group, consists of postural disorder, which refers to problems with balance and core stability, and dyspraxia relating to problems with motor planning and sequencing<sup>13</sup>.

### **Atypical responses are what matters**

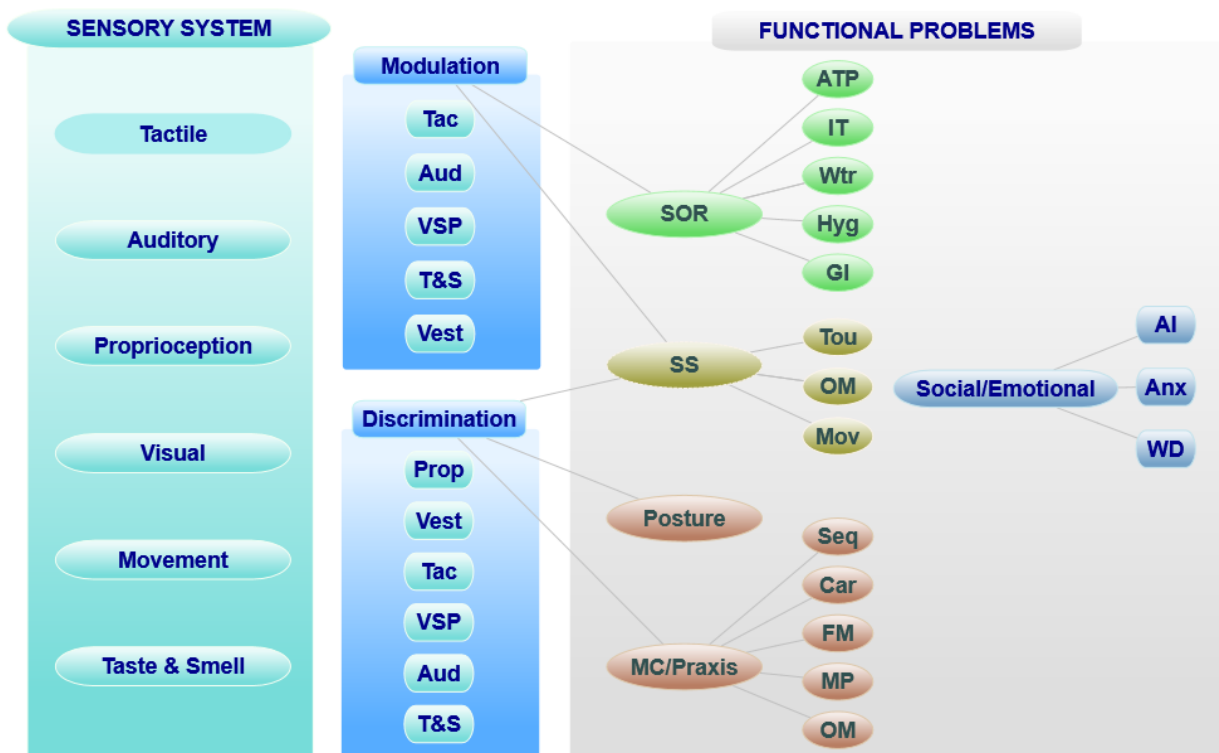
The frameworks/models mentioned above all describe atypical responses to sensory stimuli, but the different theories affect the interpretation and/or classification of resultant behaviour, contributing to the confusion regarding terminology.

Importantly, occupational therapists using a sensory integrative approach, are most interested in atypical responses to sensory stimuli<sup>27,29,46</sup> and the emphasis should be on describing the problem related to processing and integration of sensory information, rather than attempting to label/diagnose the person with sensory difficulties<sup>46</sup>. Terminology should be carefully considered, especially when doing research and descriptions of data should be aligned with the measurement instrument used<sup>46</sup>.

The current study uses terms related to the recently-developed Adult/Adolescent Sensory History (ASH) assessment<sup>8</sup>, based on ASI<sup>®</sup>, and identifies sensory modulation (SM) and sensory discrimination (SD) difficulties as well as functional difficulties related to SM, namely sensory over-responsiveness (SOR) and sensory seeking (SS), while functional difficulties related to SD, includes posture/postural control (PC) and motor coordination(MC)/praxis. See Figure 2.3 below).

The term sensory processing dysfunction (SPD), as reflected in the ASH's manual<sup>8</sup>, will be the preferred terminology throughout this study and its publications, to describe persons with difficulty integrating and processing sensory stimuli.

The ASH also identifies difficulties in specific sensory systems, as shown in Figure 2.3 below, which will be discussed next.



**Figure 2.3 Aspects evaluated by ASH.** Adapted from: (May-Benson 2015:p.35)<sup>8</sup>

## **Sensory systems**

The sensory systems, including functional impacts related to SM and SD will be discussed below.

### ***Tactile system***

The tactile system is one of the first systems to develop in utero<sup>67,68</sup> and it forms the foundation for the development of motor, social and communication skills<sup>67</sup>. Touch is always present and we constantly receive tactile input from our surroundings e.g. surfaces, objects, clothing textures, animal and individuals. Touch is important for the development of a sense of oneself, improving human well-being, emotional connection, psychological well-being and physiological development<sup>69,70</sup>. An interesting development is the finding that imposed touch, including interpersonal and intimate touch, is fundamental to intimacy<sup>69</sup>, which, in the context of this study, is an important consideration.

Difficulties related to tactile processing can present as tactile defensiveness (which is the tactile expression of SOR), tactile seeking and/or tactile discrimination<sup>11</sup> (which relates to SD). Persons with tactile defensiveness react negatively to tactile input which could elicit strong emotional outbursts, often reflected as fight-or-flight reactions<sup>71,72</sup> due to the activation of the sympathetic nervous system<sup>50,58,73–75</sup>.

In contrast, persons displaying tactile seeking behaviour, may find some tactile stimuli as highly pleasurable, causing them to seek these experiences out e.g. rubbing certain textures like fabric, hair etc.<sup>67</sup>. Tactile seeking and tactile based interventions can be effectively used to regulate sensory input, resulting in improved SM, arousal, attention and sensory defensiveness<sup>67</sup>.

Tactile discrimination refers to difficulty perceiving tactile stimuli<sup>8</sup> and affects the interpretation of spatial and temporal aspects of sensory stimuli<sup>13</sup>. A recent study associated poor tactile discrimination with difficulties related to motor planning<sup>58</sup>.

### ***Visual system***

Sensory modulation difficulties, specifically SOR, related to the visual system can present as visual defensiveness<sup>76,77</sup> displaying sensitivity to bright lights, getting annoyed by objects close to their face or a moving visual field, increased distractibility by visual stimuli, getting overexcited by a busy/complex visual field, fear visual cliffs and avoiding eye contact<sup>37,60</sup>. Visual defensiveness can therefore impact

negatively on concentration<sup>54,78,79</sup>, interpersonal relationships<sup>33</sup>, social and communication skills<sup>67</sup>.

Visual discrimination provides information about our body's position in space, where we are in relation to other objects, maintain posture, identify objects and to guide motor actions in space<sup>11</sup>. Visual-spatial processing, together with the proprioceptive and vestibular systems, are fundamental in the development of motor coordination<sup>11,80</sup>.

### ***Proprioception***

The proprioceptive system is essential to the development and execution of motor skills, via its inter-relatedness with the tactile and vestibular systems. It provides discriminatory feedback regarding movement and the body's position in space<sup>11,12</sup>. The proprioceptive system, together with the tactile system provide essential feedback regarding body position, facilitating the development of spatial and temporal concepts, all prerequisites for movement to become automatic<sup>11,12</sup>. Furthermore, the inter-relatedness of the proprioceptive and vestibular systems, forms the foundation of automatic background activity, namely postural tone and balance<sup>11,12</sup>.

### ***Vestibular System***

The vestibular system provides feedback regarding movement via the balance receptors in the inner ear<sup>11,12</sup>. It is interconnected with most of the senses and is the reference point against which sensory input from the tactile, visual, auditory and proprioceptive systems, is measured<sup>11,12,52</sup>. Difficulty processing vestibular information related to sensory modulation, can result in hyper-sensitivity to movement, gravitational security, movement seeking, while discrimination difficulties result in poor vestibular discrimination<sup>8,11,12,54</sup>. A recent study reported a relationship between gravitational insecurity, anxiety and sensory processing difficulties<sup>81</sup>.

Importantly, postural control and motor coordination rely on integration of sensory input from the proprioceptive, vestibular, tactile and visual systems, while, sequencing difficulties are contributed to inadequate processing of proprioceptive and vestibular input<sup>11,37,54,82</sup>.

The vestibular and auditory systems are closely linked via neurological pathways<sup>11</sup>.

### ***Auditory system***

The auditory system has complex connections throughout the brainstem, cerebellum and cortex<sup>11</sup>. At brainstem level the nuclei in the auditory centre process information

obtained from the vestibular system as well as from the muscles and the skin<sup>11,12</sup>. The auditory organising centre also has connections with the visual processing centre and both systems integrate information with other sensations and motor input, and this is sent to various areas in the cortex<sup>11,83</sup>.

The auditory and tactile systems are closely linked via extensive neural interactions<sup>84–86</sup> and studies have also found that tactile and auditory defensiveness often occur together<sup>85–87</sup>.

Auditory processing difficulties related to modulation are reflected in auditory defensiveness and distractibility<sup>8</sup>. Auditory defensiveness refers to persons who respond negatively to loud noises, cover their ears when exposed to certain noise, dislike high pitched sounds, are easily distracted by auditory stimuli, get irritated or unable to tune out noise in the background, get irritated by the pitch of certain sounds and have difficulty listening when other background noise is present<sup>31,37,60,88</sup>.

Discrimination difficulties present as poor auditory discrimination and difficulty following instructions<sup>8,11</sup>.

Difficulties in the auditory system are often more prominent when several of the sensory systems are involved in SPD<sup>12</sup>.

### ***Taste and smell***

Taste (gustatory) and smell (olfactory) assist with discrimination between different tastes/smells and also relates to hyper-sensitivities to taste and smell<sup>11</sup>. Smell is not processed with information from the other senses in the brain stem, but information is relayed directly to the olfactory and limbic areas in the brain<sup>37,89</sup>. Therefore, certain smells can elicit very strong emotional reactions<sup>37,89</sup>.

### ***Interoception***

While not described in the ASH *per se*, interoception<sup>90,91</sup> has gained prominence in recent literature<sup>48,92–97</sup>. It is described as the eighth sense<sup>48</sup>, and is discussed in greater detail in Paper 2 (Chapter 4) and will not be repeated here. Reference to interoception is included here, for comprehensiveness.

## **Neurophysiological aspects related to Sensory Processing Dysfunction**

Neurophysiological aspects have received more attention lately, and confirm the neurological basis of SPD<sup>50,68,84,98</sup>.

An early study found children with SPD displayed distinct atypical patterns of sympathetic activity<sup>99</sup> while a more recent study found parasympathetic nervous system (PsNS) activity to be an important biomarker of SPD<sup>50</sup>. According to the results children with the lowest PsNS regulation were diagnosed with more severe SPD, and had the poorest adaptive behaviour responses resulting in a possible delay in communication and activities of daily living<sup>50</sup>. It was suggested that the sympathetic nervous system could be functioning in an over-aroused state due to the lack of regulation by the PsNS<sup>50</sup>.

Recent ground breaking studies<sup>68,98</sup> investigated the role of white matter (WM) in SPD by using diffusion tensor imaging. The initial study found children with SPD displayed specific reduction in the WM micro-structure, affecting mainly the posterior cerebral tracts<sup>98</sup>, while the more recent study, using a larger group of children of mixed gender, supported the initial findings<sup>68</sup>.

Systemic conditions can affect sensory processing and especially sensory defensiveness<sup>37,100–102</sup> via the interconnectedness of the neurological, endocrine and immune systems and the necessity of systemic harmony between the systems<sup>37,103</sup>. Sensory over-stimulation activates the autonomic nervous system, while also triggering the endocrine system to release stress hormones. An increase in stress hormones suppresses the working of the immune system, specifically the white cells<sup>37</sup>. Various conditions can develop as a result of stress related health problems and these include e.g. allergies, fibromyalgia, arthritis, cystitis, irritable bowel syndrome, headaches, migraines, high blood pressure, coronary heart disease<sup>37,104–106</sup> and atopic dermatitis<sup>102</sup>.

### **Impact of Sensory Processing Dysfunction**

This aspect is discussed in the papers presented in Chapters 3, 4 and 5, with selected aspects relating to occupational performance particularly with respect to social functioning and pain. This is discussed in more depth below.

Sensory processing disorder has been shown to affect interpersonal relationships. People with sensory avoidance avoid relationships and those with sensory sensitivity experience increased anxiety related to relationships<sup>107</sup>. Sensory over-responsivity could affect a person's social participation through avoidance of social situations resulting in perceived introversion<sup>103,108</sup>.

It is evident from the literature that SPD not only affects personal feelings, but also the fulfilment of various life roles, social participation, interaction with the environment as well as occupational performance<sup>64,77</sup>. Atypical neurological response patterns have been identified in persons with SOR<sup>35</sup>, suggesting persons with SOR are in a state of hyper-arousal and display defensive behaviours as a coping mechanism against prolonged and repetitive stimuli. Individuals with SOR also display greater pain sensitivity affecting their QoL negatively<sup>43</sup>.

### **Sensory Processing dysfunction and pain**

Pain is a complex sensation and consists of behavioural, cognitive, emotional<sup>109</sup> and psychological aspects<sup>110</sup>. According to the literature persons with SPD, specifically those with increased sensory responsiveness/sensitivity, have atypical response patterns related to sensation of pain impulses<sup>35,36,39,43,111</sup> and reflect greater sensitivity to pain<sup>43</sup>.

Persons with SOR tend to display passive pain coping strategies e.g. pain catastrophizing, and these maladaptive strategies make them more vulnerable and they may respond worse to pain<sup>36</sup>. Problem-focused coping, including active pain coping strategies, regular exercise and emotion-focused coping, including positive self-statement and social comparison<sup>112</sup>, have been associated with SS/SUR<sup>36</sup> resulting in improved psychological and physical functioning<sup>112</sup>.

Another study found persons with SOR have reduced QoL, are more sensitive to daily pain and that sensation of pain had the biggest impact on their performance areas<sup>43</sup>. Therapeutic interventions, targeting SOR and pain hyper-sensitivity, were suggested to improve QoL<sup>43</sup>. The perception of pain therefore plays a vital role in the performance of daily activities, including women who suffer from sexual pain<sup>16</sup>.

### **Interventions related to sensory processing dysfunction**

Occupational therapists with training in SI are in a unique position to treat patients directly but also to act as consultants to individuals<sup>61</sup>, professionals and organisations in the mental health field. Sensory integration based interventions (SIBI) can be used for various mental health conditions<sup>61,77</sup> and be used in both inpatient<sup>61,113</sup> and outpatient<sup>113,114</sup> programs.

Literature regarding intervention for SPD are described in Chapter 5, which describe the article titled, "Sensory processing dysfunction and genito-pelvic pain/penetration

disorder: women share their experiences of participating in a sensory-based home program”, while some intervention approaches are reviewed in more detail below.

Several studies have investigated the effect of SIBI and results indicate positive outcomes for interventions of SPD<sup>50,72,76,114–118</sup>.

Tactile based therapies can be effectively used to modulate arousal, attention and sensory defensiveness<sup>67</sup> and a literature review on therapeutic touch indicated the positive effect of touch on the health status of patients with cancer<sup>119</sup>.

Movement input, specifically proprioceptive and vestibular input, has been identified as a key aspect in the intervention for SPD<sup>77,120,121</sup>. Increased vestibular input has also been linked to a reduction in anxiety<sup>122,123</sup>. Yoga, especially sensory-enhanced yoga is an evidence-based intervention in occupational therapy<sup>124</sup> and assists with self-regulation and reducing hyper-arousal<sup>124,125</sup>. Sensory-enhanced yoga incorporates elements in yoga that provide increased proprioceptive and deep tactile input, slow rhythmical movements, calming breathing exercises and postures that balance the nervous system, resulting in a more relaxed state<sup>124</sup> and mindfulness<sup>126</sup>. Yoga also increases the parasympathetic nervous system activity and gamma-aminobutyric acid (GABA) system levels in the thalamus<sup>127</sup>.

The tactile, proprioceptive and vestibular senses form the foundation of sensory integration intervention<sup>11,128</sup>. Proprioception and deep tactile pressure, have been more extensively investigated<sup>115</sup> during intervention of sensory processing difficulties. Deep touch pressure can be provided through firm touch, holding, stroking, and swaddling<sup>116,129</sup> and has an organising effect on the nervous system<sup>130,131</sup>. In a recent study<sup>130</sup> most individuals benefited from deep pressure, but the use of it should be individualised to the person.

The positive effect of the Wilbarger Therapressure Program (WTP), which consists of applying deep tactile input with a therapressure brush, followed by joint compressions<sup>71</sup> has been investigated in various populations<sup>72,114,132–135</sup>. The WTP is used extensively during the intervention of SPD and other conditions<sup>71,72,114,117,132,134,135</sup>. Deep pressure can also be provided through weighted objects e.g. weighted blankets and jackets<sup>136</sup>. The therapeutic use of weight has been widely used in sensory diets for various conditions and should be considered when designing SIBI<sup>115,120,130,136–143</sup>. Persons who suffer from mental health problems showed a marked decrease in anxiety when a weighted blanket was used as an intervention technique<sup>139</sup>.

Literature regarding the aetiology and interventions for sensory processing difficulties support a complex inter-relationship between not only sensory systems, but also the impact it has on QoL<sup>144</sup>. Furthermore, sexual functioning, an occupational performance area, is negatively affected by sexual pain, also impacting negatively on QoL<sup>145,146</sup>. Sexual pain, specifically GPPPD, will be discussed next.

## **SEXUAL DYSFUNCTION / GENITO-PELVIC PAIN/PENETRATION DISORDER**

In this section a brief history of sexual pain disorders, the diagnostic criteria of GPPPD and the impact and aetiology of sexual pain, as well as current intervention ideas related to sexual pain will be discussed.

### **History of sexual pain disorders**

Sexual dysfunction was first included in the DSM III in 1980<sup>14</sup>. Since then, the diagnosis of sexual dysfunction for both genders has undergone many changes. Most recently, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5), published in 2013, classified female sexual dysfunction into three sub-categories: female sexual interest/arousal disorder, orgasmic disorder and GPPPD<sup>14</sup>. The new category of GPPPD<sup>147</sup> has combined the previous diagnoses of dyspareunia and vaginismus found in the DSM-IV-TR<sup>4</sup>.

The DSM5 states that GPPPD refers to four commonly co-morbid symptom dimensions, namely difficulty having intercourse, genito-pelvic pain, fear of pain or vaginal penetration, and tension of the pelvic floor muscles. Symptoms of chronic pain related to the female sexual functioning have a significant impact on the lives of women of all ages<sup>18,148–152</sup>.

Generally, there is an increasing societal openness to discuss sexual matters<sup>23,153</sup>, and the prevalence of GPPPD will probably increase as more women are comfortable seeking help for sexual difficulties<sup>14</sup>. Female sexual dysfunction is often misdiagnosed due to the multifactorial nature thereof and it can either be a side-effect or a symptom of another causative condition, and therefore not the primary condition<sup>14</sup>.

The literature regarding the aetiology of female sexual pain disorders (FSPD) indicate biomedical, psychological and relationship factors<sup>14,18,154</sup>. These could have an impact on QoL but very few studies have been done to assess any impact on QoL<sup>155</sup>, including intimacy and sexual activities.

Women diagnosed with vaginismus<sup>156</sup> and dyspareunia<sup>157</sup> experienced more negative emotions, anxiety and fear related to sexual functioning<sup>14</sup>. The link between anxiety and sexual functioning has been supported by various studies<sup>21,158</sup> and a diagnosis of anxiety and depression increases the risk of vulvodynia developing<sup>159</sup>.

### **Genito-pelvic pain/penetration disorder interventions**

The importance of addressing GPPPD has been highlighted by Latif & Diamond<sup>14</sup>.

“Women want their sex lives back, no matter how old they are. They want to desire sex, they want lubrication, they want orgasm, and they want it pain-free”<sup>14:903</sup>.

Attitudes regarding sexual morality and expression have changed in recent years<sup>160,161</sup> and women experience less guilt and greater freedom to discuss sexuality related issues. This has likely had an impact on awareness of conditions such as GPPPD, but it should be noted that in conservative communities talking about sex and sexuality remains largely taboo.

Assessment of female sexual disorders is very important due to the complex aetiology thereof. This assessment consists of a detailed history taking regarding the onset, severity and symptom perception, as well as a physical examination<sup>145</sup>. A detailed psychosocial and pain assessment should therefore also be conducted<sup>145,162</sup>. Formal diagnosis of, and intervention for female sexual pain are often delayed due to initial confusion about symptoms, attempts to self-manage the condition<sup>163</sup> and help-seeking barriers such as embarrassment about the problem, lack of confidence in a healthcare solutions<sup>163</sup>, relationship characteristics, professional approachability, awareness of services and perception about the problem<sup>164</sup>. Healthcare professionals therefore play a major role in the treatment or non-treatment of women with sexual dysfunction<sup>165</sup>.

Literature regarding interventions for GPPPD are discussed further in Chapter 4 (Paper 2).

The literature emphasises the complex multifactorial nature of female sexual pain intervention, which could affect the speed of progress negatively<sup>166,167</sup>. Intervention challenges have been identified, with the most prominent being difficulty coordinating the multi-disciplinary interventions<sup>18</sup>. Therefore, the different disciplines involved in the intervention must increase their interaction to assist with progress within the field<sup>18,168</sup>.

The presence of personal distress links GPPPD with anxiety and this aspect will be discussed in the next section.

## **ANXIETY**

In this section anxiety and related medical information as well as the link between anxiety SPD and GPPPD based on commonalities described in the literature, will be discussed. It will further describe the impact of anxiety on attachment and relationships and the interrelatedness of anxiety (distress) and sexual pain. Mental health strategies, more specifically related to anxiety and pain, will conclude this section.

### **Description of anxiety**

Anxiety, also called extreme apprehension and worry, is a normal human reaction to stressful situations and is marked by physiological hyperarousal<sup>169,170</sup>. It is also important to distinguish between anxiety, as a feeling or experience, and anxiety disorder, a psychiatric diagnosis which must meet certain diagnostic criteria. Women diagnosed with vaginismus have increased general anxiety<sup>22</sup> and a diagnosis of dyspareunia is associated with increased nervousness<sup>171</sup>.

### **Theory and brain mechanisms**

Anxiety is an emotional response to vague, potential threats and characterised by sustained arousal, vigilance and apprehension<sup>172</sup>. On the other hand, fear is elicited by a direct acute sensory input and results in patterns of defensive behaviour and associated autonomic responses<sup>172</sup>.

The neuronal basis for fear and anxiety are controlled by partially overlapping brain structures<sup>172</sup> and the limbic system, especially the amygdala, and frontal brain areas play a crucial role in both these emotions<sup>173</sup>. The limbic system, which relies on integrity of the WM, is central in regulation of emotions and behaviour and receives information from all cortical areas<sup>11</sup>.

Several studies have investigated the relationship between WM structures in the brain and persons with anxiety and depression displayed significantly reduced WM connections between the amygdala and core networks related to cognitive-affective function in the brain<sup>174</sup>.

## **Anxiety and Sensory Processing Dysfunction**

Anxiety and SPD and its inter-relatedness has been confirmed by several studies and this aspect is discussed in the next chapter<sup>47</sup>.

Anxiety has also been linked to sensory processing via the eighth sense, namely interoception and this is discussed further in Chapter 4 (Paper 2). A recent study<sup>175</sup> found increased awareness of interoceptive stimuli is obtained through interventions promoting relaxation, resulting in decreased anxiety.

The relationship between affective symptoms and sensory integration are not causative<sup>41,107,176,177</sup>, but sensory integration works in conjunction with other factors to either increase or decrease negative affective symptoms<sup>178</sup>. Emotional regulation was suggested as a mediating factor through mindfulness and acceptance based strategies<sup>179</sup>.

## **Interventions for anxiety**

Literature regarding interventions for anxiety are reported in Chapters 3<sup>47</sup>, 4 and 5, with some techniques discussed in more detail below.

Muscle relaxation therapy (MRT) or progressive muscle relaxation (PMR)/progressive relaxation technique (PRT), has been found to be effective in reducing anxiety<sup>170,180</sup>, stress<sup>181</sup> and improving cognitive function<sup>182</sup>. Jacobson progressive muscle relaxation (JPMR) and deep breathing exercises have been linked to interventions for anxiety, psychological distress and quality of sleep<sup>183</sup>.

Recent studies investigating the effect of MRT on metabolic process have found a reduction in glucose consumption in the brain<sup>184</sup> as well as a reduction in cortisol secretion in individuals who regularly participated in an abbreviated progressive muscle relaxation program<sup>181</sup>.

Mindfulness is a cognitive approach that has become more prominent in interventions pertinent to SPD and psychological conditions in recent years<sup>178,185,186</sup>. Sensory awareness is a key element of mindfulness, and training in mindfulness might be beneficial to individuals with specific sensory processing patterns<sup>187</sup>. A recent study suggested that mindfulness could be responsible for changes in the neuroplasticity of areas in the brain, responsible for regulating attention, emotion and self-awareness<sup>186</sup>.

## CONCLUSION

Sensory processing dysfunction and GPPPD both feature neurological involvement. The perception of pain is not only part of sensory integration, but is also influenced by SPD<sup>35,36</sup> and is central in women who suffer from GPPPD<sup>18</sup>. The literature has not previously investigated sensory processing of women with GPPPD and a gap exists in the literature.

Occupational therapists who treat SPD in adults have mostly looked at the interpersonal and relationship aspects affected by SPD but sexual functioning and dysfunction are seldom addressed<sup>188</sup>. Current interventions for women with GPPPD do not include occupational therapy, even though literature support commonalities, including pain perception<sup>35,189</sup>, predisposition for developing affective conditions<sup>179,190</sup> and negatively impacting in QoL<sup>144,191</sup>.

Both, SPD<sup>38,144,192,193</sup> and GPPPD<sup>146,156,169,190,194–198</sup> were found to be predisposing factors for the development of affective conditions and mood disorders e.g. anxiety, depression, bipolar mood disorder and borderline personality disorder.

Furthermore, SPD<sup>34,39,43,64,72,77,187</sup> and sexual dysfunction<sup>199</sup> have also been found to negatively impact on QoL.

It is evident from the literature that intervention options for SPD, anxiety and GPPPD cover a broad spectrum of interventions, techniques, strategies and approaches<sup>32,198,200</sup>. Some intervention options are exclusive to one condition i.e. surgical intervention for the treatment of certain GPPPD conditions<sup>198</sup>, but many strategies are inclusive and overlap e.g. cognitive-based techniques and relaxation techniques, are included in interventions for all three conditions<sup>32,198,200</sup>.

However, certain techniques, e.g. sensate focus, for GPPPD and psychological intervention can activate the sympathetic nervous system (fight/flight/freeze)<sup>201</sup> in persons with SPD, resulting in emotional reactions, increased anxiety, feelings of negativity towards self and strained interpersonal relationships, including intimacy. It is therefore imperative that sensory processing is investigated in women who suffer from sexual pain. Not investigating the sensory processing of women with GPPPD is likely to be unethical, having regard for the commonalities between SPD and GPPPD illustrated above as well as the potential harm that conventional GPPPD treatment could cause women with SPD.

The next chapter is a paper that was published in 2019, and reflects the methodology of the study.

# CHAPTER 3. PAPER 1

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## INTRODUCTION TO PAPER 1

This paper represents the methodology of the current study.

The following documents pertaining to Paper 1 are attached as appendices:

- Cover letter & Consent (Appendix C)
- Sensory Processing Information Leaflet (Appendix D)
- Demographic Questionnaire (Appendix E)
- Adult/Adolescent Sensory History: Self-report Questionnaire - sample pages (Appendix F)
- Adult/Adolescent Sensory History: Report Form (Appendix G)
- Hospital Anxiety and Depression Scale (HADS) (Appendix H)

## PAPER 1: SENSORY PROCESSING OF WOMEN DIAGNOSED WITH GENITO-PELVIC PAIN/PENETRATION DISORDER: A RESEARCH PROPOSAL

Labuschagne E, van Niekerk M. Sensory processing of women diagnosed with genito-pelvic pain/penetration disorder: a research proposal. *BMC Research Notes*. 2019;12(1):577. <https://doi.org/10.1186/s13104-019-4612-6>.

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RESEARCH NOTE

Open Access



# Sensory processing of women diagnosed with genito-pelvic pain/penetration disorder: a research proposal

Elsie Labuschagne\* and Matty van Niekerk

## Abstract

**Objectives:** The study objectives are to describe the sensory processing patterns of women diagnosed with genito-pelvic pain/penetration disorder (GPPPD), to explore the level of anxiety when both GPPPD and sensory processing disorder (SPD) are present and to investigate participants' experience of participating in a sensory-based home programme.

**Methods:** A descriptive two-phased study design will be used. Phase one is a quantitative, cross sectional non-experimental descriptive study, using the Adolescent/Adult Sensory History (ASH) and Hospital Anxiety and Depression Scales (HADS) to obtain data from purposive sampling. Phase two is an exploratory qualitative study involving participants who were identified with SPD in phase one. They will participate in a sensory-based home programme and their experience thereof will be established during semi-structured interviews.

**Outcomes:** Descriptive studies are known to be useful in planning health services and to develop hypotheses for future testing. This study could improve practitioners' understanding of GPPPD and SPD and make alternative, non-invasive, non-pharmacological treatment options available to better assist these patients. The study could further clarify the role of the occupational therapist in sexuality. Exploring participants' anxiety has important implications for treatment protocols in occupational therapy and assisting in describing the signs and symptoms of GPPPD.

**Keywords:** Sensory processing disorder, Genito-pelvic pain/penetration disorder, Female sexual pain, Anxiety, Occupational therapy, Sensory integration

## Introduction

The role of sexuality is often ignored in occupational therapy. Literature regarding sensory processing and female sexual dysfunction, specifically genito-pelvic pain/penetration disorder (GPPPD), is virtually non-existent. In occupational therapy, sexuality falls into the performance of activities of daily living (ADL) as well as the fulfilment of various roles. Dysfunction in this performance area is therefore of concern to occupational therapists, as it may affect a client's occupational performance, activity participation and thus well-being [1]. A study

by Engel-Yeger et al. [2] recommends that occupational therapists address intimate relationships during sensory processing disorder (SPD)-related intervention with adults.

Women diagnosed with GPPPD experience sexual and psychological difficulties as well as significant relationship impairments [3]. The sensation of pain (which is linked to interoception [4, 5]) is an important symptom of GPPPD and is the only sensory modality that is commonly researched and explored. A recent study [6] found pain sensitivity to be related to over-responsivity in a person with sensory modulation disorder (SMD), a sub-component of SPD.

Sensory processing disorder (SPD) [7–9] is a result of difficulty grading and/or regulating responses to sensory input and collectively refers to three diagnostic groups,

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namely sensory modulation disorder (SMD), sensory discrimination disorder (SDD) and sensory-based motor disorder (SBMD) [7, 10]. The diagnostic groups and their respective sub-types [7, 10] are illustrated in Table 1.

Individuals with SOR experience non-painful sensations as abnormally irritating, unpleasant or painful [7, 12], which can result in defensive behaviour, such as tactile defensiveness. Atypical sensory processing responses have significant implications for quality of life (QoL) [11, 13–15], pain [6, 16–19], socio-emotional aspects [20–24], interpersonal relationships [25–28], and intimacy [2, 29].

A multi-disciplinary, multi-modal approach [30–34] is emphasised for treatment of GPPPD. Current GPPPD treatment options range from medical intervention, physical therapy, and psychosocial treatments, which reflect the current concepts regarding its aetiology [33]. Physical touch is often emphasised in relationships [29], therefore many professionals introduce touch therapy (e.g. sensate focus) as a treatment modality for sexual dysfunction [34, 35]. However, conventional treatment methods used by the multi-disciplinary team to treat female sexual dysfunction may be rendered ineffective, or may actually exacerbate the condition in persons with SPD.

The possible inter-relatedness of GPPPD and SPD could have significant implications, not only in understanding SPD and its impact on intimate relationships, but also for conventional treatment methods used by the multi-disciplinary team. It could uncover another factor in the aetiology of female sexual pain and lay the foundation for inclusion of sensory integrative occupational therapy treatment in the current multi-modal approach.

Anxiety has been confirmed to accompany diagnoses of both sensory processing [20, 22, 23, 36] and sexual pain disorders [37–42]. The presence of SPD is not only a risk factor for the development of mental health conditions, e.g. anxiety, [6] but is also known to have an impact on the treatment of anxiety. The presence of sensory defensiveness hampers the treatment of mental health problems, e.g. anxiety, and pharmacological and psychological approaches only offer a short term solution [11]. A 2010

study of sensory defensiveness (a form of SOR) and mental health [11] found that treating anxiety through mainly cognitive strategies was ineffective in persons with SOR. Since tactile-based therapies have been shown to be effective at modulating arousal, attention and sensory defensiveness [43], these treatment modalities should be used in conjunction with traditional treatment of anxiety, particularly for people with SPD.

### Objectives

The objectives of the study are to describe the sensory processing patterns of women diagnosed with GPPPD, to explore the level of anxiety when both GPPPD and SPD are present and to investigate participants' experience of participating in a sensory-based home programme.

### Main text

#### Study design

Since there is a dearth of information related to SPD and GPPPD in combination, a descriptive two-phased study [44] will be conducted.

Phase one consists of a quantitative, non-experimental descriptive study. Online questionnaires will be used to collect data regarding participants' sensory processing.

Phase two consists of a qualitative study using semi-structured individual interviews to gather information regarding participants' experience of participating in a sensory-based home program. Qualitative research designs can, however, evolve and may only be finalised once data collection ends [44].

### Phase one

#### Participants

Sex, intimacy and sexual pain remain private topics which may result in a reluctance to participate. In an attempt to overcome this barrier, healthcare professionals (HCP) working in the field of sexual health will be recruited to invite their patients to participate in the study, which introduces omission bias, as potential participants in the public sector are likely to be excluded. Purposive sampling [45, 46] with snowballing will be

**Table 1 Sensory processing disorder: diagnostic groups and subtypes. Adapted from: (Miller et al. 2007: page 137) [8]**

Diagnostic groups:	Sensory modulation disorder (SMD)	Sensory discrimination disorder (SDD)	Sensory based motor disorder (SBMD)
Subtypes	Sensory over-responsivity (SOR) Sensory under-responsivity (SUR) Sensory seeking/craving (SS)	Auditory Proprioception Tactile Taste/smell Vestibular Visual	Postural disorder Dyspraxia

used in an attempt to overcome the omission bias. All women who meet the inclusion criteria will be included. The estimated number of patients seen per annum by healthcare professionals consulted prior to commencing the study indicated a population size of 200 women. In order for the survey results to be statistically valid a minimum of 132 completed questionnaires are required. The margin of error was set at 5% and the confidence level at 95%. With an estimated response rate of 25% for online surveys, a total of 528 participants would have to be invited to achieve the required sample size. Inclusion criteria are (i) females from the age of 18 and (ii) a diagnosis of GPPPD. Exclusion criteria are (i) previous treatment for SPD; (ii) diagnosis affecting the neurological system e.g., Multiple Sclerosis; (iii) cancer-related diagnosis; and (iv) pregnant at time of completing questionnaire.

#### **Research instruments**

**Sensory processing** Sensory processing patterns will be measured by 163 items on the Adolescent/Adult Sensory History (ASH) questionnaire [47]. Reliability of the ASH's total score is 0.85 and concurrent validity 0.78 ( $p < 0.001$ ) [47–49]. The ASH is relatively new, but has already been used in a few studies [50, 51]. This self-report questionnaire identifies dysfunction in five key areas, namely sensory discrimination, sensory modulation, postural/ocular skills, praxis/motor coordination, and social-emotional functioning, [47] as well as functional problems related to each of these areas. Additionally, it describes overall sensory processing which is also divided into sub-sections based on sensory modalities (e.g., touch and taste). It uses a five-point Likert-type scale and can be used by individuals aged 13 to 95 years. The questionnaire takes 15 to 20 min to complete.

The ASH provides a total score, reflecting the functioning in overall sensory processing. This is followed by sub-scores for the sensory section, sensory modulation, sensory discrimination, functional problems and motor/social sections respectively. Each sub-score also consists of separate modalities which identify problems in specific areas.

While the original instrument allows for a small number of questions not to be completed, the online questionnaire will only proceed to the next section if all items have been completed, thus attempting to minimise incomplete questionnaires which cannot be included for analysis.

**Anxiety** Levels of anxiety will be assessed by the Hospital Anxiety and Depression Scale's (HADS) scales for Anxiety (HADS-A). This self-administered subscale consists of seven questions for anxiety, with a four-point (0 to 3) ordinal response format. The instrument takes between

two to five minutes to complete. The HADS-A has a correlation score of 0.80 and the validity has been described as good to very good [52]. Cut-off scores are available for quantification, for example a score of 8 or more for anxiety has a specificity of 0.78 and a sensitivity of 0.9, and for depression a specificity of 0.79 and a sensitivity of 0.83 [53, 54].

Cut-off scores existed for the following diagnostic categories: normal (score 0 to 7), borderline (8 to 10) and clinical/abnormal (score 11 to 21).

#### **Procedure/data collection**

Potential participants will receive an e-mail from the HCP containing information regarding SPD and a link to a secure online questionnaire on the Research electronic data capture (REDCap) platform. Participation in both phases will be completely voluntary and participants can withdraw from the study without any detriment at any time. Informed consent will be obtained electronically, prior to completing the demographic information (age, gender, additional diagnosis, highest qualification, marital status, number of children and age, sexual history, province) and online questionnaires (ASH and HADS). Data can be submitted anonymously, or an e-mail address can be provided should participants wish to be considered for phase two of the study. Each online questionnaire will receive a unique identification number. All identifying data (including consent regarding participation in phase two and e-mail addresses) will be kept securely, separate from the questionnaires. Once a questionnaire has been scored and SPD identified, the questionnaire number will be compared to the list of participants who gave consent to be contacted regarding participation in phase two.

Ethical clearance has been obtained from the Human Ethics Research Committee at the University of the Witwatersrand (Certificate Number M170829).

#### **Data analysis**

Responses to the questions will be assigned a numeric value within REDCap software. The raw data for each participant will be exported from REDCap to Excel.

The responses to the ASH will be entered into the AASH-Scoring Program®, which generates individual reports providing raw scores, z-scores and interpretation of scores. Standardised scores will be divided into three categories (nominal variables), namely "typical performance", "mild difficulties" (frequently demonstrates functional difficulties in some areas of sensory, motor or social/emotional processing) and "definite difficulties" (performance is well outside typical performance and almost always results in functional difficulties). Clinically, a diagnosis of "mild difficulty" requires further investigation or assessment whereas a diagnosis of

“definite difficulty” requires intervention. For analysis purposes, the “mild difficulty” and “definite difficulty” categories will be combined, to indicate the percentage of participants who fall outside the parameters of typical functioning.

The responses to the HADS-A will be exported to Excel and scored according to its categories, namely normal, borderline and clinical/abnormal.

Results obtained on the ASH and HADS-A (only anxiety items will be computed as the presence of depression is beyond the scope of the current study) will be transferred to Excel for each participant and then to an Excel summary sheet for each instrument. The cleaned data will be imported into Statistica analytics software program.

Descriptive statistics will be used to analyse data. Ordinal data obtained via the demographic questionnaire, specifically age and sexual history will be analysed using measurement of central tendency, specifically the mean and median, as well as measurement of dispersion of the data, specifically the standard deviation and range.

Categorical data obtained via the ASH and HADS-A will be analysed using frequencies and percentages.

## Phase two

### Participants

Purposive sampling will be used and participants who meet the inclusion criteria of phase two will be invited to participate in a sensory-based home program. Inclusion criteria are (i) a diagnosis of SPD identified in phase one; (ii) consent to take part in phase two; and (iii) resides in Gauteng or Kwazulu-Natal provinces to attend interviews.

### Procedure/data collection

The sensory-based home-programme consists of an initial interview, followed by implementation of strategies and a follow-up interview.

Qualitative data will be collected through initial individual interviews, during which information regarding personal experiences and impact of sensory processing, SPD, personalised interventions, and possible treatment techniques will be discussed and/or demonstrated. The home programme will be client-centred and may include interventions, such as changes to the environment, adaptations to tasks, preventing and/or avoiding potential sensory triggers, as well as self-regulation strategies. The researcher will be available telephonically should any questions arise during the execution of the home programme. Semi-structured, individual follow-up interviews will be conducted to obtain information regarding participants' experience of participating in a sensory-based home programme. The follow-up interview may be

conducted via electronic media e.g., Skype. All interviews will be audio-recorded and transcribed. The researcher will take field notes during the interviews. Data will be collected until saturation is reached and no new information is obtained during the interviews. According to Guest et al. [45] six to twelve interviews should suffice when the aim is to describe a homogeneous group's perceptions and experiences using nonprobability sampling. Malterud et al. [55] introduced the model of “information power” for qualitative studies where sample size is determined by the amount of relevant information related to the research question. Data collected will be checked on an ongoing basis and these sampling methods will assist in determining the sample size/data saturation [56].

### Data analysis

Inductive thematic content analysis [57–59] will be used to analyse data obtained from the interviews. A computer-assisted qualitative data analysis software program, Atlas.ti8, will be used to analyse qualitative data. Vertical analysis of the individual transcripts will be done, and data will be grouped according to themes/topics identified, resulting in codes that capture the essential elements in the data. An inductive thematic network approach will be used, utilising a coding framework containing a list of codes emerging from the data. Codes could be added to the list or changed as the process unfolds. Once all the data have been coded, codes will be grouped into themes. Horizontal analysis will be used to look for common threads [56, 60].

Various parameters of trustworthiness will be applied to ensure rigor. This includes using an interview protocol [60] consisting of a list of open-ended questions supporting the research question, to ensure a consistent style of data collection. The implementation of the sensory-based home programme will follow a standard framework, but include individual treatment activities based on participants' unique sensory processing profile obtained from phase one. Furthermore, the researcher will ensure prolonged engagement in the field, thus data will be collected until saturation is reached and no new information is obtained during the interviews. An inductive thematic saturation model will be used to ensure saturation [61]. Reflexivity will be practised throughout the process and continuous self-examination will be done to ensure that researcher-subjectivity does not interfere with data collection. This will also assist in limiting bias during data collection and contribute to the quality and objectivity of the results.

Findings will be reported using thick, rich descriptions of data, ensuring validity [56, 60]. Member checking will be done to ensure data were interpreted accurately [62].

An audit trail will assist with checking procedures followed and conclusions reached, enhancing credibility and dependability of the results. Dependability of data will be further enhanced by peer coding. Codes will be checked with an independent person, i.e. the researcher's supervisor.

A data management system is crucial to rigorous qualitative research. All records and data will be managed, maintained and backed-up using the Office365 cloud, with assistance from the University's data librarian. Once the study has been completed, the data will be stored in the University library's research repository.

### Conclusion

This is to our knowledge the first study investigating the sensory processing patterns of women diagnosed with GPPPD.

Although much has been written about GPPPD and SPD as separate entities, there is a paucity of literature describing the potential co-existence of these two conditions. The study results could be used to assist in planning healthcare services for women with GPPPD and to develop hypotheses for future research [63]. Since a multidisciplinary and multidimensional approach is already recommended for treating GPPPD, describing the sensory processing patterns of women with GPPPD may have important implications for future treatment of GPPPD. Sensory processing intervention has not been evaluated as a possible option for managing GPPPD, despite evidence suggesting that SPD intervention assists with pain management [18]. Current conventional, multidisciplinary treatment methods for female sexual dysfunction, e.g. sensate focus, may be rendered ineffective or actually worsen the condition in persons with SPD, thus necessitating identifying the sensory processing patterns of women with GPPPD prior to commencing treatment.

A common theme in both these study fields is the presence of affective symptoms, i.e. anxiety in women diagnosed with a sexual disorder [38], or adults diagnosed with SPD [64], necessitating investigating the extent of participants' anxiety.

### Limitations

SPD is not necessarily a well-known field outside of occupational therapy, thus a lack of knowledge regarding SPD among participants and referring HCPs could result in non-participation because HCPs and/or women with GPPPD do not grasp the value of understanding sensory processing patterns and its importance in managing pain (and thus potentially GPPPD). Non-participation may give rise to sampling bias. In an attempt to overcome this aspect of selection bias, the researchers developed

a concise information sheet describing SPD, to educate both the HCPs and the participants.

Since phase one data are obtained via self-report questionnaires, participants may want to give socially desired responses which could give rise to measurement bias. This was ameliorated by ensuring anonymity. Providing socially desired responses on the ASH could result in misinterpreting sensory processing difficulties. Thus, using the ASH and interpreting it carefully will assist in mitigating measurement bias in cases where participants agreed to be identified for inclusion in phase two.

Study sample size may be limited due to purposive sampling, because recruitment will be done by HCPs practicing in the field of sexual health. Thus the sample is potentially limited to clients with access to private medical facilities and more extensive personal resources. For this reason, snow-ball sampling was included to encourage both HCPs and participants to include practitioners/participants from the public health sector.

Voluntary participation may also impact on sample size as sensitivity and possible stigma surrounding sexual dysfunction may limit study participants to those whose symptoms are severe enough to seek help. Very anxious/sensitive clients may not be accessed due to their fear of seeking help. Phase two's sample size may be further affected by clients' willingness to take part in a sensory-based home programme and limited participants may be available in the provinces indicated.

However, despite these limitations, this is an important study due to the dearth of information and thus will potentially make a valuable contribution to the body of knowledge.

### Abbreviations

ASH: Adolescent/Adult Sensory History; ADL: activities of daily living; GPPPD: genito-pelvic pain/penetration disorder; HADS: Hospital Anxiety and Depression Questionnaire; HADS-A: Hospital Anxiety and Depression Scale's scales for Anxiety; HCP: Healthcare professionals; QoL: quality of life; REDCap: research electronic data capture; SBMD: sensory based motor disorder; SDD: sensory discrimination disorder; SMD: sensory modulation disorder; SOR: sensory over-responsivity; SPD: sensory processing disorder; SS: sensory seeking; SUR: sensory under-responsivity.

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### Authors' contributions

EL was involved in conception and EL and MVN were involved in the design of the study. EL drafted the manuscript and MVN reviewed the manuscript. Both authors read and approved the final manuscript.

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**Availability of data and materials**

Not applicable. This is a research proposal and no datasets were generated.

**Ethics approval and consent to participate**

This study has been approved by the Human Research Ethics Committee of the University of the Witwatersrand (Certificate Number M170829). Written, informed consent, assent and permission will be obtained from the necessary parties.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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## CHAPTER 4. PAPER 2

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### INTRODUCTION TO PAPER 2

An earlier version of this paper was presented as a poster (Appendix J) at the World Federation of Occupational Therapists Congress, May 2018 in Cape Town.

Preliminary results were reported as a pilot study (Appendix J).

Paper 2 represents results from the first phase of the descriptive two-phased study. The results describe sensory processing patterns of women diagnosed with GPPPD as well as the level of anxiety when both SPD and GPPPD are present. Participants completed self-report questionnaires via a secure online platform and the data collection period was extended to allow more participants from this 'hard-to-reach' population to participate.

From the results we learnt that a significant number of participants presented with SPD (requiring further investigation and/or intervention) and anxiety was present in just more than two-thirds of participants. The tactile sense was the most affected sensory modality with an atypical pain response and tactile related functional difficulties featuring prominently among participants.

For the purposes of the dissertation, tables and figures are kept within the text for ease of reference. Tables, figures and page numbers will be formatted and included as per submission guidelines when the manuscript is submitted to the Archives of Sexual Behaviour. Submission guidelines are included as an appendix (Appendix K).

## **PAPER 2: SENSORY PROCESSING DYSFUNCTION IN WOMEN WITH GENITO-PELVIC PAIN/ PENETRATION DISORDER**

### **TITLE PAGE**

#### **Sensory Processing Dysfunction in Women with Genito-Pelvic Pain/ Penetration Disorder**

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Ethical clearance was obtained from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand with clearance certificate number: M170829.

## **ABSTRACT**

**Background:** Conventional multi-disciplinary treatment methods for female sexual dysfunction may be rendered ineffective or actually worsen the condition if the person has sensory processing dysfunction (SPD). Conventional treatment methods can activate the sympathetic nervous system (SNS), resulting in fight-or-flight-or-freeze reactions, affective responses and sensory overload.

**Aim:** To describe the sensory processing of women diagnosed with GPPPD and to explore the presence of anxiety when both GPPPD and SPD are present.

**Methods:** A quantitative, non-experimental cross-sectional descriptive study was conducted, using the Adult/Adolescent Sensory History (ASH) and Hospital Anxiety Scales (HADS-A) to obtain categorical data. Purposive sampling, with snowballing, was used to recruit 'hard-to-reach' participants via healthcare practitioners (HCPs). Forty-four women who met inclusion criteria completed questionnaires online.

**Results:** Quantitative descriptive analyses indicated that the majority (79.5%; n=35) of participants presented with SPD requiring further investigation and/or intervention for SPD. Tactile processing was the most (79.5%; n=35) affected and 75% (n=33) of participants experienced sensory discrimination (SD) difficulties. Significantly, 77.3% (n=34) of participants had an atypical pain response and 68.2% (n=30) presented with aggressive/impulsive behaviour. Results of the HADS-A indicated 68.1% (n=30) of participants experienced anxiety.

**Clinical implications:** Occupational therapy, based on a sensory integrative (OT/SI) approach, provides an additional, non-invasive, non-pharmacological intervention option and should be included in the current holistic treatment approach. This study's results should improve HCPs' understanding of GPPPD to better assist these patients and improve understanding of the role of OT in sexuality.

**Conclusion:** Sensory processing dysfunction has been identified as an alternative factor in women with GPPPD.

**Key words:** Genito-pelvic pain/penetration disorder, sensory processing dysfunction, sensory integration, anxiety; occupational therapy intervention.

## INTRODUCTION

Conventional treatment of genito-pelvic pain/penetration disorder (GPPPD) includes a multi-disciplinary, multi-modal approach (Aerts et al., 2016; Bergeron et al., 2011; Goldstein et al., 2016). Current treatment options vary from medical intervention, physical therapy and psychosocial treatments and reflect the current concepts regarding its aetiology (Bergeron et al., 2015). Physical touch is often emphasised in relationships (Maclaren, 2014) and many professionals introduce touch therapy e.g. sensate focus, as a treatment modality for sexual dysfunction (Clayton & Valladares Juarez, 2017). However, these interventions may be rendered ineffective or actually exacerbate the condition in persons with comorbid sensory processing dysfunction (SPD), particularly in view of the dearth of literature investigating SPD and females with sexual pain, specifically GPPPD.

An integrated model (Bergeron et al., 2011), which includes biomedical, cognitive, affective, behavioural and interpersonal factors, has been proposed for GPPPD intervention, and the complexity of female sexual dysfunction and the role of physical, psycho-social, hormonal, and genetic factors was acknowledged (Clayton & Valladares Juarez, 2017). The only sensory aspect mentioned in this approach is pain. The absence of other sensory modalities, especially sensory processing, is alarming for two reasons. Firstly, sensory input and processing are integral to sexuality, and secondly, sensory processing may influence, or be affected by, pain.

The concept of sensory integration (SI) was first identified by Jean Ayres, and involves the registration, integration and organisation of information obtained from the environment and the body itself by the different sensory systems, namely visual, auditory, gustatory, olfactory, tactile, vestibular and proprioception (Ayres & Robbins, 2005; Schaaf & Davies, 2010; Su & Parham, 2014). The pervasive tactile system is fundamental in social, emotional, motor and neurological functioning of human beings (Bodison & Parham, 2017; S. J. Lane & Schaaf, 2010).

The field of sensory integrative therapy is evolving (Roley et al., 2007; Schaaf & Davies, 2010) and this has led to confusion about terminology related to sensory integration, sensory integration dysfunction, sensory processing dysfunction/disorder and the proposed subtypes (Dunn, 2001; Lucy J Miller et al., 2009; Roley et al., 2007; Schaaf & Davies, 2010). For the purpose of this paper, the term sensory processing dysfunction (SPD) (which is used in the manual of the outcome measure for sensory functioning (May-Benson, 2015)) will be used to

refer to persons who experience difficulties related to registration, integration and organisation of sensory input.

Atypical SI has a significant impact on quality of life (QoL) (Abernethy, 2010; Bar-Shalita & Cermak, 2016; Kinnealey et al., 2011), occupational performance (Brown & Fisher, 2015), pain (Bar-shalita et al., 2014; Bar-Shalita et al., 2015; Engel-Yeger & Dunn, 2011a; Meredith, Rappel, et al., 2015), sleep (Engel-Yeger & Shochat, 2012), mindfulness (Hebert, 2016), socio-emotional aspects (Brindle et al., 2015; Engel-Yeger et al., 2018; Engel-Yeger & Dunn, 2011c), motor coordination (Lucy Jane Miller et al., 2017; Schaaf, Schoen, et al., 2015) interpersonal relationships (Ben-Avi et al., 2012; Branjerdporn et al., 2019; Meredith, Bailey, et al., 2015) and intimacy (Engel-Yeger et al., 2015; Maclaren, 2014). Despite its impact on QoL and specifically intimacy, literature regarding SPD and intimate relationships is limited. A recent study (Engel-Yeger et al., 2015) specifically recommends that occupational therapists (OTs) must address intimate relationships during intervention. Other studies often only mention that SPD can impact on intimate relationships, without describing the specific impact of SPD on intimacy (Abernethy, 2010; Engel-Yeger et al., 2015, 2018) or potential intervention aimed at intimacy.

A recent review emphasised the role of SI, especially interoception, in mental health conditions (Harrison et al., 2019). Interoception provides information regarding bodily processes e.g. pain, temperature, itch, tickle, sensual touch, muscle tension, hunger, fullness, thirst, heart rate, breathing rate, nausea, sleepiness, stomach discomfort and need for the bathroom (Craig, 2002; De Preester & Manos, 2018; Mahler & Craig, 2017), and assists with homeostasis (Craig, 2002, 2003, 2008; Khalsa et al., 2018; Mahler & Craig, 2017). Interoception plays an important role in self-regulation, emotional experiences, decision making and consciousness (Khalsa et al., 2018) and several studies have linked it to emotional regulation (Barrett, 2016; Craig, 2008; Khalsa et al., 2018).

Sensory processing disorder (Lucy J. Miller et al., 2007; Lucy J Miller et al., 2009) is a result of difficulty grading and/or regulating the intensity of responses to sensory input and has a significant impact on a person's activities of daily living, including intimacy (Heller, 2003). Should women with GPPPD also present with SPD, it could have significant implications, not only in understanding SPD and its impact on intimate relationships, but also for conventional treatment approaches used by the multi-disciplinary team in GPPPD. Understanding the sensory integration of women with GPPPD could lay the foundation for inclusion of non-

invasive, non-pharmacological occupational therapy, using a sensory integrative (OT/SI) (Schaaf & Davies, 2010) approach, as intervention in the current multi-modal approach, since occupational therapists with postgraduate training in SI are best suited to provide treatment for SI difficulties (Abernethy, 2010).

Thus, this study aimed to describe the sensory processing of women diagnosed with GPPPD and to explore the presence of anxiety when both a diagnosis of GPPPD and SPD are present.

## **BACKGROUND/LITERATURE**

No research literature investigating SPD and females with sexual pain, specifically GPPPD, could be sourced. This literature review will therefore discuss sensory processing, anxiety and its relationship to both sensory processing and GPPPD, as well as GPPPD in a discrete manner. Where possible, the potential influence of SI on pain and GPPPD will be highlighted using the literature from domains other than sexuality or sexual functioning.

The recently developed Adult/Adolescent Sensory History (ASH) assessment (May-Benson, 2015), based on ASI®, identifies sensory modulation (SM) and sensory discrimination (SD) difficulties as well as functional difficulties related to SM, namely sensory over-responsiveness (SOR) and sensory seeking (SS), while functional difficulties related to SD, includes postural control and motor coordination/praxis.

### **Sensory Modulation**

Sensory modulation difficulty is an over-reaction to otherwise harmless sensory stimuli (Kinnealey et al., 2011) and may occur in one or multiple sensory systems (Abernethy, 2010; S. J. Lane & Schaaf, 2010). It is a dual process of responding to the intensity and duration of sensory stimuli, where the central nervous system enables neurological regulation and processing thereof, followed by a behavioural response to these stimuli (Brown et al., 2019). Sensory modulation is associated with inadequate inhibition of irrelevant sensory stimuli (Brett-Green et al., 2010) and may result in a fight-or-flight reaction. The fight-or-flight reaction is due to the activation of the autonomic nervous (ANS) system, specifically the sympathetic nervous system (SNS) (Kinnealey et al., 2011; Lucy J. Miller et al., 2007; Schaaf, 2010) and may elicit strong emotional outbursts (Jagiellowicz et al., 2016; Lucy Jane Miller et al., 2017; Pfeiffer et al., 2018).

Emotional regulation, including regulating anxiety, is central to the limbic system via the sympathetic and parasympathetic systems. Both the sympathetic and parasympathetic systems have been linked to atypical sensory processing (Lucy J. Miller et al., 1999; Schaaf, 2010; Schaaf, Benevides, et al., 2015), emotional regulation and pain (Basson, 2012; Dunkley & Brotto, 2016).

People with SM difficulties spend a lot of energy coping with their sensitivities and they tend to avoid or withdraw from activities/sensory experiences which often result in them feeling isolated (Kinnealey et al., 2011). The isolation/withdrawal further impacts interpersonal communication and interaction, ultimately affecting QoL (Kinnealey et al., 2011).

Sensory modulation difficulties present as SOR/defensiveness, SS/craving and sensory under-responsivity (SUR) behaviour (Schaaf, 2010; Schaaf & Davies, 2010). Sensory under-responsivity is not described in the ASH, but refers to a lack of awareness or reduced sensitivity to sensory stimuli and persons with SUR need more intense stimulation before registering sensory input (Lucy J Miller et al., 2009). The current paper will only focus on SOR and SS behaviour as these are described by the ASH (May-Benson, 2015).

Non-noxious sensations are experienced as irritating, unpleasant or painful by persons with SOR (Blanche et al., 2014; Lucy J Miller et al., 2009). Problems are usually displayed as sensory defensiveness (Abernethy, 2010; Pfeiffer & Kinnealey, 2003) and impacts negatively on functional abilities (self-care tasks, patterns of intimacy and choice of clothes, occupations, leisure activities, friends and accommodation), mental health, behaviour and emotions (Abernethy, 2010). An adverse reaction to movement due to SOR, results in gravitational insecurity (GI) (extreme fear and anxiety associated with movement in space, especially as the position of the head changes) (May-Benson, Teasdale, & Santos Faria, 2016).

In contrast, SS is a tendency to seek/engage in behaviours which generate sensations that are more intense and/or frequent when compared to the general population (Blanche et al., 2014). Seeking behaviour, an active coping mechanism, can assist with regulation of sensory input (Reynolds et al., 2015) and thus may be used to assist with SM difficulties. Sensory seeking behaviour further decreases signs of depression (Dean et al., 2017) because SS behaviour requires one to actively engage in activities and the environment (Bar-Shalita & Cermak, 2016).

Sensory seeking may also be present in persons with sensory discrimination difficulties, due to poor perception of sensory stimuli (May-Benson, 2015).

Functionally, SM difficulties may present as SOR to sensory input (which results in sensory defensive behaviour, such as avoidance or hyper-sensitivity (Ayres & Robbins, 2005)) or in SS behaviour (which has also been described in persons with SD difficulties because they find it difficult to register input), which will be described below. Both avoidance and hyper-sensitivity to touch or certain sounds could affect the quality of intimate relationships, since other strategies to foster intimacy in women with GPPPD may depend on touch and using auditory techniques (e.g. music or “dirty talking (Winks et al., 2002)”), inadvertently triggering the ANS and thus defeating the purpose of the alternate strategies.

### **Sensory Discrimination**

Sensory discrimination refers to the interpretation of spatial and temporal elements of sensory stimuli (Lucy J Miller et al., 2009). Discrimination is essential for the development of body scheme, postural control, motor planning and motor coordination (Ayres & Robbins, 2005). Difficulty discriminating between sensory stimuli affects motor planning, sequencing, oral motor planning and fine motor skills negatively (Ayres & Robbins, 2005), resulting in frustration and feelings of failure (Purcell et al., 2015).

### **Sensory Processing Dysfunction and mental health**

The presence of SPD is a risk factor for the development of mental health conditions e.g. anxiety (Bar-Shalita & Cermak, 2016). Anxiety has been confirmed to accompany diagnoses of both sensory processing (Brindle et al., 2015; Engel-Yeger et al., 2011; Serafini et al., 2017) and sexual pain disorders (Leusink et al., 2016; Watts & Nettle, 2010). Additionally, SM can assist in the management of anxiety via improved regulation of sensory stimuli (Wallis et al., 2018).

Treatment of anxiety using mainly cognitive strategies was found to be ineffective in persons with SOR (Abernethy, 2010). Tactile input is a very important treatment modality in the treatment of SPD and tactile based therapies can be effectively used to modulate sensory arousal, attention and sensory defensiveness (Bodison & Parham, 2017). Women diagnosed with GPPPD often experience sexual and psychological difficulties as well as significant relationship impairments (Kingsberg et al., 2017; Pukall et al., 2016; Rancourt et al., 2017). It is evident that both SPD and GPPPD impact negatively on QoL.

## **Female Sexual Dysfunction**

The Diagnostic and Statistical Manual 5<sup>th</sup> edition (DSM 5) classifies female sexual dysfunction into three sub-categories, namely female sexual interest/arousal disorder, orgasmic disorder and GPPPD (Dunkley & Brotto, 2016), which is a radical deviation from the previous edition (i.e. DSM IV TR). The new category of GPPPD (American Psychiatric Association, 2013) has combined the previous diagnoses of dyspareunia and vaginismus. Dyspareunia and vaginismus encompass various sub-diagnoses/conditions and a variety of terms are associated with GPPPD (American Psychiatric Association, 2013). These terms could include provoked vestibulodynia, vulvodynia, hyperactive pelvic floor, chronic pelvic pain, pudendal neuralgia and painful bladder syndrome.

Best evidence intervention protocols to address female sexual pain conditions, require a holistic (bio-psychosocial) and multi-professional approach (Bergeron et al., 2015; Maseroli et al., 2018; Weinberger et al., 2019). Conventional treatment of GPPPD includes topical treatments, injections, vestibulectomy, laparoscopic surgery, physical therapy (incl. electromyographic biofeedback, electrical stimulation, vaginal dilators), cognitive behavioural therapy (incl. coping strategies, desensitization, relaxation techniques, mindfulness, education, communication skills training), sensate focus, couples therapy, acupuncture and hypnosis (Al-Abbadey et al., 2016).

This literature review briefly described types of SPD, highlighting its potential impact on intimacy and sexual function. The importance of anxiety for both SPD and GPPPD was discussed and conventional treatment strategies of GPPPD were mentioned.

## **MATERIALS AND METHODS**

### **Study design**

A quantitative, non-experimental descriptive study was used to describe the sensory processing of women diagnosed with GPPPD (Labuschagne & van Niekerk, 2019).

### **Participants**

Purposive sampling (Etikan, 2016) with snowballing was used to recruit appropriate participants. Sexual pain and intimacy are sensitive topics, making this a hard-to-reach

population (Shaghghi et al., 2011). Therefore, healthcare professionals (HCPs), specialising in sexual health, were requested to invite patients who meet the inclusion criteria to participate in the study and complete electronic questionnaires online. Most of these HCPs work in the private sector and potential participants in the public sector would have been excluded. Participants were invited to share information regarding the study with others. Snowball sampling was thus used to overcome the possible sampling bias (Kirchherr & Charles, 2018) and to increase sample diversity (Kirchherr & Charles, 2018; Shaghghi et al., 2011). Females from the age of 18 and who have a diagnosis of GPPPD were included in the study. Exclusion criteria were (i) previous treatment for SPD; (ii) diagnosis affecting the neurological system e.g. multiple sclerosis; (iii) cancer related diagnosis; and (iv) being pregnant at time of completing the questionnaire. This study will mainly focus on anxiety (rather than anxiety disorder), and specifically the level of anxiety experienced by participants in relation to SPD and female sexual pain. However, patients with a co-morbid diagnosis of anxiety disorder will not be excluded from the study as they often experience greater sexual dysfunction (Watts & Nettle, 2010).

## **Procedure**

Ethical clearance was obtained from the Human Research Ethics Committee at the University of the Witwatersrand prior to commencing with the study (Certificate Number M170829).

Potential participants received an e-mail from the HCP containing information regarding SPD and a link to a secure online questionnaire on the Research electronic data capture (REDCap) platform. REDCap is a secure, web-based application designed to support data capture for research studies and to ensure confidentiality as no identifying participant information is captured.

Participation was voluntary, and participants could withdraw from the study without any detriment at any time. Informed consent was obtained electronically prior to completing the demographic information (age, gender, additional diagnosis, highest qualification, marital status, number of children & age, sexual history, province) and online questionnaires (ASH & HADS-A). Data could be submitted anonymously and each online questionnaire received a computer-generated unique identification number. Participants could request the results by providing an e-mail address.

## **Measures/Measurements**

### ***Descriptive Variables***

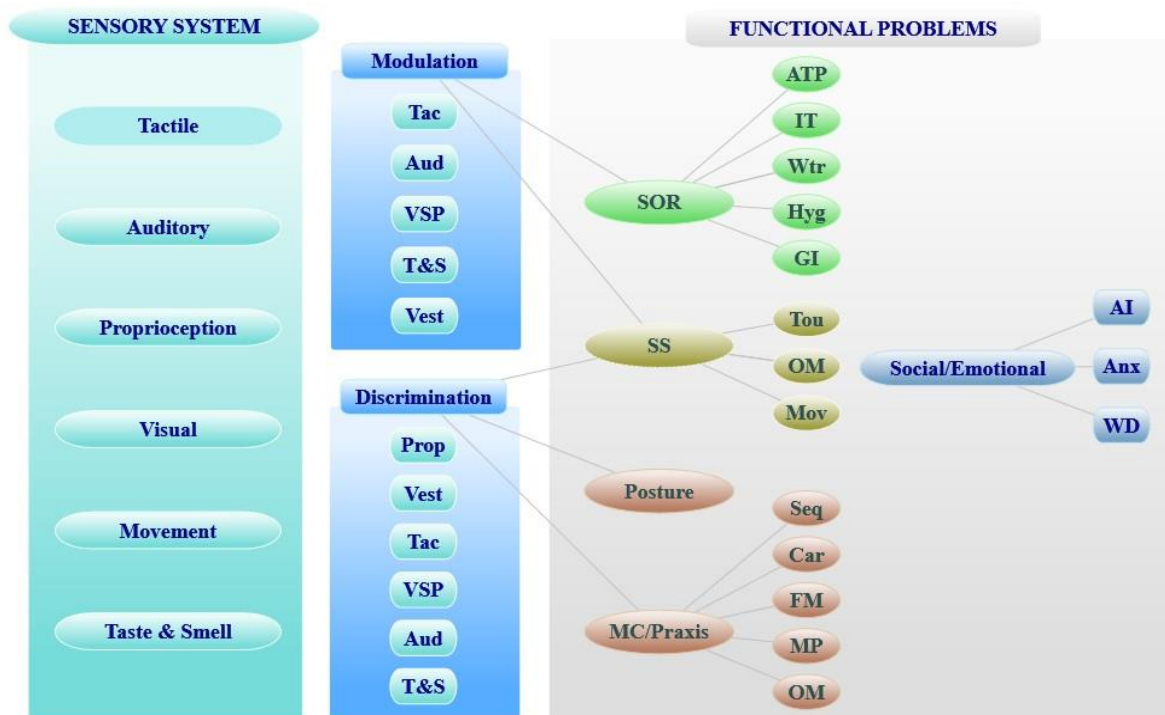
Participants completed online questionnaires which gathered information on socio-demographics, sexual pain history, sensory processing and anxiety.

### ***Main outcome measures*** (Labuschagne & van Niekerk, 2019)

#### *Sensory functioning*

Sensory processing are measured by 163 items on the Adult/Adolescent Sensory History (ASH) questionnaire (May-Benson, 2015). Reliability of the ASH's total score is 0.85 and concurrent validity 0.78 ( $p < .001$ ) (Chang et al., 2016; Holland et al., 2015; May-Benson, 2015). The ASH is relatively new but has already been used in a few studies (May-Benson, Teasdale, & Santos Faria, 2016; May-Benson, Teasdale, Amin-Arsala, et al., 2016). In line with ASI®, this self-report questionnaire identifies dysfunction in five key areas, namely, SD, SM, postural ocular skills, praxis/motor coordination (MC) and social-emotional functioning (May-Benson, 2015) as well as functional problems related to these areas (Figure 1). Additionally, it describes overall sensory processing which is also broken down into sub-sections based on sensory modalities (e.g. touch and taste). It uses a five-point Likert-type scale and can be used by individuals aged 13 to 95 years. The questionnaire takes 15 to 20 minutes to complete.

The ASH can be administered paper-based or electronically. Paper-based administration allows participants to omit a few questions, but online administration will only permit a participant to proceed once all items have been completed.



**Figure 1 Aspects evaluated by ASH. Adapted from: (May-Benson, 2015:p.35)**

### *Anxiety*

Levels of anxiety were assessed by the Hospital Anxiety and Depression Scale's (HADS) scale for Anxiety (HADS-A), because anxiety has been described in both women with GPPPD and persons with SPD. This self-administered subscale consists of seven questions for anxiety, with a four-point (0 to 3) ordinal response format. The instrument takes between two and five minutes to complete. The HADS-A has a correlation score of 0.80 and the validity has been described as good to very good (Bjelland et al., 2002). Cut-off scores are available for quantification, for example a score of 8 or more for anxiety has a specificity of 0.78 and a sensitivity of 0.9, and for depression a specificity of 0.79 and a sensitivity of 0.83 (Stern, 2014; Zigmond & Snaith, 1983). Cut-off scores exist for the following diagnostic categories: normal (score 0 to 7), borderline (8 to 10) and clinical/abnormal (score 11 to 21).

### **Statistical Analysis**

Descriptive statistics were used to analyse data and Statistica (v.13.4) was used to perform the statistical analysis.

Ordinal data collected on REDCap via the demographic and sexual pain history questionnaire were cleaned, coded in REDCap and imported into Statistica.

Responses to the ASH were entered into the ASH-Scoring Program©, and generated individual reports providing raw scores, z-scores and interpretation of scores. Standardised scores were divided into three categories (nominal variables), namely “typical performance”, “mild difficulty” (frequently demonstrates functional difficulties in some areas of sensory, motor or social/emotional processing) and “definite difficulty” (performance is well outside typical performance and almost always result in functional difficulties) (May-Benson, 2015). Clinically, a diagnosis of “mild difficulty” requires further investigation or assessment whereas a diagnosis of “definite difficulty” requires intervention. Scores for “mild difficulty” and “definite difficulty” categories were combined during analysis to indicate the percentage of women who fell outside the parameters of typical functioning but were reported separately on graphs for SI purposes.

Responses to the HADS-A were scored according to the three categories, namely “normal”, “borderline” and “clinical/abnormal”.

The results of the ASH and HADS-A were checked for accuracy and cleaned data were imported into Statistica for analysis.

Ordinal data were analysed using measurements of central tendency (mean and median) and dispersion (standard deviation and range), while categorical data obtained via the ASH and HADS-A were analysed descriptively using frequencies and percentages.

## **RESULTS**

### **Study Sample/Participant Characteristics**

Questionnaires were completed by 44 females which is below the target of 132 (Labuschagne & van Niekerk, 2019). The majority (79.5%; n=35) of participants were in the age band 20 to 39. Location demographics indicated that the majority of participants (72.7%; n=32) were from the Gauteng area, with no participants from the Eastern Cape and the Northern Cape. Ninety-one percent (n=40) of participants had a tertiary level of education. The majority (79.5%; n=35) of participants were married or in a domestic relationship and 54.5% (n=24) had children, of which 68.2% (n=30) of the participants who had children, had small children (i.e. in the age band infant to six years).

## **Diagnosis and Sexual pain history**

The diagnosis (Table 1) related to GPPPD that was most prevalent was marked vulvovaginal/pelvic pain during vaginal intercourse/penetration attempts, followed by marked tensing/tightening of pelvic floor muscles during attempted vaginal penetration. Participants could choose more than one diagnosis.

Additional diagnoses were reported by 25% (n=11) of participants. The diagnoses included: fibroadenoma, depression, lumbar spine disc injuries, pudendal entrapment, septate hymen, endometriosis, vulvodynia, Lichen Sclerosus, and bipolar disorder. One participant listed various additional diagnoses, namely borderline personality disorder, obsessive compulsive disorder, anxiety and depression, endometriosis, stomach ulcers, psoriasis, food allergies and allergies to external factors such as, pollen, dust, insect bites, grass and latex. None of the participants were excluded based on the additional diagnosis as SPD is often accompanied by co-morbid conditions involving the neurological (Mayer, 2017), immune (Engel-Yeger et al., 2011, 2014) and affective systems (Brindle et al., 2015; Serafini et al., 2017).

Sexual pain history indicated on average a 5-year difference between when the symptoms started (n =44; Mean = 2009) and when sexual dysfunction was diagnosed (n=44; mean=2014). The section as to when treatment for sexual pain commenced, was completed by only 84.1% (n=37) and the mean was 2013 and it is therefore possible that not all participants have received treatment for sexual pain.

Responses regarding treatment received for sexual pain varied greatly (Table 1).

Treatment was stopped by 13.6% (n=6) of participants as it did not work for them. A number of participants (15.9%; n=7) indicated other reasons for stopping treatment, which included: treatment was too painful, embarrassing and costly; symptoms still present after operation to widen the vagina; symptoms recurring; operation for endometriosis; working hours; Z-plastic operation and a diagnosis of Lichen Sclerosus.

**Table 1 Sexual dysfunction diagnosis, treatment received and additional diagnosis**

<b>Demographic Variable</b>	<b>n</b>	<b>%</b>
<b>Specific diagnosis re sexual dysfunction</b>		
Inability to have vaginal intercourse/penetration	7	15.9
Marked vulvovaginal/pelvic pain during vaginal intercourse/penetration attempts	35	79.5
Marked fear/anxiety about vulvovaginal/pelvic pain/vaginal penetration	17	38.6
Marked tensing/tightening of pelvic floor muscles during attempted vaginal penetration	30	68.2
<b>Treatment received</b>		
Never received treatment	7	15.9
Received treatment & cured	9	20.5
Still receiving treatment & symptom free	1	2.3
Receiving treatment & mild symptoms	8	18.2
Receiving treatment & still have significant symptoms	6	13.6
Stopped treatment as it did not work	6	13.6
Other	7	15.9
<b>Additional diagnosis</b>		
No	33	75
Yes	11	25

**Table 2 Pain experiences currently and prior to treatment**

Pain experience related to sex	Prior to treatment		Currently	
	n	%	n	%
Impossible	13	29.5	5	11.4
Extremely painful but possible	20	45.5	6	13.6
Moderately painful	8	18.2	11	25.0
Mildly painful	1	2.3	10	22.7
Uncomfortable	2	4.5	9	20.5
Pain free	0	0	3	6.8

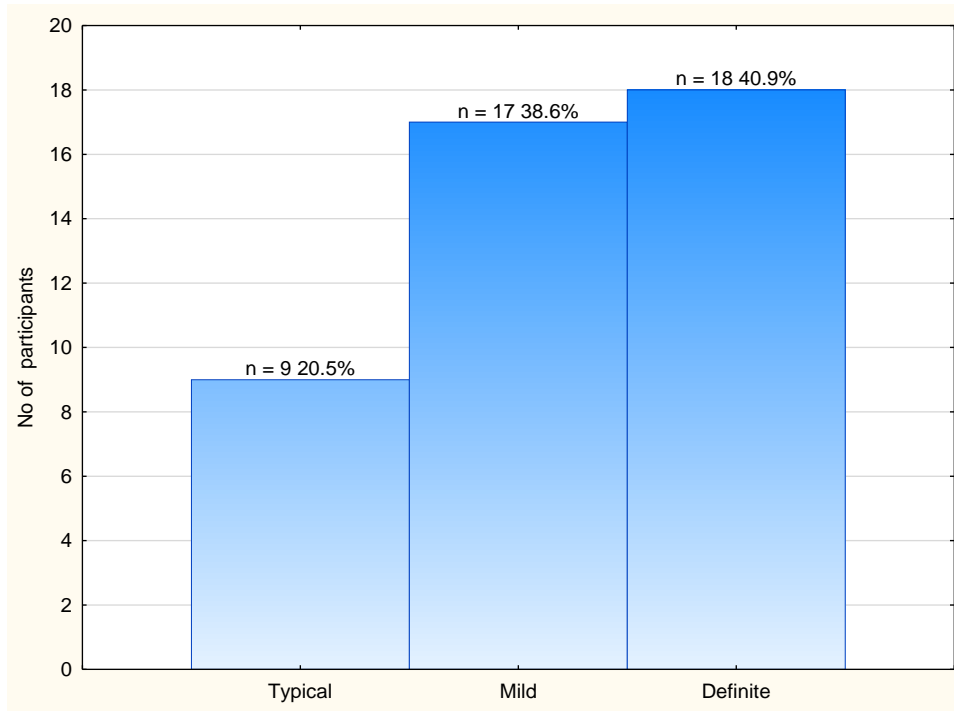
Participants' pain experiences (Table 2) displayed improvement after treatment for sexual pain.

### **Adult/Adolescent Sensory History (ASH)**

Because both the mild and definite categories of the ASH suggest atypical sensory processing, these were combined when describing the overall presence of SPD. However, these were kept separate in graphs. The results will be described starting with the total score, followed by individual sensory systems.

#### ***Total score***

The combined total score of the ASH provides a bird's eye view of the sensory processing of participants. Most of the participants (79.5%; n=35) presented with SPD. Scores for the mild and definite categories were very similar (Figure 2) and each was double (or near double) that of the participants with typical sensory processing.



**Figure 2 Total scores on ASH**

***Individual Sensory sections***

The tactile system was the most involved system with 79.5% (n=35) of participants presenting with difficulties related to tactile processing (Table 3). The remaining sensory systems, except for movement and taste & smell, had combined scores between 61.4% (n=27) and 70.4% (n=31) (Table 3). Movement, and taste & smell sensory systems were affected in slightly less than half of participants.

**Table 3 ASH’s combined scores (mild & definite scores) for sensory section, sensory modulation, sensory discrimination, functional problems and motor/social areas, including sub-scores (ranked from most to least involved) for each sensory modality**

<b>Sensory Section sub-scores</b>	<b>n</b>	<b>%</b>
Tactile	35	79.5
Auditory	31	70.4
Proprioception	27	61.4
Visual	27	61.4
Movement	21	47.7
Taste & Smell	20	45.4
<b>Sensory Modulation &amp; Discrimination sub-scores</b>		
<b>Sensory Modulation (SM)</b>	<b>30</b>	<b>68.2</b>
Tactile (Tac)	36	81.8
Auditory (Aud)	28	63.6
Visual Spatial Processing (VSP)	22	50.0
Taste & Smell (T&S)	16	36.3
Vestibular (Vest)	13	29.5
<b>Sensory Discrimination (SD)</b>	<b>33</b>	<b>75.0</b>
Proprioception (Prop)	28	63.7
Vestibular (Vest)	27	61.3
Tactile (Tac)	23	52.3
Visual Spatial Processing (VSP)	22	50.0
Auditory (Aud)	20	45.5
Taste & Smell (T&S)	20	45.5
<b>Functional Problems sub-scores</b>		
<b>Sensory Seeking (SS)</b>		
Seek Touch (Tou)	24	54.6
Visual Seeking/ Oculo-Motor (OM)	19	43.2
Seeks movement (Mov)	11	25.0

<b>Sensory Over-Responsivity (SOR)</b>		
Atypical Pain Response (ATP)	34	77.3
Discomfort with Imposed Touch (IT)	29	65.9
Discomfort with Water (Wtr)	26	59.1
Tactile-Related Hygiene (Hyg)	25	56.9
Gravitational Insecurity (GI)	16	36.3
<b>Motor/Social Section sub-scores</b>		
<b>Postural control (PC) (Posture)</b>	<b>17</b>	<b>38.7</b>
<b>Motor coordination (MC) (Praxis)</b>	<b>24</b>	<b>54.4</b>
Sequencing (Seq)	24	54.4
Difficulties Driving a Car (Car)	23	52.3
Fine Motor (FM)	15	34.1
Motor Planning (MP)	14	31.8
Oral Motor Planning (OMP)	14	31.8
<b>Social/emotional (S/E)</b>	<b>29</b>	<b>65.9</b>
Aggressive/Impulsive (AI)	30	68.2
Anxious (Anx)	21	47.8
Withdrawn/Depressed (WD)	21	47.7

### ***Sensory Modulation***

Sensory modulation difficulties were experienced by 68.2% (n=30) of participants. Significantly, the tactile (Tac) system was the most involved sensory system with 81.9% (n=36) of participants contributing difficulties in SM to tactile processing, followed by the auditory (Aud) system (Table 3).

### ***Sensory Discrimination***

Sensory discrimination difficulties were experienced by more participants when compared to SM difficulties (Table 3). Interestingly, the proprioceptive (Prop) and the vestibular (Vest) systems were the most involved systems, followed by tactile (Tac) and visual (VSP) systems.

### ***Functional problems sub-scores***

#### *Sensory seeking (SS)*

Touch seeking (Tou) behaviour were reported by just over half of participants, followed by visual seeking/oculo-motor (OM) score (Table 3). Interestingly, only 25% (n=11) of participants reported movement (Mov) seeking behaviour.

#### *Sensory over-responsivity (SOR)*

Notably, 77.3% (n=34) of participants, reported an atypical pain response (ATP) (Table 3). Functional problems involving the tactile (Tac) system followed, with discomfort with imposed touch (IT) indicated by 65.9% (n=29) of participants (Table 3). Discomfort with water (Wtr) and tactile-related hygiene (Hyg) was reported by more than half of participants.

### ***Motor/Social Sections***

This section reflects scores for postural control (PC), motor coordination (MC) (including sub-scores) and social/emotional (S/E) (including sub-scores).

#### *Postural control*

The majority of participants did not report difficulties related to PC (Table 3).

#### *Motor coordination*

Motor coordination difficulties were present in just over half of participants (Table 3) and reflects overall performance in gross and fine motor skills.

Sequencing (Seq) and difficulties driving a car (Car) were performance areas most affected by MC difficulties (Table 3).

#### *Social/Emotional*

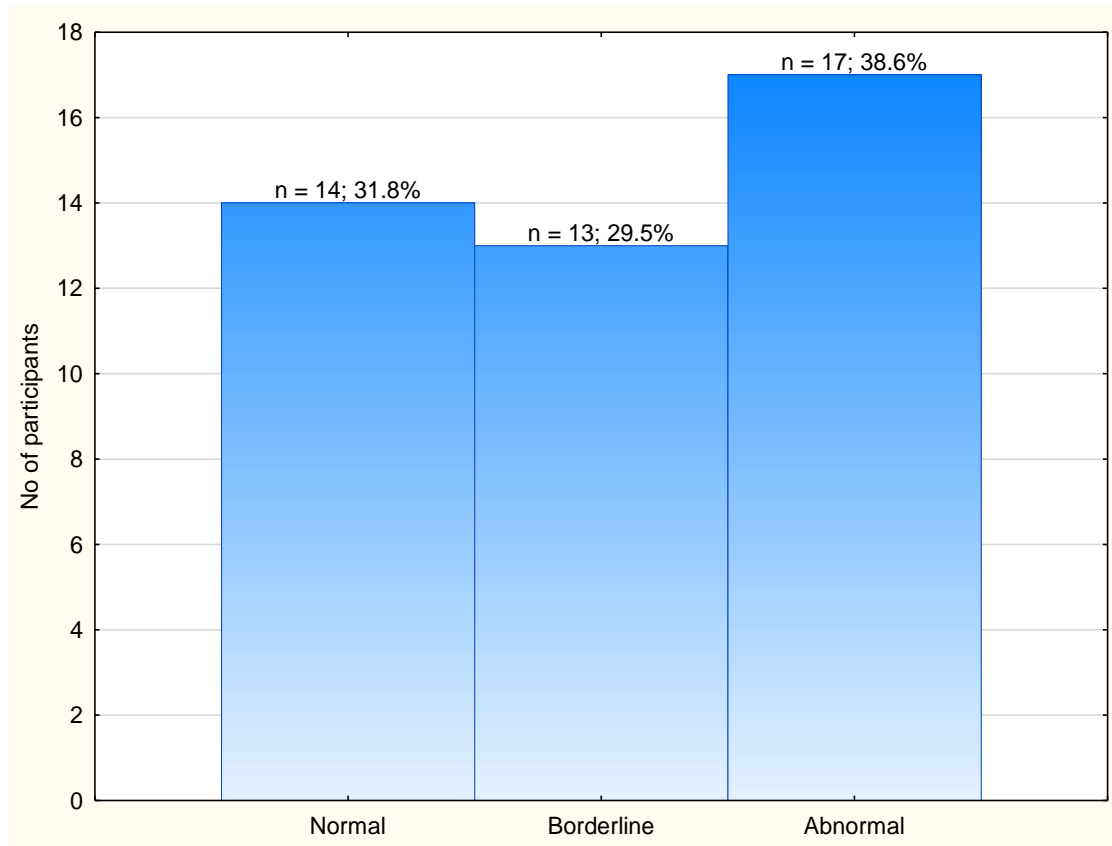
Social/emotional difficulties were reported by 65.9% (n=29) of participants (Table 3).

Significantly, aggressive/impulsive (AI) behaviour was reported by 68.2% (n=30) of participants and this score was significantly higher than the scores for anxious (Anx) and withdrawn/depressed (WD) behaviour.

## Hospital Anxiety and Depression Scale (HADS)

### *Anxiety*

The results (Figure 3) of the HADS-A indicates most participants scored in the abnormal category, followed by the borderline and normal categories. The combined score (borderline & abnormal categories) indicates 68.1% (n=30) of participants experiences anxiety.



**Figure 3 Anxiety scores on the HADS-A**

Participants' responses (borderline and abnormal categories) on individual items on the HADS-A that obtained a score of '3' (highest score) are ranked in Table 4.

**Table 4 ASH-A: responses obtaining a score of ‘3’**

<b>Response item</b>	<b>n</b>	<b>%</b>
‘I feel tense or ‘wound up’	12	40.0
‘Worrying thoughts go through my mind’	7	23.3
‘I get a sort of frightened feeling like something awful is about to happen’	5	16.7
‘I get sudden feelings of panic’	4	13.4
‘I get a sort of frightened feeling like ‘butterflies in the stomach’	2	6.7
‘I can sit at ease and feel relaxed’	2	6.7
‘I feel restless as if I have to be on the move’	1	3.3

## **DISCUSSION**

This study indicates that roughly four out of five women diagnosed with GPPPD also have SPD. This novel study was conducted as literature regarding SPD and women with a history of sexual pain, could not be sourced.

Sensory modulation and its associated functional problems will be discussed first, followed by SD and its associated functional problems (Figure 1). Discussion of social/emotional aspects, limitations and future research will conclude this section.

### **Sensory modulation**

This study found about two thirds of participants have SM difficulties, with the tactile and auditory systems most involved. It should be noted that other studies reported on sensory processing difficulties in a more global manner, due to using different instruments such as, the Adult/Adolescent Sensory Profile (Ben-Avi et al., 2012; Delahunt & Mische Lawson, 2017; Engel-Yeger et al., 2015; Engel-Yeger, Muzio, et al., 2016; Engel-Yeger & Dunn, 2011b; Engel-Yeger & Rosenblum, 2017; Hebert, 2016; Meredith, Bailey, et al., 2015; Re et al., 2014; Serafini et al., 2017), Sensory Responsiveness Questionnaire (Bar-Shalita & Cermak, 2016; Mazor-Karsenty et al., 2015), Highly Sensitive Person Scale (Branjerdporn et al., 2019; Jagiellowicz et al., 2016) and Sensory Processing Scale (Blanche et al., 2014; Schoen et al., 2014; Tavassoli et al., 2018), making this study unique in that it reports on specific sensory processing difficulties also in relation to specific sensory systems.

### *Sensory over-responsivity*

Participants in this study reported an atypical response in relation to pain (ATP), followed by problems related to the tactile system – most importantly in relation to imposed touch (IT), and GI, each of which will be discussed below.

Notably, four out of five participants have atypical pain responses as evidenced by the functional problem sub-scores for SOR. Atypical pain responses in women with SPD and GPPPD may affect the intensity of sexual pain responses. Pain perception and sensory processing could be related and expressed via pain catastrophizing (Engel-Yeger & Dunn, 2011a; Meredith, Rappel, et al., 2015). A recent study (Meredith, Rappel, et al., 2015) found catastrophizing to be used as a coping mechanism for pain and it was also associated with sensory sensitivity and sensory avoiding, but not with low registration.

After pain, many participants described SOR related to tactile input. Of these difficulties, IT is noteworthy, due to its importance in sexuality and intimacy.

Discomfort with IT, i.e. physical touch not initiated by them, was reported by two-thirds of participants. Participants reported becoming irritated/angry if being bumped, pushed unexpectedly or becoming bothered by people being too close to them, which is likely to have a negative impact on intimacy. Previous studies have found touch to be fundamental in the development of a sense of oneself, improving human well-being, emotional connection, psychological well-being and physiological development (Kreuder et al., 2017; Maclaren, 2014). Interpersonal touch is fundamental to intimacy (Debrot et al., 2013; Kreuder et al., 2017; Maclaren, 2014). Persons presenting with SOR may therefore have greater difficulty making an emotional connection, may also have intimacy issues and may limit or avoid partaking in kissing and fellatio, thus further, specific research is necessary.

Just over half of participants reported discomfort with water (Wtr) and tactile related hygiene (Hyg) due to SOR of the tactile system. Personal hygiene may be neglected, e.g. washing hair, showering and shaving (Abernethy, 2010; May-Benson, 2011), and could affect intimacy negatively. Furthermore, creams and lotions e.g. lubricants, as well as bodily fluids e.g., ejaculate could be a source of distress in a person with SOR of the tactile system, and further specific research may be necessary.

It is important to note the involvement of the tactile system, and the possible implication this has for treatment of GPPPD. Conventional treatment methods, such as applying topical

treatments and touch therapy (Al-Abbadey et al., 2016; Clayton & Valladares Juarez, 2017; Rudolph, 2017; Weinberger et al., 2019), can have devastating consequences for a person with SPD as these treatment methods influence ANS responses, specifically the SNS. Activation of the SNS results in the fight-or-flight response and increases anxiety and tension (Champagne et al., 2015) impacting QoL. The SNS could be activated by a conventional treatment technique such as sensate focus, where light stroking is used to enhance the relationship between partners. This light stroking could elicit a strong emotional outburst reflecting a fight-or-flight reaction (Brett-Green et al., 2010; Jagiellowicz et al., 2016; Pfeiffer et al., 2018) and counters the natural tendency of participants in this study to seek deep pressure/touch. Individuals with tactile processing difficulties have difficulty tolerating light touch, thus rendering the treatment ineffective. Tactile-based therapies should, however, not be excluded from treatment for conditions, such as female sexual pain and anxiety. Rather, the correct application of tactile intervention should be done by an occupational therapist trained in sensory integration. Sensory integration treatment for SPD is client specific and a comprehensive assessment of sensory processing and related difficulties is required before implementing any treatment.

A smaller number of participants reported difficulties related to GI. Gravitational insecurity may contribute to the low score on movement seeking and will be discussed below. The impact of GI on intimacy has not been investigated previously. Strategies which assist with feedback regarding body position in space include aspects such as preferences regarding surfaces (e.g. the type of bed used), preferences regarding sexual positions and surfaces, ambient light, or keeping one's eyes open/closed (Heller, 2003), but were not specifically investigated in this study .

### ***Sensory seeking***

Interestingly, participants in this study seek tactile (Tou) input, e.g. crave being held, prefer wearing tight clothing and mouthing objects or clothing, despite the tactile system being the most affected system. It is important to note that the tactile input participants seek in this study refer to deep touch pressure, which is often used in treatment of tactile defensiveness (Champagne et al., 2015; Losinski & Ennis, 2016) and can elicit changes in automatic sensory arousal (Reynolds et al., 2015). This is also different from conventional touch therapy used in the treatment of women with GPPPD (Al-Abbadey et al., 2016; Clayton & Valladares Juarez, 2017; Vannier et al., 2017), which relate mostly to light touch. Light touch is likely to elicit

the fight-or-flight response whereas deep touch pressure is likely to inhibit such a response.

Seeking movement (Mov) activities e.g., fast movement sports, rocking, jumping, shaking/banging of head and chewing, were used least by participants despite evidence (Stoller et al., 2012; Warner et al., 2013) supporting the use of movement to assist with SM. The lack of movement seeking was also reflected on the HADS-A, where the item participants reported to experience the least was having a “feeling of restlessness and the urge to move”.

Difficulties related to MC and Seq were reported by just more than half of participants. Interestingly, a previous study found young adults with MC difficulties tend to avoid/adapt or withdraw from activities they find challenging (Tal-Saban et al., 2014). Motor coordination and sequencing difficulties, together with GI difficulties discussed earlier, could contribute to participants avoiding movement activities that can potentially assist with SM, but may also result in them avoiding sexual activities requiring MC and sequencing or may result in preferences for specific sexual positions that do not require coordination, sequencing or gravitational security. However, avoidance or preference regarding sexual positions among women with SPD and GPPPD were not the focus of this study and should be further investigated in the future.

### **Sensory Discrimination**

A significant number of participants experienced problems related to SD, and difficulties related to performance in functional areas were expected. However, PC was marginally affected and participants did not seem to use SS to compensate for poor SD. The proprioceptive and vestibular systems are the most affected systems related to SD difficulties. These two systems play a vital role in MC, specifically sequencing and contributes among others in difficulties driving a car (Ayres & Robbins, 2005; Bundy et al., 2002) .

Motor coordination difficulties were present in just more than half of participants, with an equal number of participants indicating difficulties related to sequencing, followed closely by difficulties driving a car.

Participants with sequencing and motor planning difficulties struggle with activities that include several steps, sequences, rhythm and they generally struggle with sports, exercise routines e.g. aerobics and dancing (Heller, 2003; May-Benson, 2015).

The impact of sequencing and MP difficulties during intercourse could be significant as rhythmical movements often form part of intercourse and assist with climaxing (Bø, 2012; Winks et al., 2002). Participants may lose the rhythm during intercourse, and having to start again may affect their ability to reach climax. They may also have a limited repertoire of sexual positions and be reluctant to try new positions or sexual styles. Sequencing and MP may also impact negatively on the optimal use of self-care tools (also referred to as sex toys) (Singh-Kurtz, 2019), contributing to feelings of frustration, increased anxiety and avoiding sex altogether and further research is required.

A functional aspect related to MC evaluated by the ASH is difficulty driving a car. It is interesting to note that just more than half of participants have difficulty with this activity of everyday life. While expressed in relation to driving a car, it must be noted that individual items included in the assessment are not exclusively linked to driving a car, but includes learning how to ride a bicycle, difficulty if not sitting in the front seat (intolerance of movement e.g. motion sickness), merging into traffic and difficulty driving a car (May-Benson, 2015). The first two aspects are closely linked to insufficient vestibular processing (Bundy et al., 2002; Heller, 2003; Lopez, 2016). Merging into traffic relates closely to sequencing, timing and motor planning (de Waard et al., 2009; Singh et al., 2006). The results suggest that aspects linked to inadequate processing of vestibular input, specifically intolerance of movement, may have played a bigger role during the participants' self-evaluation of driving a car than actual driving ability. This is based on the fact that motor planning, which is an important component of driving a car, is only affected in about a third of participants, whereas the vestibular system was affected in almost two-thirds of participants with SD difficulties. Difficulties driving a car as reported on the ASH may therefore be influenced more by poor vestibular discrimination in these participants than motor planning. Poor vestibular discrimination is likely to have an impact on sexuality and intimacy and requires further research.

A somewhat surprising finding is that PC, which is also largely dependent on proprioceptive and vestibular processing (S. J. Lane et al., 2019), is not significantly affected. Most studies related to PC and SI have been performed on children and postural difficulties are more evident in that population (Ayres & Robbins, 2005; A. E. Lane et al., 2014). The results of the current study do not reflect what is reported in the literature regarding postural difficulties. The adult population might have developed coping strategies, such as using vision or partaking in core strengthening exercises, to reduce clumsiness and to compensate for poor

posture and tone. Furthermore, lifestyle demands related to PC could be less due to ergonomic adjustments and/or avoidance of certain activities.

### **Social/Emotional**

Significantly, aggressiveness/impulsiveness behaviour were experienced by just more than two-thirds of participants and may explain why persons with SPD often have difficulty with interpersonal interaction and relationships (Ben-Avi et al., 2012). Aggressive/impulsive behaviour is most likely due to a defensive coping mechanism during sensory overload (Branjerdporn et al., 2019; Meredith, Bailey, et al., 2015).

Sensory defensiveness and overload usually triggers autonomous fight-or-flight reactions (S. J. Lane et al., 2012; Schaaf, 2010; Schoen, 2009), which could result in aggressive/impulsive behaviour.

The current study supports the negative impact of SM difficulties on S/E functioning previously described (Bar-Shalita & Cermak, 2016). Interestingly, the percentage of participants in the current study who presented with SM difficulties were very similar to participants identified with aggressive/impulsive behaviour under S/E difficulties on the ASH (Table 3), and anxiety on the HADS-A (Figure 3). Anxious and withdrawn/depressed behaviour, as identified by the ASH, were present in just under half of the study sample.

Anxious and withdrawn/depressed behaviour were present in just less than half of participants and supports previous studies identifying emotional distress and persons with sensory processing difficulties (Bakker & Moulding, 2012; Bar-Shalita & Cermak, 2016; Engel-Yeger et al., 2018; Engel-Yeger & Dunn, 2011c; Levit-Binnun et al., 2014; Meredith, Bailey, et al., 2015; Serafini et al., 2017).

The low scores for anxiety as identified on the ASH do not correlate with findings of previous studies investigating sensory processing and anxiety (Engel-Yeger & Dunn, 2011b, 2011c; Kinnealey & Fuiiek, 1999; Meredith, Bailey, et al., 2015). Anxiety on the ASH is assessed using only four questions which refer to very distinct behaviours that occur as a result of anxiety (May-Benson, 2015). Previous studies used various questionnaires, some of which measure only anxiety (Engel-Yeger & Dunn, 2011b), while others measure emotional/psychological distress and could possibly explain the difference in anxiety scores in those studies (Bakker & Moulding, 2012; Bar-Shalita & Cermak, 2016; Engel-Yeger et al., 2018; Levit-Binnun et al., 2014).

Anxiety score on the ASH also did not reflect the scores obtained on the HADS-A. The combined score for the borderline & abnormal categories for anxiety on the HADS was higher than the combined score for mild & definite dysfunction for categories (anxious category only) on the ASH. The HADS detected higher levels of anxiety compared to the anxious scores of the ASH.

While depression has been linked to sensory processing (Engel-Yeger et al., 2018; Engel-Yeger, Gonda, et al., 2016; Engel-Yeger & Dunn, 2011c) the results on the ASH for depressed/withdrawn did not support finding in those studies. Previous studies again used specific instruments to assess depression in the adult population. The ASH only has six questions related to depression and may only be able to identify very severe cases of depression (May-Benson, 2015).

Thus, the results of this study suggest that the ASH anxious and depression components do not accurately reflect the presence of (clinical) anxiety or depression, and similar to other studies, independent anxiety and/or depression scales should be used to identify the presence of anxiety or depression. Interestingly, participants' overall scores for S/E functioning on the ASH could be indicative of difficulties in this area. Further investigation is warranted should the patient report feelings of anxiety and depression during a clinical interview.

Several studies have confirmed the link between sensory processing and psychological distress in people of all ages (Bailliard & Whigham, 2017; Bar-Shalita & Cermak, 2016; Ben-Sasson & Podoly, 2017; Brindle et al., 2015; Engel-Yeger et al., 2018). The current study indicates that aggressive/impulsive behaviour and not necessarily anxiety and depression could be the biggest contributor to psychological distress in persons with SPD.

It is evident that the emotions experienced and behaviours displayed by participants with SPD are integral to the condition and support findings of previous studies (Branjerdporn et al., 2019; Brindle et al., 2015; Engel-Yeger, Gonda, et al., 2016; Kinnealey & Fuiiek, 1999; Levit-Binnun et al., 2014; Meredith, Bailey, et al., 2015) and should not be treated in isolation. It is a complex interrelationship and extra care should be taken when a person presents with socio-emotional difficulties, SPD and GPPPD.

## **Limitations and future research**

The study sample was limited as purposive sampling was mainly used to recruit participants due to the sensitive nature of the study. Participation was also voluntary. Therefore only people who were comfortable sharing their experiences related to sexual pain participated, which is likely to give rise to bias. Additionally, the small sample means that the results cannot be generalised, thus are not necessarily representative of the whole population.

Cooperation from HCPs in the field of sexual health varied and some practitioners sent out more questionnaires, which could have skewed the sample to some extent. Another limiting factor is that participants had to have access to a computer and internet. Response bias was limited as data were obtained via validated self-report questionnaires. Despite these limitations, the current study could open up new treatment modalities for women who have been diagnosed with GPPPD and at the very least highlights that conventional treatment modalities, such as touch therapy should be employed with greater circumspection.

Interoception should be assessed in future studies as internal body awareness is crucial to awareness of sexual arousal (Handy & Meston, 2018), and the ASH does not assess this aspect.

Future research is required to determine the presence of SPD in the broader spectrum of female sexual dysfunction. The impact of SPD on sexual activities and intimacy should be investigated as it could provide a better understanding of certain behaviour/sexual preferences e.g. persons with poor sensory registration might be prone to seek additional sensory input, and could result in taking part in kink (non-traditional sexual practices (Waldura et al., 2016)), particularly Bondage, Dominance and Sadoomasochism (BDSM) activities (De Neef et al., 2019; Pillai-Friedman et al., 2015; Williams et al., 2016; Wismeijer & van Assen, 2013).

## **CONCLUSION**

This is, to our knowledge, the first study investigating SPD and GPPPD. The study describes the sensory processing of most participants with GPPPD as atypical, with significant difficulties in both SM and SD areas. Tactile, auditory, proprioceptive and vestibular senses are most affected, resulting in functional problems and social-emotional difficulties that could have an impact on sexual function, sexuality and intimacy.

This finding has significant implications for the assessment and treatment of women diagnosed with GPPPD, not only for health professionals specialising in sexual dysfunction, but also for occupational therapists (Barefield, 2015; Rose & Hughes, 2018) working with adults with sensory processing difficulties. The importance of a holistic team approach cannot be emphasised enough, because the presence of SPD adds an additional layer of complexity to a condition that is already intricate.

Furthermore, understanding SPD and the impact thereof, can be an important component of cognitive behavioural therapy (CBT) which is being used as a treatment modality in both GPPPD (Dunkley & Brotto, 2016) and SPD (Edgington et al., 2016; Pfeiffer et al., 2018).

The finding that women with GPPPD present with SPD has significant implications for conventional treatment, which, in some cases, are likely to exacerbate, rather than alleviate, symptoms.

This pioneering study is important, as OT/SI intervention has not previously been included in treatment protocols for GPPPD. This study shows that OT/SI intervention adds an important dimension to the holistic treatment approach and management of female sexual pain disorders.

### **List of abbreviations**

ADL: Activities of daily living; ASH: Adult/Adolescent Sensory History; ASI®: Ayres Sensory integration®; ANS: Autonomic nervous system; BDSM: Bondage, Dominance and sadomasochism; DSM: Diagnostic and Statistical Manual of Mental Disorders; GPPPD: Genito-pelvic pain/penetration disorder; GI: Gravitational insecurity; HADS: Hospital Anxiety and Depression Scale; HADS-A: Hospital Anxiety and Depression Scale for Anxiety; HCP: Healthcare practitioner; HREC: Human Research Ethics Committee at the University of the Witwatersrand; OT: Occupational therapy; OT/SI: Occupational therapy (using a) sensory-integrative (approach); MC: Motor coordination; PC: Postural control; QoL: Quality of life; REDCap: Research electronic data capture; SD: Sensory discrimination; SE: Social/emotional; SI: Sensory ; SP: Sensory processing; SPD: Sensory processing dysfunction; SM: Sensory modulation; Seeking; SNS: sympathetic nervous system; SOR: Sensory over-responsivity; SPD: Sensory processing disorder/dysfunction; SS: Sensory; SUR: Sensory under-responsivity.

## **Declarations**

### **Ethics approval and consent to participate**

This study has been approved by the Human Research Ethics Committee of the University of the Witwatersrand (Certificate Number M170829). Written, informed consent, assent and permission will be obtained from the necessary parties.

### **Consent for publication**

Not applicable.

### **Availability of data and materials**

Datasets were generated, but are not published. Applications for access can be addressed to the second author as per institutional rules.

### **Competing interests**

The authors declare that they have no competing interests.

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### **Authors' contributions**

EL was involved in data collection, formal analysis, and writing of the original draft and secured funding. EL and MVN designed the study. MVN reviewed and revised the manuscript. Both authors read and approved the final manuscript.

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## CHAPTER 5. PAPER 3

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### INTRODUCTION TO PAPER 3

Paper 3 represents results from the second phase of the descriptive two-phased study. The results describe the experiences of women who participated in a sensory-based home program (SBHP). Women identified with sensory processing dysfunction in Phase one and whom indicated during the initial phase of the study that they would be interested in participating in Phase two, were contacted to take part in Phase two.

A total of 21 participants met the inclusion criteria for Phase two. Upon further analysis of the results of Phase one, 13 participants required intervention (scores fell in the definite category of the ASH) for SPD and were contacted. Nine participants indicated a willingness to continue to take part in Phase two. However, two participants were unable to attend the first interview due to unforeseen work commitments, and they were also unable to attend interviews on alternative dates.

Seven participants participated in the first interviews and commenced with the SBHP. However, only five participants were able to attend the face-to-face or Skype follow-up interviews. The researcher attempted on several occasions to accommodate the remaining two participants, but were unable to gather data from the remaining two participants. The small number of participants necessitated alternatives to determine sample size. The model of information power<sup>202</sup> as mentioned in Paper 1<sup>47</sup>, was decided upon as sample size is determined by the amount of relevant information, and is more suited to studies exploratory in nature<sup>202</sup>. This will be discussed further in Chapter 6.

From the results we learnt participants experienced positive changes from participating in the SBHP and employed a variety of coping strategies. Themes generated from the data included changes experienced by participants and coping strategies employed by participants. The first author's journal/notes made during the interviews are attached as an appendix (Appendix L).

For the purposes of the dissertation, original Afrikaans quotes are used, with their respective English translations in brackets. The manuscript submitted to the journal

will not include both Afrikaans and English versions of the same quote, only English will be used.

Furthermore, tables are kept within the text for ease of reference for the purposes of the dissertation. Tables and page numbers will be formatted and included as per publishing guidelines when the manuscript is submitted to the South African Journal of Occupational Therapy (SAJOT). Guidelines for publishing are included as an appendix (Appendix M).

The authors are cognisant of the fact that the current article exceeds the recommend 12 to 16 pages, but for the purpose of the dissertation/examination the paper has separate results and discussion sections. However, when submitting to the journal, the discussion will be incorporated with the results to enable adherence to the page limit set by the journal.

## **PAPER 3: SENSORY PROCESSING DYSFUNCTION AND GENITO-PELVIC PAIN/PENETRATION DISORDER: WOMEN SHARE THEIR EXPERIENCES OF PARTICIPATING IN A SENSORY-BASED HOME PROGRAM**

### **TITLE PAGE**

**Sensory Processing Dysfunction and Genito-Pelvic Pain/Penetration Disorder: Women share their Experiences of Participating in a Sensory-Based Home Program**

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### **Authors' contributions**

EL was involved in data collection, formal analysis, and writing of the original draft and secured funding. EL and MVN designed the study. MVN reviewed and revised the manuscript. Both authors read and approved the final manuscript.

Ethical clearance was obtained from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand with clearance certificate number: M170829.

## **ABSTRACT**

**Introduction:** Female sexual pain especially, genito-pelvic pain/penetration disorder (GPPPD), is virtually unknown territory for occupational therapists and current multi-disciplinary interventions do not include occupational therapy (OT).

**Aim:** To describe the experiences of women with sensory processing dysfunction (SPD) and GPPPD and their participation in a sensory-based home program (SBHP).

**Methods:** A qualitative study design, using semi-structured individual interviews, was used to gather information and purposive, non-probability sampling was used to recruit participants. Sufficient information power was reached after five participants were interviewed. Data were analysed descriptively using inductive thematic and saliency analyses.

**Results:** Two themes were identified. **Theme one: Changes experienced after participating in a SBHP**, reflected increased insight into SPD (allowing participants to identify sensory triggers) and intra-personal changes (increased tolerance of sensory stimuli, feelings of control and *“I can breathe again”*). **Theme two: Coping strategies employed by women with SPD & GPPPD**, included sensory seeking, changes to home and work environments, positive reinterpretation/growth, acceptance and socio-emotional support (*“you’re not the only one. There are plenty of us out there.”*).

**Conclusion:** A sensory-based home program, catering to specific needs/personalities is beneficial as a non-invasive occupational therapy (based on sensory integrative therapy) intervention approach for women with both SPD and GPPPD.

**Key words:** Sensory Processing Dysfunction, Genito-Pelvic Pain/Penetration Disorder, Occupational Therapy Intervention, Sensory Integration, Home Program.

## INTRODUCTION

Sensory processing dysfunction (SPD) has only recently been described in women with genito-pelvic pain/penetration disorder (GPPPD) (Labuschagne E, van Niekerk M. *Sensory Processing Dysfunction in Women with Genito-Pelvic Pain/ Penetration Disorder*. Unpublished, 2020). Very little is known about the co-occurrence of these two conditions in women.

Pain is the only sensory aspect that has been investigated in women with GPPPD, and several studies found an increased sensitivity to pain in women suffering from sexual pain<sup>1-4</sup>. Increased pain sensitivity in women with vulvovaginal pain, has also been associated with psychosocial aspects, such as anxiety and depression<sup>5</sup>. Pre-existing psychosocial conditions, especially anxiety and depression, have been found to put women at greater risk of developing vulvovaginal pain<sup>5</sup>.

Both SPD and GPPPD present with neurological involvement. Pain perception is not only part of sensory integration (SI), but is also influenced by SPD<sup>6,7</sup> and is central in women who suffer from GPPPD<sup>8</sup>. Nonetheless, occupational therapists who treat SPD in adults have mostly addressed the interpersonal and relationship aspects affected by SPD, seldom considering sexual aspects<sup>9</sup>. Current interventions for women with GPPPD do not include occupational therapy (OT), despite commonalities evident in the literature, e.g. pain perception<sup>6,10</sup>, predisposition for developing affective conditions<sup>11,12</sup> and negative impact on QoL<sup>13,14</sup>.

Female sexual pain is virtually unknown territory for occupational therapists, even in the context of SI. Women with both SPD and GPPPD, may require OT intervention in addition to other therapies. The small number of occupational therapists with postgraduate SI qualifications who also work with adults may result in women having to travel great distances to get the necessary treatment and they may be unable to see the healthcare professionals

(HCPs) on a regular basis<sup>15</sup>. A home program is often a pragmatic solution<sup>16</sup> used as part of the treatment plan and may assist with overcoming logistical problems, e.g. limited time for appointments and/or distance from HCPs<sup>17</sup>.

A treatment protocol that includes home based activities (home program), was developed for adults with sensory processing disorder<sup>18</sup>. Home programs have been used effectively in persons with sensory processing difficulties and various other conditions<sup>19-21</sup>.

There is a dearth of information regarding women with SPD and GPPPD, including OT treatment approaches. Therefore, the aim of the study is to describe the experiences of women with GPPPD and their participation in a sensory-based home program (SBHP). This could have significant implications for future interventions for women with both these conditions and could support the inclusion of OT using a sensory integrative (OT/SI)<sup>22</sup> approach, as part of the holistic intervention approach. Furthermore, it could improve the understanding of the role of OT in sexuality<sup>9,23,24</sup>. This paper draws on data collected during a two-phased study<sup>25</sup>. Data from the second phase will be presented.

The next section describes literature regarding SPD and the impact thereof, GPPPD and the impact thereof and interventions related to GPPPD and SPD, including home programs. Thereafter the methods and results of the study will be presented, followed by a discussion of the results and a conclusion.

## **LITERATURE REVIEW**

Sensory integration dysfunction (SID), pioneered by Jean Ayres<sup>26-29</sup>, was found to continue into adulthood, impacting significantly on quality of life (QoL)<sup>7,20,30-36</sup>. Sensory integration involves integration and processing of information obtained from the different sensory systems, namely visual, auditory, gustatory, olfactory, tactile, vestibular and proprioceptive. In recent years interoception has become more prominent in research, as it relates closely to

emotional regulation<sup>37-40</sup>. Terms describing atypical sensory processing have evolved over the years and for the purposes of this article it will be referred to as SPD<sup>41,42</sup>.

Sensory processing dysfunction has a complex inter-relationship with mental health conditions and may be a predisposing factor for the development of affective conditions, especially anxiety and depression<sup>43</sup>, adult attachment and coping<sup>44</sup>, attachment and emotional distress<sup>45</sup>, anxiety levels in adults<sup>46</sup> and psychological health complaints<sup>47</sup>. The impact of SPD on sleeping<sup>48</sup>, substance abuse<sup>49</sup>, impulsivity<sup>50,51</sup>, parenting and attachment styles<sup>52</sup> have been documented. Persons with SPD often employ various coping strategies to deal with the impact thereof<sup>7,14</sup>, which may include active and passive strategies<sup>7</sup>. Active strategies involve strategies such as coping self-statements, increasing activities level, ignoring pain, diverting attention, planning, using social support, acceptance, humour, venting of emotions, reflecting on self-growth and avoiding sensory stimuli, while passive strategies incorporate catastrophizing, praying/hoping, denial, using alcohol/drugs and mental disengagement<sup>7,14</sup>

Sensory avoidance, an active coping mechanism, may result in avoiding relationships, while persons with sensory sensitivity may experience increased anxiety related to relationships<sup>44</sup>. Furthermore, sensory sensitivity (low neurological thresholds) could affect social participation through avoiding social situations, resulting in perceived introversion<sup>47,53</sup>. It is evident from the literature that SPD not only affects personal feelings, but also the fulfilment of various life roles, social participation, interaction with the environment as well as occupational performance<sup>19,54</sup>. Individuals with sensory sensitivity displayed greater pain sensitivity affecting their QoL negatively<sup>30</sup>, while a recent study highlighted the association between sensory processing and pain coping strategies<sup>7</sup>.

Genito-pelvic pain/penetration disorder, a sub-category of female sexual dysfunction, was included in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5)<sup>55</sup>. This sub-category combined the previous diagnoses of dyspareunia ("recurrent or

persistent genital pain associated with sexual intercourse”) and vaginismus (“defined as recurrent or persistent involuntary spasm of the musculature of the outer third of the vagina that interferes with sexual intercourse”) found in the DSM IV TR<sup>1</sup>.

A recent review of GPPPD, not only emphasises the complex aetiology, assessment and treatment of the condition, but also emphasises the devastating impact GPPPD has on interpersonal relationships, psychosocial health and QoL<sup>1</sup>. Women with sexual pain avoid affectionate and sexual contact as they fear that it will lead to painful intercourse<sup>56</sup>.

Treatment of GPPPD is complex and consists of a multi-disciplinary, multi-modal approach<sup>1,8,15</sup> which can be expensive and at present does not include OT<sup>1</sup>. Several treatment challenges have been reported, the most prominent being difficulty coordinating the multi-disciplinary treatments<sup>8</sup>. Bergeron *et al.*<sup>8</sup> suggest that, due to the multifactorial nature of female sexual pain, the different disciplines involved in intervention must increase their interaction to assist with progress within the field of female sexual pain.

Treatment approaches for SPD have mostly focussed on children and adolescents<sup>19,49</sup>. Of late, the focus has shifted to the adult population<sup>19,35,57,58</sup>. A recent systematic review of commonly used OT interventions for children<sup>59</sup>, included sensory-based strategies and environmental adaptations<sup>60</sup>, cognitive and occupation-based interventions<sup>61</sup>, education and coaching<sup>62</sup> and Ayres Sensory Integration® (ASI®)<sup>63</sup>. Occupation-based and cognitive interventions are two of the most commonly treatment approaches in the treatment of SPD<sup>61</sup>.

Components of self-regulation, namely attention, response to sensory stimuli, feelings and learning, can be addressed in both above-mentioned interventions<sup>61</sup>. Occupation-based interventions at home, work and in the community<sup>64</sup>, are fundamental to OT and are based on the principle that engagement in activities of daily living (occupations) results in improved participation, QoL, and general well-being<sup>61,64</sup>.

Interventions for sensory processing difficulties include “therapeutic use of self, sensorimotor activities (individual and group), sensory-based modalities, sensory diet, and environmental enhancements”<sup>35(p.CE-4)</sup> and environmental and modifications<sup>35,65</sup>. The therapeutic use of self, refers to the therapist’s ability to provide verbal and non-verbal feedback during assessment and treatment, to create a “safe space”<sup>35(p.CE-4)</sup> and to encourage participation in purposeful activities and roles<sup>35</sup>.

Sensorimotor activities are activities in which persons engage due to their therapeutic benefits e.g. yoga, exercises groups and art classes. Sensory modalities include the use of special techniques or equipment like sound therapy, neurofeedback, aromatherapy or the use of weight. A sensory diet consists of sensorimotor activities that provide regulated sensory input and that can be included in a person’s daily routine<sup>58</sup> and is compiled in collaboration with the person with SPD<sup>35</sup>.

Environmental adaptations aim to either increase, decrease or avoid certain sensory input in the physical environment throughout the day<sup>35,66</sup>, affecting sensory arousal levels with the goal to improve self-regulation<sup>67</sup>. These adaptations are important when treating persons with SPD and include adjustments to sensory input like lighting, sounds, touch and movement in occupations (activities of daily living) in the home, work, leisure and social environments<sup>34,66,68,69</sup>. Environmental adaptations also include psychosocial support and strategies to develop and maintain social support networks<sup>54</sup>.

Another program, based on a home-program treatment protocol, includes three components, namely patient insight, regular daily sensory input and participation in physical activities (providing proprioceptive, tactile and vestibular input) chosen by the patient<sup>58</sup>. Home programs have been used to increase the frequency of therapy, or to provide intervention when a break is taken from therapy<sup>16</sup>. A study by Novak & Berry<sup>16</sup> found home programs are

effective if the content is based on proven effective interventions, the client's preferences are accommodated and client receives support e.g. coaching, during the implementation thereof.

Literature regarding the treatment of SPD supports the inclusion of several approaches and techniques. However, it is important that the interventions are client centred and individualised according to the persons' activity profile, needs and preferences<sup>19,35,58,60,61,68,70-72</sup>.

## **METHODOLOGY**

### **Study design**

A qualitative study design, using semi-structured individual interviews was used to gather information regarding participants' experience of participating in a sensory- based home program<sup>73,74</sup>. A descriptive approach was used to describe participants' experiences<sup>73,75</sup>. Ethical clearance was obtained from the Human Research Ethics Committee at the University of the Witwatersrand (HREC) (Certificate Number M170829).

### ***Participants/Sampling***

Genito-pelvic pain/penetration disorder is a newly reconstituted diagnosis in the DSM 5 and because sexual dysfunction is a sensitive topic, purposive, non-probability sampling<sup>76</sup> was used, based on the unpublished results of a prior study<sup>25</sup> within the overall project.

Participants from the prior study who presented with SPD and indicated a willingness to participate in the qualitative study and resided in Gauteng or KwaZulu-Natal (KZN) were invited to participate in a SBHP. Participants for Phase 2 were selected from Gauteng and Kwazulu-Natal due to logistical reasons as initial interviews had to be conducted face-to-face. This was necessary to ensure a good rapport was established with this 'hard-to-reach' population, especially due to the sensitive topic of sexual pain was to be discussed.

Furthermore, initial face-to-face interviews were conducted to ensure treatments techniques

(if applicable) were demonstrated adequately to the participants. Participants were interviewed prior to starting the home program to establish eligibility for inclusion. Results from Phase one were analysed and participants whose scores fell in the definite category, therefore requiring intervention for SPD, were contacted.

The model of information power<sup>76</sup>, whereby sample size is determined by the aim of the study, sample specificity, use of established theory, dialogue, and analysis of data, was used to guide data collection, and ultimately sample size. Preliminary analysis and appraisal of information power were done throughout the collection of in-depth data, and enough relevant data were collected after interviewing the five participants, reaching sufficient information power.

Information power was increased by the narrow study aim, describing specific perceptions and experiences not previously described in a 'hard-to-reach' population<sup>76</sup>. Specificity was increased via purposive sampling, as the sample consisted of participants with specific characteristics, namely women with GPPPD and SPD. Specificity was further increased by participants' specific and unique knowledge as well as experiences related to women with GPPPD and SPD.

Information power was further increased as the current study is supported by some theoretical background, even though most research regarding home programs have been conducted in the paediatric population<sup>16,77</sup>. The current study could therefore combine existing knowledge and contribute to new knowledge regarding the use of home programs in this specific population, resulting in a smaller sample size required.

### ***Data Collection***

Data were collected in a step-wise manner. First, an initial, face-to-face semi-structured individual interview which lasted approximately 1 ½ hours was conducted (both to ensure

eligibility for participation, but also to allow the researcher to obtain sufficient information about the participant to design a client-centred intervention strategy). When making appointments with participants, two hours were allowed for initial interviews to prevent rushing participants, which could potentially have negatively affected the quality of data<sup>78</sup>.

Participants shared personal experiences and the impact of sensory difficulties on daily life. The theory of SI and atypical integration of sensory stimuli were explained and made practical by linking it to their personal experiences. Possible interventions/strategies based on SPD-specific issues identified previously, were discussed and personalised interventions/strategies explained and demonstrated when necessary. Initial interviews were conducted over a period of eight months.

The client-centred SBHP consisted of: additional reading resources, exploring therapist-guided changes to home and work environments, adaptations to tasks, identifying and managing and/or avoiding potential sensory triggers, and self-regulation strategies, including implementing a progressive muscle relaxation (PMR) (via a video link), yoga, mindfulness and therapeutic brushing (TB) (Appendix O).

The SBHP was personalised to participants' interests/beliefs/abilities/resources and implemented over a period of six to eight weeks. The researcher was available telephonically to provide assistance and guidance if necessary<sup>16</sup>.

Follow-up interviews (either face-to-face or via Skype) lasted between 30 and 60 minutes<sup>79-81</sup>. Information regarding participants' experience of participating in a SBHP was obtained during the follow-up interviews. Open-ended questions included "have you experience any change?", "what strategy did you find most helpful?" and "what would you change?" The follow-up interviews took longer than expected to arrange and most were done between eight and 12 weeks post implementation.

One participant's interviews was conducted in English, whilst the remaining interviews were

conducted in Afrikaans. Semi-structured interviews were used, as it provides the opportunity for both participant and researcher to clarify certain concepts. Interviews also allow for sharing additional information<sup>82</sup>, which is important not only because SPD is an unfamiliar condition, but also due to the sensitivity of the topic<sup>83</sup>. All interviews were audio-recorded and transcribed and the researcher took field notes during the interviews.

The quality of the interview dialogue was important and strong, clear, open communication allowed for maximum data gathering in a non-threatening environment<sup>84</sup>. The interviews were conducted by the researcher who is experienced in the field of SI. Participants were put at ease and appeared to share information, including sensitive information, readily. The aim of the study, as well as what was expected of them were explained clearly, in layman's terms, facilitating trust and reducing uncertainty and anxiety<sup>84</sup>.

The researcher was aware of potential power imbalances during the interviews<sup>73</sup>, and care was taken to show respect to participants whilst also protecting professional ethics, and building rapport with participants<sup>78,84</sup>.

### ***Data Analysis***

Only data of the follow-up interviews were analysed, in keeping with the study objectives. The interviews were transcribed verbatim and read and edited by the researcher. Memo-ing was used to keep track of ideas and thoughts during the analysis process<sup>73</sup>. The researcher checked the accuracy of transcriptions and immersed herself in the data by simultaneously listening to and reading the transcriptions several times. Once checked, transcribed interviews were entered into Atlas.ti8 (a computer-assisted qualitative data analysis software program), and coded systematically<sup>78</sup>. The English interview was analysed first and codes generated.

Descriptive data analysis, specifically inductive thematic analysis<sup>78,85,86</sup> was used, and the

thematic network approach included saliency analysis (lower frequency codes that are pertinent to research aim are included in the analysis to enhance the coding process)<sup>87</sup>. Codes, categories and theme were not pre-determined, thus inductive and descriptive coding were used<sup>82</sup>. *In vivo* coding was used where possible, but due to the large number of Afrikaans participants, this was not necessarily possible.

First cycle coding actively generated codes and emerging codes were recorded in a codebook, while definitions/descriptions were amended as the process unfolded. The second author critically reviewed the codebook resulting in further refinement. Second cycle coding followed after a period of deep analytic reflection, and interviews were recoded, further refining codes<sup>82</sup>. Both authors coded one interview and discussed similarities and differences, resulting in further refining of the codebook. Once all the data had been coded, codes were grouped into categories. Themes were constructed via thematic analysis from across the data sets<sup>85</sup>, and visually represented via a thematic network diagram<sup>73</sup>. After analytic reflection, in-vivo codes were added to specific categories and themes, adding another dimension as participants were allowed to report personal experiences in their own words<sup>82</sup>.

### **Trustworthiness**

Various parameters of trustworthiness<sup>76,78,82,88-91</sup> were applied to ensure rigour and are displayed in Table I.

**Table I Parameters of trustworthiness**

<b>CRITERIA</b>	<b>STRATEGY</b>	<b>APPLICABILITY</b>
<b>Credibility</b>	Information power <sup>76</sup>	Quality of data more important than number of participants.
	Member checks <sup>88</sup>	Done via an e-mail to participants to ensure data were interpreted accurately <sup>88</sup> .
	Peer examinations/debriefing	

Confidentiality	Transcripts were anonymised and audio recordings were stored using a participant number. Identifying information was stored separately.
Interview protocol <sup>78</sup>	Open-ended questions supporting the research question, to ensure a consistent style of data collection.
Use of participants' words	Direct quotes from participants were used to illustrate the findings, as well as some <i>in vivo</i> codes derived from participants' words.

CRITERIA	STRATEGY	APPLICABILITY
<b>Transferability</b>	Providing thick descriptions <sup>89,90</sup> of research, participants, methodology, interpretation of data. Purposive sampling	
<b>Dependability</b>	Create an audit trail of procedures and processes <sup>91</sup>  Peer coding  Coding & recoding of data <sup>92</sup>  Sceptical peer review	Atlas.ti8 helps with the audit trail. Field notes, audio files and supervisor's feedback, electronic data files, assisted with checking procedures followed, and conclusions reached. A codebook was developed and codes were checked with the second author. Both authors coded one interview and compared their analyses. Minor adjustments were made to the codebook thereafter. Enhanced accuracy of the coding process.  This was done by the second author, who questioned the use of specific quotes in relation to the codes, as well as the organising of the codes into categories and themes.
<b>Confirmability</b>	Practice reflexivity  Audit trail of data analysis process.	Continuous self-examination was done to ensure that researcher-subjectivity did not interfere with data collection.  Kept records of field notes, raw data and transcripts. Stored raw data in organised archives.

## RESULTS

Five women ranging in age 35 to 42 participated in the study. All resided in Gauteng, were married, and varied in terms of the number of children, ranging between no children (P2, P3,

P4), one child (P1) and two children (P5). Participants' Total score on the ASH fell in the definite category and they presented with atypical (mild and definite categories on the ASH) sensory modulation, sensory discrimination and social/emotional functioning.

Two themes emerged from the data: 1) Changes experienced after participating in a SBHP, and 2) Coping strategies employed by women with SPD & GPPPD. Themes and related categories are reflected in Table II below.

**Table II Summary of themes and categories**

THEME	CATEGORY	SUB-CATEGORY	CODE		
1) Changes experienced after participating in a SBHP	Increased awareness/insight		Express SPD related issues		
			Able to identify triggers		
			Identify fluctuations in daily functioning		
			Identify sensory difficulties in others		
			Increased tolerance for sensory stimuli		
	Intra-personal changes		Feeling more in control		
			"I can breathe again"		
			Feeling safe & secure		
			"not as clumsy as I used to be"		
			Seeking touch/tactile input		
2) Coping strategies employed by women with SPD & GPPPD	Problem-focused coping	Active coping: Sensory Seeking		Seek movement and repetitive movements	
				Oral-motor actions to cope	
			Active coping: Coping in the environment		Activities engage in for relaxation
					Avoidance of sensory stimuli
					Reduce and eliminate irritating sensory stimuli
		Looking for / going to quiet space			

THEME	CATEGORY	SUB-CATEGORY	CODE
	Emotion-focused coping	Positive reinterpretation/growth	Aware of changes within self Self-talk used as tool to calm or motivate self "Thank you"
		Acceptance	Acceptance of condition and/or impact
		Socio-emotional support	"You're not the only one" Shared personal experience of SPD with others Partners' reactions to SPD and SBHP

Quotes remain unedited as participants' subjective experiences are described next. The researcher's interpretation will be described in the Discussion section.

### **THEME ONE: Changes experienced after participating in a SBHP**

Two categories emerged in Theme one, which will be discussed below.

#### ***Category 1: Increased awareness /insight***

A key finding, which relates closely to self-growth, was that participants displayed greater awareness and insight into SPD and its impact on everyday life. This category is discussed separately from the sub-category positive reinterpretation/growth (Theme two) as the insight/awareness is specific to SPD related issues.

*“'n Mens leef so saam met die goeters, jy begin vir jouself sulke strategieë uitwerk sonder dat jy dit eers weet.” (P2)*

*“One lives with these things, and you start to develop strategies without even knowing it.”(P2))*

*“Ek weet nou hoe, wanneer om ..., wanneer dinge vir my te raserig raak, en so aan.” (P4)*  
*“I now know how, when to..., when things are getting too noisy for me etc.” (P4))*

Participants found it easier to express sensory related difficulties/dislikes as a result of increased insight into SPD.

*“So you kind of tolerated it, where afterwards (i.e. after the SBHP) I was able to kind of go, “I don't like it, but I will hold your hand.” And it's actually okay, if that makes sense.” (P1)*

Because of her insight, one participant (P4) also discussed her SPD-related needs with the human resources manager, and they were able to make adjustments at work.

Participants further became more aware of sensory triggers that could result in sensory overload. Sensory triggers included high-pitched barking of dogs, light touching in the neck, clutter, kissing without brushing teeth, strange noises, overtiredness and being hugged unexpectedly from behind.

*"I felt like my brain was going to pop, from listening to too many words, and the singing was too much overload." (P1)*

*"There was clutter, and it was just everywhere, and I was like, "I can't actually do this anymore "." (P1)*

*"Jy moet nie hier (wys na agterkant van nek) aan my nek gevat het nie." (P3)*  
*("You should not have touched my neck here (point towards back of neck)." (P3))*

*"Toe ek in die huis instap, was alles vir my te deurmekaar." (P4)*  
*("Everything was too messy when I walked into the house." (P4))*

Participants were able to identify fluctuations in their daily functioning. One participant (P4) mentioned that she was able to tolerate music in the mornings, but not in the evenings. Other participants indicated that some days are better than others.

*"And then I have strange days, where all I want to do is feel hugged, feel loved, ... loved is not the right word. Feel ...secure." (P1)*

*"There are days where I'm just like, "Leave me alone." Like I just want to go and sit outside, where a gecko lands on my shoulder. ...Then there's other days when it actually doesn't bother me at all." (P1)*

*"I have moments where I can work with music on, but it's got to be like in the background."(P1)*

*“Of ek sal, ek sal ‘okay’ wees, en dan een oomblik sal ek net ontplof, en, “kom weg van my af”, jy weet, die tipe ding, ja, waar dit vir my net te erg is.” (P4)*

*(“I will be fine and the next moment I will just explode and say “get away from me”, you know, that type of thing, yes, where it is just too much for me.” (P4))*

Interestingly, participants liked the fact they were able to identify sensory difficulties in others, with P3 mentioning that she is much more attentive to the way other people process sensory information e.g. a child that does not like being touched.

*“He doesn’t like labels, which I get. I know like he doesn’t like the microfibre blankets.”(P1)*

*“Ja, dit het my baie attent gemaak op my, en op ander mense, want dan tel ek...sal ek iets optel. Jy kan sien hy’s nie daardie touchable kind nie, of so nie. So, dit is goeters wat ek opgetel het.” (P3)*

*(“Yes, it made me aware of myself and other people, because I will, I will notice something. You can see he is not a touchable child, or something like that. So, those are things that I’ve noticed.” (P3))*

*“Ek tel goed op by mense, en ek hou daarvan.” (P3)*

*(“I notice things in other people and I like it.” (P3))*

## **Category 2: Intra-personal changes / Changes experienced in own body**

Participants displayed an increased tolerance of sensory input, either tolerating previously unpleasant sensory input for longer periods, and/or by engaging in new activities with unfamiliar sensory input.

*“So I think, ja (yes), so I don’t freak out as often as I used to before.” (P1).*

*“I would probably have “gril”ed (sic) (showed disgust) more. But funnily enough, the smoother sand was not actually so bad, it was actually quite okay. So I don’t think that’s too bad.” (P1).*

*"So, now I'm more willing, more able. It doesn't freak me out as much, because I would definitely say that that's definitely a bit of a major change." (P1)*

*"But I can at least walk on the grass a little bit better than I could before." (P1)*

*"Dit sou my baie gepla het as hulle net aan my foon gevat het, en die manier wat hom hanteer het. Dit pla my glad nie. So, ek is baie meer ..., ek is meer 'chilled'." (P3)*

*("Previously, it would have bothered me a lot if they just touched my phone, or handle it in a certain way. It does not bother me at all. I am a lot more ..., I'm a lot more relaxed." (P3))*

*"Maar die geraas, daardie kan ek nou 'n bietjie beter handle." (P4)*

*("But, I can handle the noise a bit better now." (P4))*

Participants felt more in control of themselves and the environment. They were able to identify sensory triggers (Theme one) and regulate their emotional state better. One participant (P4) called it a blessing, as she did not feel like a victim anymore, while she also mentioned that she prefers predictability and dislikes a change in routine/plans. Another participant (P5) was able to control herself better in stressful situations, whilst P1 felt more secure and safe after making changes to her environment:

*"So I'm facing forward, and there's a cupboard behind me, so I feel a little bit more secure than what I did before. So I don't feel like somebody keeps going to attack me from the one side." (P1)*

*"Ek verkies om in beheer te wees. Ek sal dit (roetine) verander, maar hou nie daarvan as ander my planne verander nie." (P4)*

*("I prefer to be in control, I will change it (routine), but does not like it when others change my plans." (P4))*

*“So, ek probeer om in plaas van om te sit en soos ‘n ‘victim’ te voel, ‘to get up’, iets doen, dat ek kan voel ek het ‘n mate van beheer oor my omgewing.” (P4)*

*“(So, instead of sitting and feeling like a victim, I try to get up and do something that allows me to feel in control of my environment.” (P4))*

*“Die program het my gehelp, want ek kon ... die oomblik wat ek in ‘n situasie is, waar ek voel ek styg op rooi (sensoriese oorlading) toe, het ek my half ..., kon ek myself beheer.”(P5)*

*“(The program helped me, because I could...the minute when I got into a situation that pushed my revs into the red (sensory overload), I was almost..., I was able to control myself.” (P5))*

Participants (P1 & P5) reported less clumsiness.

*“But the clumsiness, not as much as before. No, I’m not walking into things like I used to.”(P1)*

*“Ek is nie meer so clumsy soos wat ek was nie.” (P5)*

*“(I’m not as clumsy as I use to be.” (P5))*

Changes in intimate life were reported and P3, P4 and P5 reported they are calmer/more relaxed before and during intercourse. One participant (P4) explained to her husband why she prefers firm touch, opposed to light touching during intercourse, and this adaptation has enabled her to tolerate more tactile input during intercourse.

*“Ek dink hy (my man) begin ook beter raak met die harder vat.” (P4)*

*“(I think he (my husband) is getting better with touching me more firmly.” (P4))*

Feelings of increased calmness and being able to breathe rather than feeling overwhelmed, were reported.

*“No, there’s more calmness. I feel like I can breathe again.” (P1)*

## **THEME TWO: Coping strategies employed by women with SPD & GPPPD**

A prominent theme through all the transcripts was that several coping strategies were used by women to cope with daily living. Coping strategies are broadly categorised into problem-focused and emotion-focused coping strategies based on the Coping Orientations to Problems Experienced (COPE)<sup>92</sup> which has been used in previous studies related to sensory processing<sup>14,44</sup>. Five sub-categories emerged from the second theme, namely: 1) active coping: sensory seeking, 2) active coping: coping in the environment, 3) positive reinterpretation & growth, 4) acceptance (reflecting on self-growth), and 5) socio-emotional support.

### ***Category 1: Problem-focused coping***

#### **Sub-category: Active coping: Increased sensory seeking**

Touch seeking, especially deep tactile input was sought by participants, specifically reporting they preferred the TB to be done very hard (P1, P3), with P3 also mentioning vigorously. One participant (P4) mentioned that she would have preferred a deep massage to the TB. The deep touch was found to be comforting.

*“...that (the brushing) I could do quite hard.” (P1)*

*“So, I would sit and brush my face, especially if I'd had a bad day, I would sit and do the brush quite like vigorously for like hours at a time, like while I'm busy working and I'm busy ...” (P1)*

*“Ek het daardie borseltjie, het ek so (druk hard op arm) gebruik. Maar ek kom agter ek moenie..., ek moet dit half hard doen....né, hard, nie daardie sagte aanraking nie.” (P3)*  
*(“That brush, I, used it like this (press firmly on arm). But, I could feel that I shouldn't..., I have to do it firmly, you know, firmly, not that soft touching.” (P3))*

*“Iets soos, jy weet, ‘n diep massering sou lekkerder gewees het, as die ‘n borsel. Ja, jy weet, harder druk.” (P4)*

*(“Something like, you know, a deep massage would have been nicer than the brushing. Yes, you know, firmer pressure.” (P4))*

Another participant (P5) found repetitive light touch input, via stroking her dog, extremely calming.

*“Maar hulle (my honde) het my regtig verskriklik gehelp. Ek dink net om aan hulle te vat, net om vir hulle te kyk, dit is, dit kalmeer my verskriklik baie. Vir my, om hulle te vryf.” (P5)*

*(“But they (my dogs) really helped me a lot. I think just to touch them, just to watch them, that is, that calms me a lot. For my, just to stroke them.” (P5))*

All participants mentioned increased movement activities like exercise, getting up frequently and repetitive movements e.g. moving body parts (especially fingers, legs and feet when seated), light stroking and brushing vigorously, as important activities which helped to reduce stress/irritation levels. One participant (P4) mentioned she has started taking a pen to fiddle with, when having to speak to colleagues.

*“I tend to get up more, to go and like refresh my brain a bit”. (P1)*

*“Of as ek met ‘n kollega moet gaan praat, dan vat ek ‘n pen saam om in my hand te hou.”(P4)*

*(“Or, if I have to go and speak to a colleague, then I take a pen with to keep in my hand.”(P4))*

Oral-motor activities, especially chewing crunchy food, like apples and popcorn, and sucking sweets, were found to assist with sensory modulation.

*“Ek dink die bewustheid vir my om deur die dag, ‘either’ iets by my te hê soos ‘n peppermint, of iets om te knibbel, of iets om te lees as ek in ‘n tou staan, dat ek kan uitzoom..., jy weet, myself uit ‘n situasie te kan uithaal.” (P4)*

*(“I think for me, the awareness to either have something like a peppermint, or something to nibble on, or something to read when I’m standing in a que, that I can zoom out..., you know, to remove myself from ‘n situation.” (P4))*

#### **Sub-category: Active coping: Coping in environment**

Participants avoided unpleasant sensory stimuli e.g. food and clothing textures, noise, busy environments, through removing and/or moving away from unpleasant stimuli.

*“I just want to get home and get all of this off, and get into my comfy pyjamas with no bra, and I’m happy.” (P1)*

*“I want to get in the car and drive.” (P1)*

*“Dan sit ons buite en eet aandete. En dan dit maak my eindelijk rustig. Dan is ek half rustig.” (P4)*

*(“Then we sit outside and eat dinner. And that actually calms me. Then I’m quite calm.”(P4))*

*“So, as ek in die middag by die huis kom, is dit vir my baie lekker om die gordyne toe te trek, en in die bed te klim.” (P4)*

*(“So, if I get home in the afternoons, I really enjoy drawing the curtains closed and get into bed.” (P4))*

*“Dit is een ding, ek haat, absoluut haat grimering.” (P5)*

*“That is one thing, I hate, absolutely hate make-up.” (P5)*

*“Ek druk my ore toe as iemand fluit. Dis ‘n klank wat ek glad nie kan hanteer nie. ‘n*

*Telefoon se gelui is ook vir my irriterend. Ek hou glad nie van ‘n foon nie.” (P5)*

*“I cover my ears when somebody whistles. That is a sound that I absolute cannot handle.*

*A telephone that rings, also irritates me. I don’t like a phone at all.” (P5)*

Participants engaged more in relaxation activities e.g. building a puzzle, reading, playing a game on a phone, scrapbooking, crossword puzzles and spending time with pets. Listening to music was mentioned by all participants and included different genres, including classical, contemporary and pop rock music. Two participants (P1, P4) mentioned listening to nature sounds and white noise, while P4 did not like what she called “doef-doef” (music with a prominent bass drum rhythm) music.

*“I’ve moved from playing music that you can sing along to, to just calming, the nature, dolphins squeaking, whatever.” (P1)*

*“I do still sit with the headphones on, and play the classical music.” (P1)*

*“Ek het nou nie klassieke musiek of so nie, net gewone liedjies.” (P3)*

*“Well, I don’t have classical music or something like that, just normal songs.” (P3)*

*“Ek sit met oorfoontjies, en luister na “white noise.” (P4)*

*“I sit with my earphones and listen to white noise.” (P4)*

*“Die beste ding wat vir my werk is, om bo in die kamer te gaan sit, en musiek te luister, met my kat, en of ‘n blokkiesraaisel of my iPad, net a game te speel, en ‘n mindless game soos Candy Crush, of so iets. Dis iets wat jou net besig hou, en dis absoluut mindless.*

*Ek moet sê, musiek nog ook.” (P5)*

*“The thing that works best for me, is to go sit upstairs in my room and listen to music, with my cat and a crossword puzzle or my iPad, just to play a game, and a mindless game like Candy Crush, or something like that. It’s just something that keeps you busy and absolutely mindless. I must say, music also.” (P5)*

Headphones/earphones were used, not only to listen to music, but in some instances to also eliminate/reduce background noise.

*“I’ve put ear plugs in to try and block that out.” (P1)*

*“So ek sit altyd my oorfone op, en as ek dit in het, dan kan ek niemand hoor nie.” (P5)*

*“So, I always wear my headphones, and when I have it in, I cannot hear anyone.” (P5)*

Participants also expressed avoiding personal contact/touch and interaction with other people, resulting in increased need for bigger personal space.

*“So from that perspective, there’s short moments in between, where that’s kind of okay, and other days where it’s like I’m not interested. Like, “Don’t come close to me.” (P1)*

*“So, I don’t even want ... to hug your own son, then you know that...” (P1)*

*“And I don’t want to be held...but then, I don’t want to be always with people.” (P1)*

*“So, toe sê ek vir haar (suster), ek haat ‘n bus (hardloop saam in ‘n groep). Ek voel so ingeblok, en ek het een keer saam met ‘n bus gehardloop, en ek kon nie daaruit kom nie, daar was te veel mense, en dit was ... So, as ek gewoonlik ‘n resies doen, vermy ek ‘n bus so ver as moontlik.” (P2)*

*“So, then I told her (sister), I hate a bus (running together in a group). I feel so blocked in, and I’ve ran in a bus once and I was unable to get out, there were too many people around me, and it was... So, usually when I run a race, I avoid a bus as much as*

*possible.” (P2))*

*“Ja, en ek hou daarvan om alleen ook gelos te word in die aande.” (P4)*

*(“Yes, and I like to be left alone in the evenings.” (P4))*

Participants coped better in their environments by creating order and reducing clutter in both home and work environments. Planning, organising and neatness created a sense of control and assisted with emotional regulation e.g. feeling more relaxed. One participant (P4) also mentioned that her house might not appear messy/disorganised to other people, but to her it was very messy/disorganised. Interestingly, P3 and P5 mentioned that they preferred sexual intercourse to be spontaneous, and not planned, with P3 specifically mentioning that she is more stressed/anxious if sexual intercourse is planned/scheduled.

*“I moved my office around, so my Zen space, whatever you want to call it, is far better. So I did a lot of like scaling down in a sense, where I’ve taken all my stuff that is of no value from a work perspective, and from a space perspective, and I just got rid of it. So everything is more clean, more open. I feel like I can breathe again. So I don’t know if that makes sense.” (P1)*

*“I think, in areas where I know, so like my house at the moment, I know my house. So I know where things are, where ...,” (P1)*

*“En dit moenie ‘n beplande ding wees nie. Dit haat ek, ‘n beplande ding..., want dan is ek nie so gespanne nie, en ek is nie gestres daaroor nie, maar as dit beplan is dan ‘worry’ ek...’shit’, gaan dit reg wees, gaan ek...” (P3)*

*(“And it must not be something that is planned. I hate a planned thing..., because then I’m not as tense, and I’m not stressed about it, but when it is planned then I worry...shit, is it going to be okay, am I going to.....” (P3))*

## **Category 2: Emotion-focused coping**

### **Sub-categories: Positive reinterpretation/growth & acceptance**

Participants used positive reinterpretation to manage negative emotions and showed increased self-awareness and acceptance of their conditions/circumstances throughout the interviews. One participant (P2) changed her perception about herself, whilst P5 mentioned that she now understands that there is nothing wrong with her but that she is just different, and understanding why she is different, helped a lot. She (P5) also mentioned that she is actually fine and that she is not really such a 'witch' or bad person, as she previously perceived herself to be.

*"So I think I have... I'm going to use the word... "evolved" is maybe a better word. (P1)*

*So I've had to learn to turn a blind eye to certain things that irritate the crap out of me, and go, "It's okay." (P1)*

*"It kind of made me realise that you can kind of do it on your own." (P1)*

*"And it's okay to kind of go forward until tomorrow, just take it one day at a time, and it's not so bad." (P1)*

*"I was so worried that, like, people were now going to see what I was doing, and, you know, when I scratched my ear, and tickled my nose. And it's actually fine. Like, it actually is okay, like it doesn't ..." (P1)*

*"Ek dink vir my eerstens was dit half self-insig, want ek het nooit self ..., soos ek laas met die onderhoud ook vir jou gesê het, is jy weet, ek het nooit self, myself gesien as tasdefensief of jy weet, dat dit rêrig 'n probleem by my is nie. So, ek dink in daardie opsig het dit tog vir my ..., my persepsie van myself 'n bietjie verander, na, jy weet daardie ..., nou die inligting by jou gekry." (P2)*

*“I think, firstly for me, it was basically self-insight, because I’ve never self...., like I’ve told you during the previous interview, you know, I’ve never saw myself as being tactile defensive, or you know, that it really is a problem for me. So, I think in light of that, it did change my..., my perception about myself, you know, after I got the information from you.”(P2))*

*“En toe ek met jou praat, en jy sê vir my ek is actually fine, weet, ek is rerig nie so ‘n heks en slegte mens as wat ek gedink het ek is, en gevoel het ek is, of myself laat voel dat ek is nie.” (P5)*

*“ And when I spoke to you, and you told me I’m actually fine, (you) know, I’m really not such a witch and bad person as I thought I am, and felt I am, or led myself to feel I was.”(P5)*

*“Selfkennis is vir my nog altyd baie, baie belangrik, want ek het agterkom hoe dit my absoluut net help om te verstaan wie ek is, en ek is ‘okay’, weet? Daar’s eintlik nie fout met my nie. Dis net, ek is net anders, net om te verstaan hoekom ek anders is, en hoe ek anders is, en hoe om dan dit half te openbaar aan die wêreld, jy weet, op ‘n aanvaarbare manier.” (P5)*

*“Self-knowledge has always been very, very important to me, because I realised how it absolutely helped me to understand who I am, and I’m okay, you know? There is actually nothing wrong with me. It’s just, I am just different, (and) just understanding why I’m different, and how I’m different, and how to make it known to the world, you know, in an acceptable manner.” (P5)*

Self-talk, a meta-cognitive strategy<sup>93</sup> was prominent in three of the participants (P1, P3 & P5) with P3 and P5 also using counting (repetitive action) and repetitive phrases such as “relax, relax, relax” to cope. Self-talk was used as a meta-cognitive tool to assist with positive self-statements, emotional regulation and as self-motivation, facilitating self-growth.

*“but told myself....you’re enjoying it, so just move on with life. Like, it’s really not so bad.”(P1)*

*“And then I realised ..., and, so do you need to breathe. Okay, so, do the breathing. Keep breathing. And I’m like, “I’m fine, I’m doing fine.”” (P1)*

*“You are capable, like you can do it. You don’t need anything to come and help you.” (P1)*

*“You just need to sit and take a moment. So there have been days where I go to the bathroom, and just take a moment, whether I breathe, or I just close my eyes, and go*

*“Okay, it’s fine. Like let’s just try and find your centre again.”” (P1)*

*“Ja, en dan net met myself te praat in my brein. Ek sê vir my brein, “kalmeeer, kalmeeer, raak rustig, kalmeeer, sluit dit uit, of wat ookal, sluit dit uit”. En grootliks het dit gehelp.”*

*(P5)*

*(“Yes, and then just talking to myself in my brain. I tell my brain “calm down, calm down, be calm, calm down, shut it out, of whatever, shut it out”. And that mostly helped.” (P5))*

Gratitude was only expressed verbally by P2 and P5 during the interviews. However, journaling/notes reflected P1 and P3 thanking the researcher after the formal interview was concluded. An attitude of being grateful and appreciative of help received (via the SBHP) were present among the other participants.

*“Ek wil net vir jou sê dankie vir hierdie studie, want ek dink dit is, dit help. Dis nie ‘n maklike onderwerp wat jy, jy weet, aangepak het nie. Maar ek dink rêrig daar is ‘n baie groot leemte wat nou aangespreek word, want ek dink nog steeds daar’s baie mense wat daarby kan baat, wat net nie uitkom nie, omdat dit so ‘n sensitiewe, jy weet, onderwerp is.” (P2)*

*(“I just want to thank you for this study, because I think it is, it helps. It is not an easy topic that you, you know, are addressing. But I do think there is a big gap which is now being*

*addressed, because I do think there are still lots of other people whom can benefit, but do not come forward, because it is a sensitive, you know, topic.” (P2))*

*“Ek moet net sê, jy het my baie gehelp, rêrig baie. Ek waardeer dit verskriklik baie.” (P5)*  
*(“I must just say, you helped me a lot, really a lot. I appreciate it immensely.” (P5))*

**Sub-category: “you’re not the only one. There are plenty of us out there.”**

A key finding was that participants did not feel alone anymore and were able to relate to others with SPD.

*“And also, that “Too light, too bright” book, she speaks of her own personal experiences, so it’s ..., she herself is experiencing. So, I was able to kind of connect with her in a way, not to just understand that you’re not the only one. There are plenty of us out there.” (P1)*

Participants shared their experience of SPD with others, while it also made them more aware of SPD in others, including their partners.

*“This book is for you, my buddy (her friend). You have to read this.” (P1)*

*“Dit was ook vir my makliker om met my familie te gesels, en vir hulle te sê, ek het met ‘n professionele persoon gepraat. Die professionele persoon sê dit, weet, so, ek is nie vol twak nie.” (P4)*

*(“It was also easier to discuss it with my family and tell them that I have spoken to a professional person. The professional person says this, so, I am not full of nonsense.”(P4))*

Support from partners were vital and participants reported their partners to be understanding, supportive and non-judgemental.

*“And I mean my husband’s asked me for the last couple of weeks, “Are you really okay?””(P1)*

*“He could see a difference. So, he’s like, “But you’re not bouncing off the walls, you’re not like freaking out.”” (P1)*

*“You’re a little bit weird, but I love you anyway. So just go on with what you’re doing.” (P1)*

*“Ek het ‘n ‘amazing’ man. Hy was van die begin af vreeslik baie ‘understanding’.” (P2)*

*“I have an amazing husband. Since the beginning he has been very understanding.”(P2)*

*“En dis vir my maklik om met my man te lewe. Hy is baie konsidererend.” (P4)*

*“And it is easy for me to live with my husband. He is very considerate.” (P4)*

## **DISCUSSION**

The present study sought to describe the experiences of women with SPD and GPPPD and their participation in a SBHP in order to contribute information and determine if it provides a viable intervention option for women with SPD and GPPPD. Our findings suggest that participants benefited from participating in the SBHP. Participants experienced change and described coping strategies implemented.

### **Changes experienced after participating in a SBHP**

Increased awareness and insight into understanding SPD and the impact thereof on daily life, as well intra-personal changes were prominent changes reported. These findings tie in well with previous studies wherein cognitive approaches and the importance of insight were emphasised as part of addressing SPD in adults<sup>19,94</sup>. Insight enables persons with SPD to better manage atypical processing patterns by assisting with identification and implementation of coping strategies<sup>66</sup> and empowering them to make choices supporting their sensory needs. Education/information (regarding SPD and its impact on daily living) was a vital aspect of the SPBP during the initial interview, as it empowers people by increasing health literacy<sup>95</sup>. Insight, gained via information, empowered participants to experience self-growth and self-regulation (incl. sensory processing, emotional regulation, cognitive regulation & social perspective taking<sup>96</sup>).

Notably, increased tolerance for sensory stimuli together with improved emotional well-being were prominent among participants' intra-personal experiences. The results are in line with a retrospective pre-post treatment study of OT intervention for children with SP difficulties, in which the following were noted post-treatment: improvements in adaptive behaviour, withdrawal and inattention, a reduction in aggression, anxiety, depression, a decrease in sensory symptoms and improvement in motor skills<sup>97</sup>. Earlier studies, including a literature review involving the treatment of adults with sensory defensiveness (SOR), found an increased tolerance to sensory input, improved functioning in daily life, reduction in

symptoms of sensory defensiveness and improved emotional functioning<sup>19,58</sup>. Importantly, the literature review<sup>19</sup> also reported that the treatment effect/improved functioning was still present 16 months post treatment and sensory processing was improved by seeking and implementation of activities recommended previously, to manage the sensory environment<sup>19</sup>. This has not been established in the current study and future research should consider collecting data over an extended period.

## **Coping strategies implemented**

### ***Problem-focused coping***

Active coping skills (a problem-focused strategy) used by participants in this study included sensory seeking and strategies employed to better cope in the environment. Participants reported improved emotional functioning as reflected in intra-personal changes discussed previously, also related to using active coping strategies, which supports findings in the literature. Problem-focused coping typically involves activities/strategies (occupation) employed to improve coping in stress-inducing situations<sup>92</sup> by either changing the stressor or oneself<sup>98</sup>. The use of activities makes this an occupation-based intervention, and occupation-based interventions have been found to support social, sensory and emotional outcomes in children with sensory processing difficulties<sup>61</sup>. Active coping strategies have also been found to reduce distress in healthy adults<sup>7</sup>. One study suggested people with passive coping strategies must be educated to use active coping strategies as the latter may reduce distress<sup>52</sup>. Furthermore, active coping strategies, such as exercise, social comparison and positive self-statements (coping statements), have been found to be adaptive coping strategies in persons with pain<sup>7,98</sup>, while it also improves mental QoL in persons with emotional disorders<sup>14</sup>.

Noteworthy, passive/negative coping styles were not reported by participants in the current study despite previous studies describing sensory processing styles, pain and coping

strategies that included passive coping styles<sup>7,14,44</sup>. It was however beyond the scope of the current study to explore coping styles specifically, and this coupled with participants' reported overall improvement in socio-emotional well-being (due to the therapeutic value of qualitative research interviews<sup>81</sup>) may have contributed to participants not mentioning passive coping strategies.

Participants actively seek sensory stimuli (based on their sensory functioning) as reflected in increased activity, seeking repetitive movement, eating crunchy food, and deep touch pressure. Sensory seeking assisted with sensory regulation, resulting in decreased emotional outbursts and increased feeling of calmness and control reported. This resonates with previous studies that found sensory seeking, an active self-regulation strategy, improves emotional regulation and contributes to positive affect<sup>46</sup> and improved socio-emotional functioning in children with sensory craving (sensory seeking) post-treatment<sup>99</sup>. Sensory seeking has also previously been found to be an active pain strategy<sup>7</sup>. A recent systematic review suggested deep touch pressure improves the effectiveness of interventions in children and youth with SPD<sup>60</sup>, while another study involving young people with autism, found deep pressure to be beneficial if it is adapted to the needs of the person<sup>100</sup>. The latter is noteworthy as one participant in the current study adapted the TB, resulting in prolonged periods of vigorously brushing her face and another participant specifically asked for deep pressure during intercourse.

Participants employed several actions to improve coping in the environment. The most significant was avoidance of sensory input in order to reduce/eliminate obnoxious sensory stimuli and participants actively seeking out quiet spaces. Avoidance of sensory input has been associated with persons with emotional disorders<sup>14</sup>, and this is in line with the current study as participants presented with atypical social/emotional functioning on the ASH. Even though avoidance is sometimes seen as a maladaptive response<sup>14</sup>, participants found it beneficial, and in most cases avoidance of unpleasant sensory stimuli, as a coping

mechanism, seemed to have been implemented prior to participating in the SBHP.

Significantly, participants now understood why they avoided certain sensory stimuli as it may prevent sensory overload, ultimately improving self-regulation. They were also able to communicate their needs regarding sensory avoidance more effectively to others.

Participants also used increased personal space and/or avoiding personal contact with others as a coping strategy. This has significant implications for interpersonal relationships and will be discussed together with socio-emotional support below.

Participants implemented changes in both the home and work environments, especially organising the environment and engaging in activities for relaxation which contributed to feelings of calmness and control/improved emotional well-being. This is similar to a study that found that home and work changes provided a supportive environment<sup>65</sup>. Furthermore, organising and ordering (decluttering) the environment is also often used to reduce sensory stimuli<sup>101</sup>, while a multi-faceted approach, that includes environmental changes/modifications has been recommended as interventions for children with SPD<sup>60,68,102</sup>

### ***Emotion-focused coping***

Participants used positive/coping self-statements, via self-talk, to self-motivate and self-regulate, possibly contributing to a willingness to try new sensory experiences (sensory seeking) and thus closely associated with active coping strategies discussed previously.

Participants increased socio-emotional support as they shared information regarding SPD with life partners, family members and colleagues, providing opportunities to be better understood and accepted by others. This is supported by a previous study which found social relationships improve health outcomes in adults<sup>103</sup>, while collaborative sexual communication between women with sexual pain and their partners has been associated with improved

outcomes related to sexual and psychological functioning<sup>104</sup>. Communication is facilitated by a trusting, balanced relationship as it creates a safe space in which critical/negative information can be shared<sup>105</sup> and strong relationship goals can be established, which has been linked to greater sexual satisfaction in women with sexual pain<sup>106</sup>.

However, communication and socio-emotional support could be adversely affected by increased personal space and avoidance of personal contact as a coping strategy, which some participants did report and has previously been described in the literature<sup>44</sup>. This may happen when participants experience irritability/sensory overload, resulting in fight-and-flight reactions, leading to avoidance of interpersonal contact and increased personal space<sup>33,44,107</sup>. This may further impact negatively on intimate life as physical contact and touch are crucial to intimate relationships<sup>108</sup>. However, the potential negative impact on relationships may be mitigated by improved communication, sharing information and explaining the reason for certain behaviours to others<sup>104</sup>.

## **LIMITATIONS OF THE STUDY**

The current study needs to be considered in light of the following limitations:

Participants in Phase one of the study provided the possible sample for Phase two.

Electronic surveys used for Phase one of the study may have affected the recruitment of participants, as only those with access to e-mail/internet were able to take part in this study, limiting the generalisation of the results.

The researcher is a novice in conducting qualitative interviews and thus did not probe enough, thus some observations by participants, e.g. relating to the usefulness of Facebook, were not clarified.

## **CONCLUSION**

Participants' experiences suggest/reflect that an individualised, client-centred SBHP contributed to improved QoL of women with SPD and GPPPD. Information regarding SPD facilitated insight and self-growth. Insight gained through education lead to intra-personal changes and increases awareness and insight. The latter facilitated self-growth, improved coping in the environment, increased activity (sensory seeking) and increased socio-emotional support.

Participants in the current study employed different coping strategies as reflected in the varied individualised feedback regarding specific coping strategies implemented, especially in the work environment, which reinforces findings in the literature. Previous studies<sup>16,63,66,109</sup> recommend intervention strategies to be individualised and based on the needs of the client.

Occupational therapists specialising in sensory integration are increasingly getting involved with adults with SPD, either as clinician or the evolving role as consultant<sup>110</sup>. Literature regarding the impact of SPD on sexual activity<sup>64</sup>, intimate relationships<sup>111</sup>, sexual expression<sup>23,112</sup> and sexuality<sup>106</sup> are limited to non-existent. Furthermore, sexual activity, specifically, sexuality are also expressed via other occupations such as caring for a partner, grooming, dating and intercourse<sup>24</sup>. However these occupations are often negatively affected in persons with SPD, further affecting emotional well-being, relationships and ultimately QoL<sup>14</sup> and a relational approach should therefore be included to address aspects re sexuality<sup>113</sup>.

## **RECOMMENDATIONS AND FUTURE RESEARCH**

The use of a coping measurement during the initial interview may provide additional information regarding participants' coping styles and may assist in identifying more client-centred intervention strategies.

It is suggested that future research investigate the (self-perceived) effectiveness of SBHP, including pre-and post-testing, and ideally a control group should be included.

Future research, investigating the impact of SPD on sexual activity/sexuality/intimate life, and possibly developing a measurement to assess this.

Goal setting (i.e. goal attainment scaling (GAS)<sup>114</sup>), an integral part of coaching, should be included in the SBHP as it will enable clients to be personally involved and take responsibility for their well-being<sup>115</sup>. Interpersonal goal setting, involving partners, has been linked to improved sexual and relationship satisfaction<sup>106</sup>.

Furthermore, a relational approach, including assessment of partners' sensory integration/processing, should be followed/considered. The inter-relationship between individual, potentially conflicting, sensory profiles within intimate relationships, should be explored as part of the intervention strategy. A recent study involving couples and women with GPPPD, suggests that sexual and relationship contingent self-worth to be important aspects to be addressed<sup>116</sup>.

Information and strategies, based on priority goals identified, should be introduced via a staggered approach in follow-up sessions, as information overload<sup>117</sup> may occur.

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## CHAPTER 6. INTEGRATING CHAPTER

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This chapter draws together work from the publication and two phases of the study. Three papers present the methodology and findings related to the two phases of the study, as can be seen in Table 6.1 below:

**Table 6.1 Papers and the study components/objectives they cover.**

<b>Paper (manuscript) 1</b>	<b>Study component/objective</b>
<p>Labuschagne E, van Niekerk M. Sensory processing of women diagnosed with genito-pelvic pain/penetration disorder: a research proposal. <i>BMC Research Notes</i>. 2019;12(1):577. <a href="https://doi.org/10.1186/s13104-019-4612-6">https://doi.org/10.1186/s13104-019-4612-6</a> Journal impact factor: 0.835</p>	<p>This paper describes the methodology of the study.</p>
<p><b>Paper (manuscript) 2</b> To be submitted to Archives of Sexual Behaviour. Journal impact factor: 3.116 (2018)</p>	<p>Objective 1: Describe the sensory processing patterns of women diagnosed with GPPPD. Objective 2: Describe the presence of anxiety when both SPD and GPPPD are present.</p>
<p><b>Paper (manuscript) 3</b> To be submitted to SAJOT, in terms of SAISI funding agreement. Journal Impact Factor: 0.2979 (2019)</p>	<p>Objective 3: Describe participant's experiences of participating in a sensory-based home program.</p>

This chapter will provide a critical review of the methodology, as presented in Paper 1, followed by highlighting key findings of the study, as presented in the remaining two papers. Strengths, reasoning behind methodological choices and limitations of the study are presented.

## CONTEXT OF THE STUDY

As was pointed out in the introduction to the study, commonalities between SPD, pain and GPPPD have been highlighted in the literature. Pain is central to GPPPD<sup>147</sup>, and not only is it part of sensory processing, but is also influenced by SPD<sup>35,36</sup>. Pain, SPD and GPPPD all affect QoL in various ways<sup>34,39,43,64,72,77,187,199</sup>. Despite these commonalities, these conditions have not been described in the literature in relation to one another. This study thus aims to fill that gap, in an attempt to enhance the multi-disciplinary intervention for GPPPD, and to ensure that future interventions will not cause harm by eliciting an unwanted neurological response<sup>201</sup>.

The literature review has highlighted, among other, the controversy and confusion related to sensory integration terminology. Despite reviews attempting to clarify terminology, a lack of uniformity in the use of terminology and classifying atypical sensory processing/responses persist<sup>1,5,13,46,58,203</sup>. This lack of uniformity may negatively affect uptake of a sensory approach to treating GPPPD. It is beyond the purview of this study to conduct yet another review of terminology, or even to recommend a preferred term. Because Phase one employed the ASH to collect data, its nomenclature was used in this study.

## METHODOLOGY

This section provides a critical overview of the methodology of the study, as presented in the published paper. This study consists of two discrete phases, with different objectives. Each phase will be critically discussed below.

### Phase One

#### *Study design*

A non-experimental study design was chosen to describe/explore sensory processing patterns of women diagnosed with GPPPD, as literature investigating SPD and GPPPD could not be sourced. The current study therefore explored sensory processing patterns in women with GPPPD and did not indicate a causative factor, neither established a link between the two conditions in women. This study design was chosen in view of the dearth of literature discussing both conditions. It is believed that a preliminary, descriptive research project, such as this study, lays the

necessary groundwork for future experimental designs. Recommendations for future studies will be discussed in Chapter 7.

### ***Measurement instruments***

The Adolescent/Adult Sensory History (ASH)<sup>8</sup> provided information regarding participants' sensory processing patterns. Even though the ASH has not yet been used extensively in published literature (which limited comparison with previous studies) it was decided to use the instrument as it provided information regarding SM and SD as well as functional skills influenced by sensory processing.

The ASH was only administered electronically, via REdCap. Prior to making the link to the online questionnaire available to participants, the supervisor completed a trial administration of the ASH and the HADS, to ensure that all questions displayed and that there were no glitches.

Electronic administration of the ASH meant that participants were compelled to complete the entire questionnaire, unlike a paper-based administration which would permit participants to omit sections. The advantage of electronic administration thus is that eliminates the potential of incomplete data, which may have to be excluded from analysis. However, when cleaning the data for analysis, it seemed that some participants started the survey more than once, resulting in incomplete questionnaires. It is also possible that some participants exited before completing the survey without saving any responses, thus limiting the number of participants.

A possible limitation of the ASH is the lack of information related to SUR. Sensory under-responsivity is not assessed on the ASH, but it is important to be aware of this concept when working with persons with SMD. Persons with SUR is slow to react, or show little or even no reaction to sensory input, appear tired, passive and lethargic or apathetic<sup>11,37</sup>. It affects participation in daily activities and people presenting with SUR would resist participating in active and physical activities and prefer sedentary activities, which could also spill over into sexual activity. Sensory under-responsivity should not be confused with sensory avoidance due to SOR and necessitates careful investigation when present. Emotional regulation is often also affected, as they may over-react when tired or unwell and they are at risk to develop mental health conditions such as depression and anxiety<sup>37,39,111</sup>.

However, persons with SUR may also engage in SS behaviour to increase the registration of sensory input<sup>37,65,128</sup> and to assist them with modulation. This aspect should be considered when assessing and treating clients with SPD. An assessment tool, like the Adult Sensory Processing Scale, could be used to investigate sensory under-responsiveness<sup>65</sup>.

Importantly, both these questionnaires are self-reporting instruments which may introduce reporting bias. Nonetheless, the ASH has been used in research<sup>204,205</sup>. Additionally, it is one of few tools available for the adult population. Other tools are also self-report questionnaires<sup>65,206</sup> and the ASH has shown strong ( $r = .078$  ( $p < .001$ )) concurrent validity<sup>8</sup> with the Adolescent/Adult Sensory Profile<sup>206</sup>. It is therefore important that results be triangulated, or confirmed through an interview and/or clinical observations, which may not be feasible in the research environment or escalate research costs. Internal validity checks should be inherent to all self-administered questionnaires.

### **Sampling**

It was disappointing to not have obtained a statistically valid number of participants (132 participants) as indicated in Chapter 3. Several factors contributed to this. Firstly, due to the personal nature of sexual pain, this population constitutes a 'hard-to-reach' population, making recruiting challenging.

Secondly, cooperation from HCPs working in the field of sexual health and their professional bodies was limited, despite several attempts by the researcher to have the study more widely distributed via their professional networks.

Thirdly, HCPs who mostly work in the private sector distributed the study among applicable candidates. This recruitment method limited sample variety due to study made available to persons with internet/electronic access and who are able to afford private healthcare services. The cost of treatment was a factor emphasised by a participant in Phase two, who also made recommendations regarding more cost-effective intervention methods.

A fourth limiting factor relates to cultural taboos regarding intimacy, specifically talking about intercourse. Only people who were comfortable sharing their experiences related to sexual pain participated, which could have resulted in

selection bias as well as a smaller sample size.

Sample size was most likely also affected by various help-seeking barriers preventing women in both the private and public sectors from seeking help for sexual pain.

Possible help-seeking barriers include lack of knowledge about female sexual pain and SPD, self-consciousness related to culture/social norms around intimacy (specifically intercourse), lack of HCPs specialising in sexual pain, financial constraints and lack of access to HCPs in more remote areas.

Time restrictions related to completion of the dissertation also affected sample size: because data had to be analysed, interpreted and discussed, data collection had to be closed at a point in time to enable finalisation of the project.

## **Phase Two**

### ***Sampling***

As mentioned in the introduction to Chapter 5, it proved challenging to find a sufficient number of participants for Phase two as the number of participants who met the inclusion criteria (being diagnosed with SPD in Phase one and living in Gauteng or KwaZulu-Natal (KZN)) only reached 21. Participants in Phase one were identified with SPD when ASH scores fell in the mild and definite categories. According to the ASH persons within the mild category requires further investigation and those in the definite category requires intervention. This distinction between the two categories necessitated a further refinement of the methodology, specifically the inclusion criteria. This refinement of the methodology reduced the number of eligible participants (who require intervention and live in Gauteng or KZN) to 13, of which nine indicated a willingness to participate in Phase two. However, as discussed in Chapter 5, two participants cancelled before the initial interview and an additional two participants did not partake in the follow-up interview due to time constraints/work schedules.

Saturation is a contentious aspect of qualitative research<sup>207</sup> and the model of information power<sup>202</sup>, was used instead. In the model of information power, sample size is determined by the amount of relevant data, thus information power is increased by a narrow study aim, sample specificity, use of established theory and quality of dialogue. Alternatively, data saturation might have been used to determine

sample size<sup>207</sup>, although the quality of data might have been affected by the novice researcher conducting qualitative interviews<sup>208</sup>.

### ***Data collection***

Data was collected during semi-structured interviews to allow participants to share information regarding their experiences easily. Participants were given a choice between a face-to-face interview and remote interviewing via Skype. They were also informed about the possible duration of the interview to allow them to set aside sufficient time. Follow-up interviews accommodated participants' schedules. Having regard for the real possibility of sensory overload later in the day, interviews were purposely scheduled in the morning or early afternoon.

Two follow-up interviews were done face-to-face, while the remaining three were done remotely via Skype (voice only).

Remote interviewing has the advantage of saving time and travel costs as well scheduling a time that is more convenient for participants<sup>209,210</sup>. It may also be less intimidating and easier to share sensitive information as the remote interview creates a neutral personal distance<sup>209</sup> and participants don't feel observed/surveyed, reducing the surveillant factor<sup>211</sup>.

The reason for the follow-up was explained during the initial interview as well as during arrangements for the follow-up interview, and again at the beginning of the follow-up interview to ensure relevant quality data were collected<sup>210</sup>. Good rapport was established during the initial interviews and likely allowed participants to share information (positive and/or negative) regarding their experiences of the SBHP<sup>211</sup>. Additionally, the synchronous interaction allowed experiences to be articulated, adding to rich quality data<sup>209-211</sup>

It was necessary to guide participants using the semi-structured interview prompts (Appendix N), especially during the voice only Skype calls, due to the lack of non-verbal communication/feedback<sup>211</sup>. This facilitated the sharing of more specific and relevant information related to the program, whereas participants in the face-to-face interviews tended to go off topic necessitating re-direction to the topic of discussion.

Conducting qualitative interviews was a novel experience for the researcher who still has much to learn<sup>212</sup>. A possible limitation to the study was that some aspects were

not explored further during the follow-up interview e.g. why Facebook groups are perceived to be ineffective, possibly restricting the richness of some of the data.

Some follow-up interviews took longer to arrange due to logistical demands, and this might have afforded some participants more time to implement strategies, possibly resulting in different feedback regarding changes experienced and compliance with the SBHP.

In retrospect, it would have been valuable to measure participant's progress through goal attainment scaling (GAS)<sup>213</sup>, allowing participants to monitor progress, as well as contributing to evidence-based practice<sup>214</sup>. However, it was beyond the scope of the current study to measure progress/effectiveness of the SBHP, but GAS should be included as part of a SBHP to contribute evidence regarding the effectiveness of sensory-based therapies<sup>214</sup>, including ASI®<sup>29</sup>.

### ***Data analysis***

The researcher immersed herself in the data collected during the interviews by listening to the audio recordings several times. The audio recordings were checked to ensure they were clear and they were cleaned (listened to and unrelated conversation removed) prior to sending them to the transcriber. The transcripts were checked for accuracy against the audio recordings. Since the transcriber's native language is English, the Afrikaans interviews were checked meticulously for correctness (and spelling), resulting in the researcher being very familiar with the data.

This was the researcher's first attempt at coding interviews and resulted in a three month iterative process/interaction between the researcher and supervisor to ensure codes were appropriate. The code names were revised and discussed at length.

### **Ethical considerations**

As indicated in each of the papers, the study was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, certificate number M170829 (Appendix A). Each of the ethical principles that apply to the study will be discussed below:

### ***Autonomy***

Autonomy of both HCPs who were asked to refer their patients to participate in this study, as well as participants in both phases was respected by adhering to providing informed consent (Appendix C) and the principle of voluntary participation. The researchers did not obtain data about the referral source, thus HCPs who referred participants remained anonymous. There were no consequences for any participant who wished to withdraw at any point from the study.

### ***Confidentiality***

All data collected were stored in password protected folders electronically so as to prevent access by unauthorised persons<sup>215</sup>.

Only participants who wished to be included in the second phase of the study, were required to disclose identifying information. Because the second phase is a client-centred treatment programme in the form of a SBHP, identifying data could not be separated from the ASH and HADS-A data without the possibility of re-linking the information. However, identifying information will not be included in the data which will be stored in the Wits repository<sup>216</sup> in accordance with the data management plan.

In the reporting of results, no identifying information was used and participants were referred to by number, to protect their identity. The identities of participants in phase two are only known to the researcher.

### ***Beneficence***

Participants were informed that it is not known yet whether a SBHP will have any impact on GPPPD. However, it is known that where SPD exists, specific interventions do make a difference to clients' SPD, thus there is no harm in participating in the research<sup>215</sup>.

Patient were informed that there is no evidence that the intervention will affect their GPPPD, to prevent a misconception of therapeutic benefit in relation to study, and therefore to prevent undue influence to participate in the study as a result of this misconception<sup>217</sup>.

## **Justice**

Women with GPPPD constitutes a “hard-to-reach” population, who may be vulnerable due to potential stigma as a result of being diagnosed with a sexual disorder. For this reason, HCPs were recruited to refer their patients to participate in the study. Healthcare practitioners could thus decide whether it would be appropriate and fair for their patients to participate in the study as a measure of safeguarding the participants<sup>217</sup>.

Additionally, because of the uniqueness of this population, despite possibly being regarded a vulnerable group, it was decided that doing research with them would be in the best interests of the population. Furthermore, the results have been disseminated in open-source journals, to benefit not only other occupational therapists and HCPs, but also the patients who should be able to access the data.

## **KEY FINDINGS OF THE STUDY**

This section discuss the key findings in terms of the study objectives.

### **Objective 1: Describe the sensory processing patterns of women diagnosed with GPPPD**

The first objective of this study was to describe the sensory processing patterns of women diagnosed with GPPPD. The objective was addressed through Paper (manuscript) 2, which is to be submitted for publication to the Archives of Sexual Behaviour, as contained in Chapter 4.

A key finding of this study is that most (79.5%; n=35) participants presented with SPD. This is an important finding, especially because traditional interventions for GPPPD include components such as light touch<sup>21</sup>, which may elicit a fight-or-flight response in participants<sup>38,84,201</sup>, thus likely exacerbating their condition rather than improving it.

The current study emphasises the crucial role of the tactile system in persons with SPD and GPPPD. The tactile system was the most involved system related to the sensory section, SM and SS in Phase one. This is an important finding regarding sensory processing patterns, because data from Phase two further suggests that

atypical sensory processing of the tactile system also impacted on functional problems, including discomfort with imposed touch, water and tactile-related hygiene, all of which have a bearing on sexual functioning.

This study also shows that participants with SPD have social and emotional problems. Significantly, aggressive/impulsive behaviour was identified as the most prominent social/emotional problem on the ASH during Phase one.

It is evident from this study that both the involvement of tactile system and aggressive/impulsive behaviour may have a significant impact on intimate relationships, and may also increase feelings of anxiety and influence typical sexual pain responses.

Interestingly, genital sensation, sensual touch, bladder and painful stimuli from the pelvic area have been listed as part of the interoceptive system. Notably, these areas also play a vital role in women with GPPPD. In fact, the literature indicates that painful bladder syndrome and pudendal neuralgia are comorbid conditions to GPPPD<sup>218–220</sup>. Importantly, interoception and its role in female sexual arousal, has been investigated very recently<sup>96</sup>, which may pave the way for further research regarding interoception and female sexual pain.

The question arose whether SPD influences the development of GPPPD, because an atypical pain response was present in 77.3% (n=34) of participants. The sensation of pain is central to GPPPD and feedback regarding pain forms part of interoception, a concept which has recently been described in SI literature<sup>48</sup>. However, literature regarding interoception and female sexual pain is lacking. Additionally, there has not been any longitudinal studies of girls with SPD, to establish whether they eventually present with GPPPD. This question cannot be answered by the current study and future research is required.

## **Objective 2: Describe the presence of anxiety when both SPD and GPPPD are present**

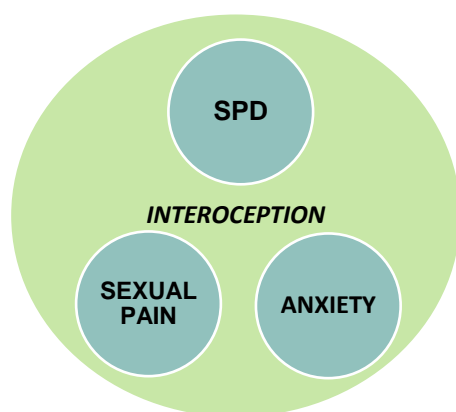
The second objective in the study was to describe the presence of anxiety when both SPD and GPPPD are present. It was also addressed in Paper (manuscript) 2, presented in Chapter 4.

Anxiety has been found to accompany diagnoses of SPD and GPPPD and it was decided to measure levels of anxiety in participants. Interestingly, according to the combined scores for anxiety on the ASH, anxiety was only detected in 47.8% (n=21) of participants compared to the combined score of 68.1% (n=30) on the HADS. The HADS is possibly more sensitive than the ASH when assessing anxiety and consists of 14 questions to determine the presence of anxiety<sup>221–223</sup>, compared to only four questions of the ASH to assess anxiety. The anxiety score on the ASH could therefore be less sensitive to anxiety and scores for individual social/emotional items on the ASH should be interpreted with caution.

Interestingly, the combined score of 65.9% (n=29) for social/emotional aspects on the ASH resonates more with the combined score of 68.1% (n=30) of the HADS-A. The ASH uses a total of 17 questions to assess all three emotional aspects, namely withdrawn/depressed, aggressive/impulsiveness and anxiety. The total score for social/emotional aspects on the ASH may therefore be more indicative of emotional difficulties.

Here also, interoception appears to play a role. Interoception has been recognised to play an important role in self-regulation, emotional experiences, decision making and consciousness<sup>94,97,175</sup>. Cardiovascular, respiratory and gastrointestinal symptoms are also associated with anxiety as well as other psychological conditions e.g. panic disorder, depression, eating disorders, somatic symptom disorders, substance abuse, posttraumatic stress, and generalised anxiety disorder<sup>95</sup>. Interoception provides feedback regarding conscious feelings of anxiety e.g. increased heart rate and nervousness from the body's systems.

Naturally, the question arises whether receiving, processing and integrating information from the different interoceptive systems are also affected by SPD. Given the evidence regarding the inter-relatedness of the different systems it is probable for interoception to be a link between SPD, GPPPD and anxiety (Figure 6.1), but this needs further investigation. A hypothesis which developed from this study that needs to be tested in future, is whether over-sensitivity to physiological signs experienced by a participant lead to atypical pain responses and feelings of anxiety (resulting in increasing sexual pain and anxious behaviour).



**Figure 6.1 Possible link between interoception, SPD, GPPPD & Anxiety**

The current study supports previous findings that anxiety is present when either a diagnosis of SPD or GPPPD are present. However, it is unknown if feelings of anxiety are compounded when both SPD and GPPPD are present and this requires further investigation.

The role of interoception should not be underestimated and must therefore be included in future research.

**Objective 3: Describe participants' experiences of participating in a sensory-based home program**

Noteworthy, is that all participants benefited from participating in the SBHP, even though compliance with, and implementation of strategies varied greatly among participants. This finding supports the need for individualised client-centred interventions<sup>61,76,77,214,224,225</sup>.

An important aspect to consider is the possible therapeutic value of qualitative research interviews (QRI) as it may not only affect participants responses but also contribute to improvements in functioning<sup>226</sup>. In the current study initial interviews were an integral part of the SBHP intervention as information regarding SPD was shared and OT/SI interventions were discussed and therefore had therapeutic value. Incidental data gathered during the initial interviews provided background information regarding participants' experiences of SPD, but this data were not analysed as it fell

beyond the parameters of the study. The purpose of the follow-up interviews was to gather data regarding their experiences of participating in the SBHP.

Changes experienced by participants was an important theme in Phase two and was categorised into increased insight/awareness and intra-personal changes.

Noteworthy changes included the ability to identify sensory triggers, increased tolerance of stimuli (especially tactile stimuli), fewer emotional outbursts and increased feelings of calmness and control after participating in the SBHP. This may have contributed to reduce feelings of anxiety and guilt, resulting in improved QoL and positively impacting on emotional closeness, interpersonal relationships, which is central to intimacy and physical closeness<sup>69,227</sup>.

Another prominent theme was the use of coping skills to assist with sensory processing of sensory stimuli. Sensory seeking of tactile input, especially deep tactile input, was used by most participants in the SBHP to assist them with sensory and emotional regulation. Participants further employed active coping skills such as avoidance and/or reducing of sensory stimuli, activity engagement, planning and creating order in their environments. It is noteworthy, that insight gained as part of the program led to greater acceptance of the impact of SPD on their lives. Socio-emotional support increased via shared experiences<sup>226</sup>.

An additional theme, that was not presented in Paper 3 due to among others space restrictions, was identified, namely:

### **THEME THREE: Sensory-based home program (SBHP): implementation and recommendations.**

This theme included feedback regarding implementation of and recommendations regarding the SBHP (Table 6.2).

**Table 6.2 Summary of theme and categories: Theme three**

THEME	CATEGORY	SUB-CATEGORY	CODE
SBHP: implementation & recommendations	Implementation of SBHP	Compliance with SBHP	Apologetic about not implementing "very busy lives" Willing to try strategies/interventions
		Strategies implemented	Additional reading Relaxation technique/ mindfulness Deep breathing Yoga Therapeutic brushing
	Recommendations SBHP		Frequency of follow up Methods of follow up Cost of treatment Additional suggestions and comments re SBHP

Feedback regarding the SBHP are described in the following categories: 1) Implementation of SBHP, and 2) Recommendations for future programs (Table 6.2).

## Results

### Category 1: Implementation of SBHP

#### ***Sub-category: Compliance with SBHP***

Implementation of, and compliance to strategies (recommended during the initial interview) varied among participants with different strategies and/or combination of strategies being implemented. Participants easily shared information regarding compliance with the SBHP.

*"To a certain degree. I don't think I followed everything, but I did follow as much as I possibly could." (P1)*

*"Ek moet dit (borsel en ontspanningstegnieke) net meer uitgeoefen het." (P3)*  
*("I should have done it (brushing and relaxation techniques) more." (P3))*

Participant (P1) also reported feelings of guilt for not implementing some strategies and apologised.

*"No, I don't think I even got there. Sorry about that. Oh, I feel terrible." (P1)*

A key finding was that all participants identified limited time as hampering/preventing the implementation of strategies. One participant (P2) started during the school holidays, and reported that it was much easier to adhere to the TB protocol during the holidays. Participants mentioned busy, hectic lives and that going forward, they will have to put time aside to implement some of the strategies.

*"If I have enough time in the morning. We've all got very busy lives, and we tend to forget." (P1)*

*"Maar ja, dit het net so hectic raak, dat ek ...," (P2)*

*("But, yes, it just got so hectic, that I... " (P2))*

*"Ek het nie eers daaraan gedink nie. Ek het nie eers tyd gehad nie." (P5)*

*("I did not even think about that. I did not even have time." (P5))*

Importantly, all participants were willing to try new experiences and showed a willingness to change.

*" I am able to walk around a little bit better in the dark, but not in complete darkness. It still doesn't ..., before the first thing I did was turn on the light. Now I'm actually able to walk into the kitchen, into the lounge without turning the light on. I'm not overly excited about it, I'm not going to lie, like so that I can do it, where before I wouldn't even try." (P1)*

*"So I tried new bread that has got more seeds and stuff in it. I tried crackers that are also seed-based and they've got stuff on the top, and whatever." (P1)*

*"I would go and stand in the sand with my feet ..., which I don't ..., it's not my forte to do. So I tried things like that." (P1)*

*"Maar dan probeer ek eerder 'n vrug, ek kan darem 'n vrug eet." (P3)*

*("But then I would rather try a fruit, I can at least eat a fruit." (P3))*

*“En toe probeer ek by die ding (om self uit situasie te verwyder) bly...’okay’, so, kom ons gaan eet roomys, dat ons ‘n bietjie uit die huis uit kan kom.” (P4)*  
 *(“And then I tried to stay with the thing (to remove oneself from a situation)...okay, lets go and eat ice cream to get out of the house for a bit.” (P4))*

***Sub-category: Strategies implemented***

Almost all participants (P1, P2, P3, P4) engaged in additional reading, while P5 mentioned she does not like reading. Only one participant (P2) followed the PRT via the video link, while P3 engaged in a self-adjusted relaxation technique. Participants P1, P4 & P5 mentioned breathing techniques to decrease stress.

*“You need to breathe in and out. In through your nose, out through your mouth.”(P1)*

*“Ek meen, dit was r rig nogal goed, die ontspanningsterapie, om daardie deel weer, jy weet, in te bring en so aan. Maar wat ek wil vir jou s , is, daardie ontspanningsterapie goed, dankie vir daardie videos. Dit was nogal cool gewees.”(P2)*

*(“I mean, it was really good, the relaxation therapy, to bring that in again etc. But, what I want to tell you, is those relaxation therapy stuff, thank you for those videos. That was quite cool.” (P2))*

One participant (P3) implemented some yoga, but did not persevere, while P1 reportedly did not try it due to a sprained ankle. The remaining participants mentioned that they have seen yoga classes being offered but have not yet considered it. The first author’s reflective journal showed that participants seemed unfamiliar/ not at ease with yoga, or saw it as not fitting into their frame of reference/culture.

Therapeutic brushing was implemented by P4 and she described the TB as intense and once the holiday was over, she was only able to do it intermittently. Two participants (P3 & P1) adapted the TB protocol, with P3 only brushing her arms in the evenings, and mentioning her legs were very sensitive and she could not brush them. While P1 brushed her face, interestingly, she could also not brush her legs.

*“So, but it didn’t really do much for my arms and stuff. I didn’t try my legs. That I couldn’t really do. But ja (yes), so it definitely did calm down.” (P1)*

*“En die vakansie was vir my baie makliker, ek meen, dis nogal ‘n ..., dis intens, nogal dis nou die eerste keer wat ek dit self doen. Dit was nogal intens gewees, maar ek kon dit ..., jy weet, ek kon dit doen. Maar toe ek nou begin het by die skool, yo, dit het moeilik begin raak.” (P2)*

*“And the holidays was easier for me, I mean, its quite a..., its intense, it would have been the first time that I do it myself. It was quite intense, but I could..., you know, I was able to do it. But, when school started again, yo, it became difficult.” (P2))*

## **Category 2: Recommendations for future programs**

Participants’ recommendations regarding adaptations and changes to the SBHP again varied, which is expected as the purpose is to create a client-centred program. Suggestions included more frequent follow-up via telecommunication, including WhatsApp, Skype etc., with the frequency recommended ranging from once a week, every second week to only when requested.

Additional suggestions by P4 included monthly newsletters, blogs, articles and attending a support group, as the latter will provide opportunities to learn from others and may be a more affordable/ a cost effective option. She also mentioned follow-up messages could be perceived as pressure, but that the pressure could actually also increase compliance with the SBHP. Interestingly, this participant perceived groups on Facebook to be ineffective.

*“Vir my, werk goed soos FaceBook groepe en so, werk nie. Iets wat my half skerp hou op ‘n topic, is ..., ek lees baie blogs, en om gereelde emails te kry, met ‘n artikel of so iets, hou dit net vir my op die voorgrond, iets om weer op te gaan lees, of om weer my brein net op die topic te kry.” (P4)*

*“For me, stuff like FaceBook groups don’t work. Something that keeps me sharp (focussed) on a topic, is..., I read a lot of blogs, and to get regular e-mails with an article or something like that, it keeps it on the foreground, something to read again, or allows me to keep the topic in the foreground.” (P4))*

*“Ek dink een keer elke twee weke, dit sou meer as genoeg gewees het. Maar as ek vir jou sê, na die eerste twee keer wat jy opvolg, nee, ek’s ‘okay’, dan is dit half nie nodig om op te volg nie. Maar as ek ‘n ander keer vir jou sê, nee, ek sukkel hiermee, of ek sukkel daarmee, dan verstaan ek dalk kan jy die frekwensie opbring of wat ookal.” (P5)*

*“I think once every second week, that would have been more than enough. But if I tell you, after you have followed-up twice, no, I’m okay, then it is more or less not necessary to follow up again. But if I tell you sometime, no, I struggle with this, or I struggle with that, then I understand that maybe you can increase the frequency, or whatever.” (P5)*

## **Discussion**

Participants in the current study implemented different coping strategies as reflected in the varied individualised feedback regarding interventions and specific changes implemented, especially in the work environment, which reinforces findings in the literature. Previous studies<sup>29,228–230</sup> recommend intervention strategies to be individualised and based on the needs of the client.

Participants tended to implement familiar strategies that met their needs and they adapted interventions especially, to fit their needs and/or daily routines both at home and work. This supports several other studies, mostly related to the paediatric population, which reported increased adherence to strategies if interventions are embedded into daily routines<sup>12,231,232</sup>.

Importantly, time restrictions due to busy lives were the main limitation in implementing and complying with SBHP strategies. Similarly, a recent study on parental adherence to a two week TB program reported difficulty fitting the intervention into daily routines and that it was time consuming<sup>232</sup>. The study further recommended that TB lasting longer than two weeks, be implemented during the holidays<sup>232</sup>. Interestingly, one participant who was able to comply with the TB during the holidays, described it as intense and she was only able to continue with it intermittently once the holiday was over.

Additional recommended reading benefited participants as they reported that it helped them to understand SPD and the resultant behaviour. Similarly, education as cognitive intervention has been emphasised in previous studies<sup>40,64,75,76,118,225</sup>,

Relaxation activities, such as breathing and mindfulness, were beneficial and reduced stress. The PMR technique was used most frequently, although it was adapted by some participants due to time constraints. A very recent study found relaxation activities to reduce stress<sup>233</sup> while breathing techniques and mindfulness have been used quite extensively in the treatment of SPD<sup>178,187</sup>, anxiety<sup>21,185,234</sup> and GPPPD<sup>235–237</sup>. These findings are supported by the current study.

Interestingly, yoga was only implemented by one participant, despite studies confirming that yoga, especially sensory-enhanced yoga, assists with self-regulation<sup>124,125</sup>. A possible reason is that participants did not feel comfortable with yoga, possibly due to a lack of knowledge, and people tend to engage in activities they felt comfortable with<sup>229</sup>. Another limiting factor could again be time constraints, and adding another activity to an already busy schedule might have increased stress<sup>238</sup>. Therefore, additional education, guidance and support might be necessary when introducing yoga to some clients.

Notably, only one participant used the video link to implement the progressive relaxation technique (PRT), with another not even noticing the link sent via e-mail, possibly due to poor visual discrimination, sensory overload or mental fatigue due to information overload<sup>239</sup>. A recent study found information overload, especially healthcare information obtained online, could affect people's well-being negatively<sup>239</sup>. It is possible that the format of the current SBHP contributed to information overload and feelings of guilt, which may explain the range of responses received regarding strategies implemented and recommendations.

Participants in the SBHP shared personal experiences during the first interview of what it is like to live with SPD, including information regarding the impact thereof on their intimate lives. However, sharing of information regarding intimacy varied among participants. Importantly, the need for a measurement instrument to assess the impact of SPD on intimacy/sexual health was highlighted, since such a measurement instrument is not yet available. It was beyond the scope of the current study to assess the impact on intimacy in greater depth, and due to time constraints valuable

information might have been lost. Additional information regarding the impact of sensory processing may assist therapists with more specific and applicable interventions related to intimacy.

## CHAPTER 7. CONCLUSION

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The purpose of the study was to describe the sensory processing of women diagnosed with GPPPD, to explore the presence of anxiety when both SPD and GPPPD are present, and to describe their experiences of participating in a SBHP.

At the outset of the study, very little was known about the role of OT in the field of sexual health and the study was conducted to provide a greater understanding of the role of OT in the field of sexual health, and especially the sensory processing patterns of women suffering from sexual pain.

Results from both phases provide some insight into participants' experiences of living with SPD as well as changes experienced after participating in the SBHP.

Phase one of the study found the majority of participants presented with SPD that required further investigation and/or intervention. Anxiety, which has independently been associated with both GPPPD and SPD, was also present.

Phase two described experiences relating to partaking in a SBHP and three themes were identified: 1) "Changes experienced after participating in a SBHP"; 2) "Coping strategies employed by women with SPD & GPPPD"; and 3) "SBHP: implementation and recommendations" (although only two themes were presented in Paper 3).

The findings of the current study point towards a complex inter-relatedness between female sexual pain, SPD and emotional difficulties, especially anxiety. It also provides us with additional insights re the role of not only sensory processing patterns, but also OT in the field of sexual health.

Specific implications for practice and possible further research that is necessary to better understand the role of SPD in female sexual pain, as well as the role of occupational therapy in the field of sexual health have been described.

## LIMITATIONS

Many of the limitations of the study have been discussed above, but herewith a summary:

- The current design did not allow for an in-depth evaluation of participants experiences of living with SPD and GPPPD. An explanatory sequential mixed methods study design<sup>240</sup> (to get a greater understanding of the impact of SPD on intimacy) could have allowed a more comprehensive description of the impact of SPD on intimacy. Phase one would have consisted of a quantitative study design to gather information regarding sensory processing patterns, followed by a qualitative study in Phase two in which information regarding participants' responses in Phase one and experiences of living with SPD would have been gathered to help explain their experiences of SPD. The drawback of such a study, is that there still would be no information as to whether SI OT as a SBHP, with all its benefits as explained in Chapter 5, is a potentially viable intervention option for these women. It was therefore decided that, in view of ethical standards in occupational therapy that indicate that one cannot identify a disorder without making treatment available, to rather investigate the possibility of a SBHP as a treatment option. A SBHP also provides access to people who may otherwise find it very difficult, or expensive, to access treatment.
- Purposive sampling limited the study sample. The sampling method was mainly used to recruit participants due to the sensitive nature of the study. Participation was also voluntary and only people who were comfortable sharing their experiences related to sexual pain participated.
- Participants in Phase one of the study provided the possible sample for Phase two. Limited access to e-mail/internet to complete the electronic surveys may have further affected the recruitment of participants.
- The small sample means that the results cannot be generalised, thus are not necessarily representative of the whole population.
- A possible limitation of the ASH measurement is the lack of information related to sensory under-responsivity (SUR).
- Some aspects were not explored further by the novice researcher during the follow-up interviews, possibly contributing to less rich data gathered.

## IMPLICATIONS OF THE STUDY

Occupational therapists trained in SI should probe aspects related to intimacy when SPD is identified in an adult woman. Intimacy, an important occupational performance area, is negatively affected by sexual pain, SPD and anxiety and needs to be addressed during OT interventions. Sexual pain should therefore not be neglected, but should be investigated, and if necessary, referred to HCPs in the field of sexual health.

Occupational therapy, based in sensory integrative theory, should be included in the multi-disciplinary intervention approach for women with sexual pain. Intervention protocols addressing emotional difficulties, especially anxiety, could be beneficial as well as a SBHP. Occupational therapists, have a holistic approach and occupational therapists working in the mental health field can also make valuable contributions to women suffering from sexual pain<sup>24,241</sup>.

Additional measurements may assist (after the initial interview) to get a comprehensive picture of the client, as various conditions such as affective conditions<sup>39,40,242</sup> and ADHD<sup>79,87</sup> are associated with persons with SPD. A measurement for female sexual pain should also be included in the assessment<sup>168</sup>.

It is recommended that two hours be allocated for initial interviews for adults with possible SPD. Sufficient background information, including sensitive information regarding intimate life, must be obtained during the initial interview and enough time must be allocated to establish a good rapport with the client.

Interventions for GPPPD, SPD and anxiety share several strategies, e.g. CBT, mindfulness and stress management<sup>21,75,235,236,243,244</sup>, and close collaboration with the multi-disciplinary team is required to ensure that intervention strategies are aligned and complimentary.

Participants in the current study benefited mostly from information related to SPD and developed insight regarding the impact of SPD on everyday life, including intimacy, which enabled them to make adaptations to their environments and regulated their emotional state better. Information about SPD is vital to treatment of SPD, but care should be taken not to cause information overload. One way of mitigating information overload is to make resources available to patients/clients online with asynchronous discussion fora (either individual or collective) to allow for

questions and answers. Asynchronous fora are anticipated to better enable digestion of information<sup>245</sup>.

As mentioned in Chapter 5, the role of a women's partner should not be underestimated during intervention. Ideally, the partner's sensory processing patterns should also be investigated as SPD can have a devastating impact on interpersonal relationships.

## **FUTURE RESEARCH**

The current study highlighted the need for further research and as mentioned earlier, the current study lays the foundation for a future experimental study, investigating a possible association between GPPD and SPD. The experimental study should include a healthy control group and a proposed hypothesis could be: "Women diagnosed with GPPPD do not present with/have co-morbid SPD".

Development of a measurement instrument to measure the impact of SPD on intimacy.

Interoception could be an important link in the complex inter-relationship between GPPPD, SPD and anxiety and requires further investigation in future research studies.

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# APPENDICES

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## APPENDIX A: Human Research Ethics Committee (Medical): Clearance certificate



R14/49 Ms E Labuschagne

### HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M170829

**NAME:** Ms E Labuschagne  
**(Principal Investigator)**  
**DEPARTMENT:** School of Therapeutic Sciences  
Department of Occupational Therapy  
Medical School

**PROJECT TITLE:** Sensory processing of women diagnosed with geneto-pelvic pain/penetration disorder

**DATE CONSIDERED:** 25/08/2017

**DECISION:** Approved unconditionally

**CONDITIONS:**

**SUPERVISOR:** Ms M van Niekerk

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

**DATE OF APPROVAL:** 23/10/2017

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

#### DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **August** and will therefore be due in the month of **August** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

\_\_\_\_\_  
Principal Investigator Signature

\_\_\_\_\_  
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

## APPENDIX B: Plagiarism Report

Dissertation Complete doc Elsie

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57	Judith Giencke Kimball, Caryn T. Birstler, Erica Franck Bosse, Lisa M. Nelson, Mark R. Woods. "The Relationships Among Sensory Processing Styles, Personality Traits, and Body Mass Index: A Pilot Study", Occupational Therapy in Mental Health, 2012 Publication	<1 %	66	Submitted to Mansoura University Student Paper	<1 %
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Tercero et al. "Sensory processing disorder: Key points of a frequent alteration in neurodevelopmental disorders", Cogent Medicine, 2020

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## APPENDIX C: PAPER 1 - Cover letter & Consent

Good day,

I, Elsie Labuschagne, am a master's student in Occupational Therapy at the University of Witwatersrand and am conducting research regarding the **sensory processing patterns** of women who suffer from **genito-pelvic pain/ penetration disorder (GPPPD)**. You might not have received this specific label, but this includes a diagnosis of **vaginismus, provoked vestibulodynia, pudendal neuralgia, vulvodynia, hyperactive pelvic floor, chronic pelvic pain and painful bladder syndrome** amongst others. Your diagnosis could also have included the following:

1. Inability to have vaginal intercourse/penetration
2. Marked vulvovaginal or pelvic pain during vaginal intercourse/penetration attempts
3. Marked fear or anxiety either about vulvovaginal or pelvic pain or vaginal penetration
4. Marked tensing or tightening of the pelvic floor muscles during attempted vaginal penetration.

Please read the information leaflet on sensory processing disorder in adults provided with the questionnaire (also attached).

The purpose of the study is to investigate the presence of sensory processing disorder (SPD) in females who have been diagnosed with GPPPD, as well as the level of anxiety that is present when both SPD and GPPPD are present.

A second phase of the study will investigate whether participating in a personalised sensory home program has an effect on the female's participation in activities of daily living, specifically related to sexuality.

These findings could assist in filling the information gap regarding female sexual disorders and to identify a **possible link between GPPPD and sensory processing disorder**. It could also lead to broaden the current treatment options for women diagnosed with GPPPD/sexual pain, by the potential inclusion of sensory integrative occupational therapy.

You are invited to participate in the research program to gain more clarity regarding female sexual pain and sensory processing patterns and treatments options.

The study will be conducted in 2 phases and you can choose to be part of phase one only, or phase one and two.

In **phase 1** you will be required to complete two questionnaires. Please note that the first questionnaire is more complex than the second. It should take about 40 minutes to complete both questionnaires. Your participation is completely voluntary and all information will be confidential. You will be informed of the results on request and an

e-mail address will have to be provided. All data will be submitted online via REDCap which maintains the confidentiality of the sender. On submitting the data each questionnaire will receive a unique participant ID. Your e-mail address will be kept separate from the data and will be linked to your questionnaire via the unique participant ID. Participants who were identified with SPD will be given the choice to be referred to occupational therapists who specialises in sensory integration.

**Phase 2** will be open to participants who meet the following criteria:

- Identified with SPD in phase 1
- have given consent to be contacted and provided an e-mail address
- Reside in Gauteng and KwaZulu-Natal.

Confidentiality of personal information in phase 2 will also be ensured. Participant's details will only be accessed if they were identified with SPD and have given consent to be contacted.

Participants in phase 2 will take part in a personalised sensory integration based home program and will be required to comply with the 6-8 week program. Interviews will be conducted to explain and demonstrate suggested activities. A follow-up interview will be conducted after 6 to 8 weeks to gather information regarding the participant's perception of the program as a mode of treatment. As part of the home program, you will receive sensory modulation input which Moore and Henry in 2002 found could benefit Sensory Defensive adults, but that more research is necessary.

Participation in both phases of the research is completely voluntary, non-participation is without consequence and withdrawal at any time will be without consequence.

If you have any questions about the research please contact the research supervisor Mrs. Matty van Niekerk on 011 717 3701.

The ethical clearance number for this study is: M170829. For any ethical concerns please contact the chairperson of the Human Research Ethics Committee at the University of Witwatersrand, Prof P Cleaton-Jones at [peter.cleaton-jones@wits.ac.za](mailto:peter.cleaton-jones@wits.ac.za) Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252, or email: [Zanele.ndlovu@wits.ac.za](mailto:Zanele.ndlovu@wits.ac.za); [Rhulani.mkansi@wits.ac.za](mailto:Rhulani.mkansi@wits.ac.za); [Lebo.moeng@wits.ac.za](mailto:Lebo.moeng@wits.ac.za)

Completion and return of the questionnaire will be assumed informed consent. By selecting the START THE SURVEY you are confirming that you are over 18 years old and have read and understood the above explanation about the study, and that you agree to participate.

Please click on the link below to complete the questionnaires online.

**You may open the survey in your web browser by clicking the link below:**  
[Sensory Processing of women diagnosed with genito-pelvic pain/penetration disorder](#)

If the link above does not work, try copying the link below into your web browser:  
<https://redcap.core.wits.ac.za/redcap/surveys/?s=LWXHLELDR4>

Thank you for taking time to consider this invitation and your participation would be greatly appreciated.

Kind regards,

Elsie Labuschagne

Occupational Therapist

[elsieot@absamail.co.za](mailto:elsieot@absamail.co.za)

# SENSORY PROCESSING

## ...In Adults

### What are Sensory Processing Problems ?

Sensory processing problems invariably result from difficulties in the nervous system's processing of received information. Sensory information comes from vision, hearing, touch, smell, taste, balance and bodily perception. Adequate sensory processing is necessary in order provide appropriate responses to the demands of the environment and are used for self-regulation, motor planning, and skill development.

*When my body becomes a safer place to live, I will interact with you differently.*

*- Rosie Spiegel*

For some people, sensory integration does not develop as efficiently as it should.

This is known as *Sensory Processing Disorder (SPD)*. SPD describes the problem some people's nervous systems have with taking in, integrating and making use of sensory information. This disintegration affects how the person often sub-consciously responds to changes in their own body, the environment and how they interact with it and others around them. This may have an impact on one or several of the

following: self-image, emotional regulation, attention, problem solving, behaviour, skill performance, sexual health and the capacity to develop and maintain interpersonal relationships.

In adults, these integration problems may negatively impact on the ability to parent, work, or engage in home management, social, and leisure activities.

Sensory processing difficulties can occur across a person's lifespan. They may be seen in isolation, or more frequently in combination with other diagnoses and disorders such as Anxiety, Panic & phobias, Eating, Addiction and Attention Deficit Disorders.

SPD also impacts on the autonomic nervous system which may contribute to secondary impacts, such as psychosomatic symptoms, stress responses, exhaustion, sleep disturbances, allergies and hormonal changes to name a few of the common ones.

*It is very confusing, and very frustrating, to spend so much effort being so afraid to be touched, and working so very hard to avoid being touched, when it is touching and being touched that I need most of all.*

*- Pat Holbrook*

### SOME INDICATORS

•••

- Dislike/pulling away from being touched incl. intimate touch.
  - Bothered by clothes; certain materials, tags, seams, pantyhose, ties, belts, turtlenecks.
  - Bothered by "light touch"; someone lightly touching/rubbing your hand, face, leg or back.
  - Difficulty "snuggling" with partner.
  - Frequently get car sick, air sick, motion sickness.
  - Difficulty riding on elevators, escalators, or moving walkways.
  - Difficulty eating foods with mixed textures, or one particular texture.
  - Become nauseated or gag from certain cooking, cleaning, perfume, public restroom, or bodily odors.
  - Avoid crowded places.
  - Sensitive to noises.
  - Over-react to loud noises.
  - Fearful of heights.
  - Bothered by hands or face being dirty.
  - Clumsy, un-coordinated, accident prone.
  - Dislike changes in plans or routines.
  - Difficulty seeking out / maintaining relationships.
  - Avoid eye contact.
- (list not complete)*

## APPENDIX E: PAPER 1- Demographic Questionnaire

<b>What is your age:</b>	
<b>Gender:</b>	<ul style="list-style-type: none"> <li>• Female</li> <li>• Other</li> </ul>
<b>Province:</b>	
<ul style="list-style-type: none"> <li>• Eastern Cape</li> <li>• Gauteng</li> <li>• Limpopo</li> <li>• North West</li> <li>• Western Cape</li> </ul>	<ul style="list-style-type: none"> <li>• Free State</li> <li>• Kwazulu-Natal</li> <li>• Mpumalanga</li> <li>• Northern Cape</li> </ul>
<b>What is the highest degree or level of school you have completed? (If you're currently enrolled in school, please indicate the highest degree you have <i>received</i>.)</b>	<ul style="list-style-type: none"> <li>• Less than a matric</li> <li>• Matric or equivalent</li> <li>• Some college, no degree</li> <li>• Bachelor's degree</li> <li>• Master's degree</li> <li>• Doctorate</li> </ul>
<b>What is your marital status?</b>	
<ul style="list-style-type: none"> <li>• Single (never married)</li> <li>• Widowed</li> </ul>	<ul style="list-style-type: none"> <li>• Married, or in a domestic partnership</li> <li>• Divorced</li> <li>• Separated</li> </ul>
<b>Children</b>	
<ul style="list-style-type: none"> <li>• Yes</li> <li>• # &amp; Ages</li> </ul>	<ul style="list-style-type: none"> <li>• No</li> </ul>
<b>How many years have you been sexually active?</b>	
<b>Additional diagnosis/ other conditions</b>	
<p><b>Please list your specific diagnosis made by your doctor.</b></p> <p><b>Genito-pelvic pain/penetration disorder (GPPPD) includes one or more of the following and</b> you might not have received this specific label, but this includes a diagnosis of vaginismus, provoked vestibulodynia, pudendal neuralgia, vulvodynia, hyperactive pelvic floor,</p>	<p><b>Persistent or recurrent difficulties for at least 6 months with one or more of the following:</b></p> <ol style="list-style-type: none"> <li>1. Inability to have vaginal intercourse/penetration</li> <li>2. Marked vulvovaginal or pelvic pain during vaginal intercourse/penetration attempts</li> </ol>

<p>chronic pelvic pain and painful bladder syndrome amongst others.</p>	<p>3. Marked fear or anxiety either about vulvovaginal or pelvic pain or vaginal penetration</p> <p>4. Marked tensing or tightening of the pelvic floor muscles during attempted vaginal penetration</p>
<p><b>When did your symptoms start?</b></p>	
<p><b>When did you start to get definite treatment for the problem?</b></p>	
<p><b>Treatment received related to sexual pain:</b></p>	<ul style="list-style-type: none"> <li>• I have never received treatment for my pain</li> <li>• I have received treatment and have been cured</li> <li>• I am still receiving treatment and is symptoms free on treatment</li> <li>• I am receiving treatment and still have mild symptoms on treatment</li> <li>• I am receiving treatment and still have significant treatment</li> <li>• I have stopped treatment because it did not work</li> <li>• Other: explain</li> </ul>
<p><b>Pain experience – prior to treatment sex was:</b></p>	<ul style="list-style-type: none"> <li>• Impossible</li> <li>• Extremely painful but possible</li> <li>• Moderately Painful</li> <li>• Mildly painful</li> <li>• Uncomfortable</li> <li>• Pain free</li> </ul>
<p><b>Pain experience – currently sex is:</b></p>	<ul style="list-style-type: none"> <li>• Impossible</li> <li>• Extremely painful but possible</li> <li>• Moderately Painful</li> <li>• Mildly painful</li> <li>• Uncomfortable</li> <li>• Pain free</li> </ul>

APPENDIX F: PAPER 1 - Adult/Adolescent Sensory History: sample pages



## Adult/Adolescent Sensory History Self-Report Questionnaire

Jane Koomar, PhD, OTR/L, FAOTA & Teresa May-Benson, ScD, OTR/L, FAOTA  
(Contributions by Mandy Hurwitz, Rebecca Kahler-Reis, Stacey Szklut)

**GENERAL INFORMATION**

**Date:** \_\_\_\_\_

**Name:** \_\_\_\_\_ **Birth Date:** \_\_\_\_\_  
(First) (Last) (Nickname)

**Address:** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**Gender:**  Male  Female      **Race/Ethnicity:**  Caucasian/White  Native-American  Hispanic  Asian  African-American/Black  Other (*specify*) \_\_\_\_\_

**Marital Status:**  Married  Separated  Divorced  Widowed  Single  
 Other (*specify*): \_\_\_\_\_

**Highest Education Completed:**  
 Less than high school       High school       Some college/Associate's  
 Bachelor's       Post-graduate       Doctorate/Post-doctorate

**Occupation:** \_\_\_\_\_

**Reason for referral:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**What do you hope to gain from this evaluation and/or treatment?** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Scoring Key:**  
 5 = You almost **Always** respond this way (e.g., more than 95% of the time)  
 4 = You **Often** respond this way (e.g., about 70 - 95% of the time)  
 3 = You **Sometimes** respond this way (e.g., about 30 - 69% of the time)  
 2 = You **Rarely** respond this way (e.g., about 5 - 29% of the time)  
 1 = You **Never** respond this way (e.g., less than 5% of the time)

Scale: 5-Always 4-Often 3-Sometimes 2-Rarely 1-Never

Do you...	5	4	3	2	1	Comments
<b>TASTE AND SMELL</b>						
1. React negatively or seem overly sensitive to odors (e.g., perfume, foods, cleaners)?						
2. React negatively to the taste of foods?						
3. React negatively to the texture of foods?						
4. Find it uncomfortable to eat at restaurants because of food or smells?						
5. Have more difficulty eating textured than smooth foods?						
6. Have difficulty eating smooth foods with a few lumps (e.g., soup)?						
7. Lick, suck or chew on non-food items (e.g., hair, pencils)?						
8. Tend to explore with smells, or deliberately smell objects?						
9. Like drinks/food that are only room temperature, not hot or cold?						
10. Feel as though all foods taste the same?						
11. Seek out crunchy or chewy foods?						
<b>TOUCH (TACTILE PROCESSING)</b>						
1. Become irritated by tags in the back of your shirts?						
2. Become bothered by clothing or socks?						
3. Avoid getting your hands into messy things?						
4. Tend to be more sensitive to pain than others?						
5. Become especially bothered by small cuts?						
6. Notice irritating bumps on your bed sheets?						
7. Over or under dress for the temperature?						
8. Seem overly sensitive to food or water temperature?						
9. Crave being held or cuddled?						
10. Prefer tight exercise-type clothing?						
11. Seem excessively ticklish?						
12. Prefer to touch rather than be touched?						

# APPENDIX G: PAPER 1 - Adult/Adolescent Sensory History: Report Form

Raw Score				z-scores			Interpretation								
<b>Total Score</b>	463	-2,92	Definite	<b>Functional Problem Subscores</b>											
<b>Sensory Section Subscores</b>				<b>Sensory Seeking</b>											
Visual-Spatial Processing	80	-3,04	Definite	Visual Seeking/ Oculo-Motor	12	-1,40	Mild	Seeks Movement	22	<-3,50	Definite	Seek Touch	10	-1,19	Mild
Auditory & Language Processing	41	-1,91	Mild	<b>Sensory Over-Responsivity</b>											
Movement (Vestibular Processing)	80	-2,59	Definite	Discomfort with Imposed Touch	25	-3,16	Definite	Tactile-Related Hygiene	8	-1,17	Mild	Discomfort with Water	17	<-3,50	Definite
Taste & Smell	39	<-3,50	Definite	Atypical Pain Response	8	-1,61	Mild	Gravitational Insecurity	23	-0,80	Typical				
Touch (Tactile Processing)	89	-2,52	Definite	<b>Motor/Social Section Subscores</b>											
Proprioception	21	-0,67	Typical	<b>Motor/Social Section Subscores</b>											
<b>Sensory Modulation &amp; Discrimination Subscores</b>				<b>Motor/Social Section Subscores</b>											
<b>Modulation</b>	195	<-3,50	Definite	Postural Control	31	-1,32	Mild	<b>Motor Coordination</b>							
Visual	45	-3,23	Definite	Motor Planning						12	-0,57	Typical			
Auditory	29	-2,54	Definite	Sequencing	13	-1,13	Mild	Oral Motor Planning				11	-0,41	Typical	
Vestibular	28	-2,28	Definite	Fine Motor						9	-0,14	Typical			
Taste & Smell	24	<-3,50	Definite	Difficulties Driving a Car						10	-2,00	Definite			
Tactile	69	-2,46	Definite	<b>Social/Emotional</b>						57	-2,92	Definite			
<b>Discrimination</b>	164	-2,20	Definite	Withdrawn/Depressed						23	-1,90	Mild			
Visual	35	-2,09	Definite	Aggressive/Impulsive						24	-2,77	Definite			
Auditory	12	-0,44	Typical	Anxious						10	-2,24	Definite			
Vestibular	52	-2,10	Definite												
Taste & Smell	15	-2,13	Definite												
Tactile	20	-1,83	Mild												
Proprioceptive	30	-1,25	Mild												

## APPENDIX H: PAPER 1 - Hospital Anxiety and Depression Scale (HADS)

### Hospital Anxiety and Depression Scale (HADS)

**Instructions:** Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

<b>I feel tense or 'wound up':</b>	<b>A</b>	<b>I feel as if I am slowed down:</b>	<b>D</b>
Most of the time	3	Nearly all of the time	3
A lot of the time	2	Very often	2
Time to time, occasionally	1	Sometimes	1
Not at all	0	Not at all	0
<b>I still enjoy the things I used to enjoy:</b>	<b>D</b>	<b>I get a sort of frightened feeling like 'butterflies in the stomach':</b>	<b>A</b>
Definitely as much	0	Not at all	0
Not quite so much	1	Occasionally	1
Only a little	2	Quite often	2
Not at all	3	Very often	3
<b>I get a sort of frightened feeling like something awful is about to happen:</b>	<b>A</b>	<b>I have lost interest in my appearance:</b>	<b>D</b>
Very definitely and quite badly	3	Definitely	3
Yes, but not too badly	2	I don't take as much care as I should	2
A little, but it doesn't worry me	1	I may not take quite as much care	1
Not at all	0	I take just as much care as ever	0
<b>I can laugh and see the funny side of things:</b>	<b>D</b>	<b>I feel restless as if I have to be on the move:</b>	<b>A</b>
As much as I always could	0	Very much indeed	3
Not quite so much now	1	Quite a lot	2
Definitely not so much now	2	Not very much	1
Not at all	3	Not at all	0
<b>Worrying thoughts go through my mind:</b>	<b>A</b>	<b>I look forward with enjoyment to things:</b>	<b>D</b>
A great deal of the time	3	A much as I ever did	0
A lot of the time	2	Rather less than I used to	1
From time to time but not too often	1	Definitely less than I used to	3
Only occasionally	0	Hardly at all	2
<b>I feel cheerful:</b>	<b>D</b>	<b>I get sudden feelings of panic:</b>	<b>A</b>
Not at all	3	Very often indeed	3
Not often	2	Quite often	2
Sometimes	1	Not very often	1
Most of the time	0	Not at all	0
<b>I can sit at ease and feel relaxed:</b>	<b>A</b>	<b>I can enjoy a good book or radio or TV programme:</b>	<b>D</b>
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

Questions relating to anxiety are indicated by an 'A' while those relating to depression are shown by a 'D'. Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'

## APPENDIX I: PAPER 1 - Copyright BioMed Central: BMC Research Notes

Elsie Labuschagne de Jager

---

**From:** Parthiban Gurusamy <parthiban.gurusamy@springer.com>  
**Sent:** 18 January 2020 09:02 AM  
**To:** Elsie Labuschagne de Jager  
**Subject:** RE: Contact Us Enquiry for BMC Research Notes 13104, RESN  
**Categories:** STUDY

Dear Dr. Labuschagne,

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With best regards,  
Parthiban

**Parthiban Gurusamy (Mr.)**  
Journals Editorial Office (JEO)

---

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**Sent:** Friday, January 17, 2020 11:56 AM  
**To:** Parthiban Gurusamy  
**Subject:** Contact Us Enquiry for BMC Research Notes 13104, RESN

RESN-D-19-01182R2

Dear Editor,

### **BMC Research Notes: Copyright letter – Master dissertation**

A letter is required providing consent to submit the article published in BMC Research Notes (reference below), as part of the fulfilment of the requirements for the degree of Master of Occupational Therapy at the University of the Witwatersrand, Johannesburg.

- Labuschagne, E., van Niekerk, M. Sensory processing of women diagnosed with genito-pelvic pain/penetration disorder: a research proposal. *BMC Res Notes* **12**, 577 (2019) doi:10.1186/s13104-019-4612-6

We look forward to hearing from you at your earliest convenience.

Yours sincerely,



**Elsie Labuschagne**



**Matty van Niekerk**

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# APPENDIX J: PAPER 2 - POSTER PRESENTATION: WFOT CONGRESS, MAY 2019



**WITS UNIVERSITY**

## SENSORY PROCESSING OF WOMEN DIAGNOSED WITH GENITO-PELVIC PENETRATION PAIN DISORDER

Pilot study  
Elsie Labuschagne<sup>1</sup>, Matty van Niekerk<sup>1</sup>  
<sup>1</sup>MSc OT student

<sup>1</sup>Department of Occupational Therapy, School of Therapeutic Sciences, Faculty of Health Sciences, University of Witwatersrand  
This presentation was made possible with a grant from the National Research Foundation. Ethical Clearance Certificate: M170829



**THERAPEUTIC SCIENCES**

WHY

- Role of sexuality often ignored in OT
- Dearth of literature exploring sensory processing disorder (SPD) and sexual function
- Sexual pain significantly affects:
  - Quality of life
  - Fulfillment of life roles

RESULTS

ADULT/ADOLESCENT SENSORY HISTORY TOTAL SCORES



Results support link between SPD and sexual pain – 78% requires intervention (R)

FUNCTIONAL PROBLEM SUBSCORES



- Sensory-seeking
- Touch – 60%
- Sensory over-responsivity
- Imposed touch – 66%
- Tactile related hygiene – 56%
- Discomfort with water – 60%

SENSORY SECTION SUBSCORES



- Touch – 82%
- Auditory & Language – 69%
- Proprioception – 60%
- Visual-spatial – 53%

MOTOR / SOCIAL SECTION SUBSCORES



- MOTOR CONTROL – 80%
- Sequencing – 59%
- Difficulties driving car – 50%
- SOCIAL / EMOTIONAL – 86%
- Aggressive / Impulsive – 89%

SENSORY MODULATION & DISCRIMINATION SUBSCORES



- MODULATION – 88%
- Tactile – 86%
- Auditory – 83%
- DISCRIMINATION – 76%
- Vestibular – 83%
- Tactile – 50%
- Proprioception – 60%

AIM

Determine sensory processing patterns of women diagnosed with genito-pelvic penetration pain disorder (GPPPD).

APPROACH

- Cross sectional surveys
- Electronic questionnaires distributed via health professionals:
- Adult/ Adolescent Sensory History (ASH)
- Convenience sampling

REFERENCES

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10. Sensible, M. et al. (2010). Adult Behavioral Sensory Processing and Clinical in Health Adults. *The American Journal of Occupational Therapy*. Official publication of the American Occupational Therapy Association, 74(3), 201-210.
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TAKE HOME MESSAGE

- Sensory processing disorder and sexual pain in women are linked.
  - Supports multi-disciplinary approach
- Treatment options for sexual pain need to be broadened to include sensory based OT.
- Treatment methods based on light touch e.g. sensate focus treatment (often used by health professionals) could have the opposite reaction in eliciting an autonomic nervous system reaction e.g. fight/flight response.
  - Education of multi-disciplinary team (MDT)

[elcie@worksense.co](mailto:elcie@worksense.co)

## APPENDIX K: PAPER 2 - Archives of Sexual Behaviour: Submission guidelines

[https://www.springer.com/journal/10508/submission-guidelines#Instructions%20for%20Authors\\_Manuscript%20Submission](https://www.springer.com/journal/10508/submission-guidelines#Instructions%20for%20Authors_Manuscript%20Submission)

[Journal home](#) > [Submission guidelines](#)



### Archives of Sexual Behavior

The Official Publication of the International Academy of Sex Research

## Submission guidelines

### Contents

- [Instructions for Authors](#)
  - [IMPORTANT REMINDER](#)
  - [Manuscript Submission](#)
  - [Manuscript Style](#)
  - [Illustrations](#)
  - [References](#)
  - [Footnotes](#)
  - [Style Guide](#)
  - [Research Data Policy](#)
  - [No Page Charges](#)
  - [English Language Editing](#)
  - [Springer Open Choice](#)
  - [Ethical Responsibilities of Authors](#)
  - [Authorship principles](#)
  - [Compliance with Ethical Standards](#)
  - [Disclosure of potential conflicts of interest](#)
  - [Research involving human participants, their data or biological material](#)
  - [Informed consent](#)

### Instructions for Authors

#### IMPORTANT REMINDER

Be sure to read the sections on ethical requirements located at the end of these instructions. Be sure to submit all the required ethical statements in a **separate section** of your manuscript entitled "Compliance with Ethical Standards." This section will print immediately before the References section in accepted articles.

The journal's peer-review system is **masked (i.e., double-blind)**. Thus, leave all identifying information off the manuscript.

[Back to top ↑](#)

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## Manuscript Submission

Manuscripts, in English, should be submitted to Editor's Office via the journal's web-based online manuscript submission and peer-review system:

<http://aseb.edmgr.com>

Inquiries regarding journal policy, manuscript preparation, and other such general topics should be sent to the Editor:

Kenneth J. Zucker, Ph.D.

e-mail: [kzucker.phd@gmail.com](mailto:kzucker.phd@gmail.com)

The online system offers easy straightforward log-in and submission; supports a wide range of submission formats [such as Word, WordPerfect, RTF, TXT, and LaTeX for manuscripts; TIFF, GIF, JPEG, EPS, PPT, and Postscript for figures (artwork)]; eliminates the need to submit manuscripts as hard-copy printouts, disks, and/or e-mail attachments; enables real-time tracking of manuscript status by the author; and provides help should authors experience any submission difficulties.

For books for review, please contact Editor Zucker at the above e-mail address for details. Submission is a representation that the manuscript has not been published previously and is not currently under consideration for publication elsewhere. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to Springer Science+Business Media, LLC is required. Upon commencement of typesetting, the contact author will receive an e-mail directing him/her to a webpage where the transfer-of-copyright form can be signed online. Such a written transfer of copyright, which previously was assumed to be implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for the publisher to carry through the dissemination of research results and reviews as widely and effectively as possible.

[Back to top ↑](#)

## Manuscript Style

- Type double-spaced and left-justified in 12-point Times New Roman font using 1-inch margins on all sides. Number all pages (including table pages and figure-caption page), except the title page, consecutively with Arabic numerals placed in the upper right-hand corner. In order to facilitate **masked (previously termed “double-blind”)** review, leave all identifying information off the manuscript, including the title page and the electronic file name. Appropriate identifying information is attached automatically to the electronic file. Upon initial submission the title page should include only the title of the article.
- An additional title page should be uploaded as a separate submission item and should include the title of the article, author’s name (including highest degree received), and author’s affiliation. Academic affiliations of all authors should be included. The affiliation should include the department, institution, city, and state (or nation) and should be typed as a numbered footnote to the author’s name. The title page should also include the complete mailing address, telephone number, fax number, and e-mail address of the one author designated to review proofs.
- An abstract, preferably no longer than 250 words, is to be provided as the second page.
- A list of 4–5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.
- The Acknowledgments section (if any) should be included as part of the **separate title page** to facilitate masked (i.e., **double-blind**) peer review.

[Back to top ↑](#)

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## Illustrations

Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals and cited in numerical order in the text. Photographs should be high-contrast and drawings should be dark, sharp, and clear. Artwork for each figure should be provided on a separate page, placed at the end of the manuscript (i.e., after the References section). Each figure should have an accompanying caption. The captions for illustrations should be listed on a separate page.

Tables should be numbered consecutively with Arabic numerals and referred to by number in the text. Each table should be typed on a separate page, placed at the end of the manuscript (i.e., after the References section), and should have a descriptive title. Center the title above the table, and type explanatory footnotes (indicated by superscript lowercase letters) below the table.

[Back to top ↑](#)

## References

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order): last names and initials of all authors, year published, title of article, name of publication, volume number, and inclusive pages. The style and punctuation of the references should conform to strict APA style -- illustrated by the following examples:

### Journal Article

Meston, C. M., & Frohlich, P. F. (2000). The neurobiology of sexual function. *Archives of General Psychiatry*, 57, 1012–1030.

### Book

Dixson, A. F. (1998). *Primate sexuality: Comparative studies of the prosimians, monkeys, apes, and human beings*. New York: Oxford University Press.

### Chapter in a Book

Bem, D. (2000). The exotic-becomes-erotic theory of sexual orientation. In J. Bancroft (Ed.), *The role of theory in sex research* (pp. 67–81). Bloomington, IN: Indiana University Press.

[Back to top ↑](#)

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## Footnotes

Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript numeral for citation in the text.

[Back to top ↑](#)

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## Style Guide

The 2010 Publication Manual of the American Psychological Association (Sixth Edition) should be used as the style guide for the preparation of manuscripts, particularly with respect to such matters as the citing of references and the use of abbreviations, numbers, and symbols. Manuscripts departing significantly from the Sixth Edition style will not be reviewed until a corrected manuscript has been received.

## **APPENDIX L: PAPER 3 - First author's journal/notes**

### **Journal/field notes – Follow up interviews:**

#### **P1 – FOLLOW-UP INTERVIEW:**

P1 chose a face-to-face interview and arrived timeously for weekday mid-morning appointment. Took some time off at work, boss very understanding.

Very talkative, lively, outgoing and does not complete sentences! Re-focus with guided questions. Elaborated with little prompting.

Data from initial interview: have never tried yoga and currently have a sprained ankle –so could not try.

Short of stature and fidgeted a lot to get comfortable in chair as feet did not touch the floor. Verbalised that chair was not comfortable and changed position (sat on her foot - folded one leg in under her) – maybe seeking proprioception??

Good sense of humour. Positive attitude towards life and tackles issues. Resilient?

Thanked researcher for including her in the program after interview was terminated, whilst letting her out the office.

Researcher reflections: Was very easy to chat to. Not difficult to get info as she shared easily, but could possibly have gone on for another hour. Looked forward to her feedback as she was very interested and willing to try techniques.

#### **P2 – FOLLOW-UP INTERVIEW:**

Preferred Skype appointment due to work commitments and limited time to travel to face-to-face appointment. Was only able to do voice calling via Skype due to insufficient data connection.

Interview conducted on a Saturday mid-morning. Just returned from gym – Saturday routine (especially exercise) important to her. Likes the impact of running.

Relaxed and analytical – likes to understand.

Researcher felt compassion (maybe a bit more than for other participants) for P2 as she has had a long journey and has seen various specialists – with limited success. Have a friend who's an OT (she was not sure if friend qualified in SI) and have heard about sensory issues, but was very interested in her results on the ASH. Was

surprised by tactile score as she has chatted to her OT friend in general but the tactile difficulties did not feature. However, upon further discussion and explaining, she almost had an 'Aha' moment during the first interview. "Dit maak sin".

Very diligent person who likes to do things properly. Also sticks to routines – maybe a bit rigid in approach to everyday life. Really wanted to try this as it made a lot of sense to her.

She heard about the study from her OT friend and she actually contacted the researcher via e-mail asking to be part of the study.

### **P3 – FOLLOW-UP INTERVIEW:**

It was challenging arranging a follow-up interview via Skype with P3. She verbalised that she was not familiar with Skype, are not able to do it from home (insufficient internet connectivity) and she works in an open-plan office which does not allow privacy.

A face-to-face interview was scheduled at her place of work as she was unable to travel to attend dates and times in Johannesburg due to family commitments. Interview was conducted in the morning in a private office and participant was at ease.

Participant shared information easily and easily distracted and went off track at times. Had to ask questions to re-focus.

Seems anxious in general and dislikes change, difficulty adapting?? Thanked researcher for the program after interview was terminated and walking down passage.

P3 came over as quite anxious and precise. Was very early for her appointment and brought her mom (who has slight Dementia) with and she waited in waiting area with receptionist. Very close to her mom and brought her with for an outing to Joburg as they live in Meyerton.

No previous knowledge re SPD but was able to identify SPD issues in her sister's son who is on Autism spectrum while explaining SPD to her. Shared lots of info in initial interview about things that she does not like/find irritating. Took a bit more emotional energy from researcher as had to re-focus.

#### **P4 – FOLLOW-UP INTERVIEW:**

P4 preferred a Skype interview and when given the choice between video and voice vs voice only, she preferred voice as desktop computer not having a webcam.

Seemed slightly unsure (self-confidence?) during first interview...voice call maybe less intimidating as not being observed? Safer option?

Interview done during a weekday afternoon at work. Made arrangements to use a colleague's office for privacy.

Likes structure and predictability?

Data 1<sup>st</sup> interview: yoga – have never considered it. Seemed hesitant to try it.

P4 seemed to be from a strict cultural background and researcher thinks it took a lot of courage to initially seek help for sexual pain.

#### **P5 – FOLLOW-UP INTERVIEW:**

P5 preferred a Skype interview and when given the choice between video and voice vs voice only, she preferred voice only. Probably less invasive??? as she a webcam. Mentioned in first interview that she dislikes talking on a phones. Voice and video too much sensory input? Voice call on computer maybe easier to process and directly on phone??

Interview done on a Saturday afternoon. Her quiet time?

Preferred to walk on treadmill at gym. Not sure if yoga is offered at gym – not interested.

Had dog on her lap during interview and started with telling how getting two Pekinese puppies and stroking them, helped her to relax and self-regulate.

Understanding more about SPD helped a lot – did not read any of the books recommended but searched online for info. Implemented few other strategies.

Likes to understand things? Appears very analytical.

Relaxed interview and actually carried on longer than anticipated – initially she was a bit reserved but relaxed and started to chat. Got the impression she is not very social...maybe some good close friends, but not one for big parties.

## APPENDIX M: PAPER 3 - SAJOT: Guidelines for publishing

# GUIDELINES FOR PUBLISHING IN THE SOUTH AFRICAN JOURNAL OF OCCUPATIONAL THERAPY

The South African Journal of Occupational Therapy (SAJOT) accepts scientific articles, scientific letters, literature reviews, commentaries, opinion pieces, book reviews, and biographies for publication.

The language of the Journal is English (abstracts may be provided in Afrikaans or the Vernacular as well as in English).

All articles that are published in SAJOT may be found at [www.sajot.co.za](http://www.sajot.co.za), [www.sceilo.org.za](http://www.sceilo.org.za), EBSCOHost, or OTDBASE. In addition articles are preserved via Portico which is a digital preservation service provided by ITHAKA, a not-for-profit organisation with a mission to help the academic community use digital technologies to preserve the scholarly record and to advance research and teaching in sustainable ways.

### POST-ACCEPTANCE PUBLICATION FEES:

In line with the policy of most Open Access Journals, all submissions to the SAJOT are subject to a publication fee of R5000-00 per article once the submission is accepted for publication.

This post-acceptance publication fee will be applied to cover both retrospective and prospective processes involved in peer-reviewed articles, including:

- ❖ Peer-review management
- ❖ Manuscript preparation (e.g. copy editing)
- ❖ Journal production (e.g. layout)
- ❖ Open-access online publication and hosting
- ❖ Indexing (e.g. PubMed)
- ❖ Archiving.

The fee is waived in the following instances:

- ❖ If at least one of the listed authors of the article is a member of the Occupational Therapy Association of Southern Africa (OTASA). (Proof of membership will be verified prior to publication.)
- ❖ If an application for exemption submitted and subsequently granted by the OTASA Chairman of the Publications Committee (see details below).
- ❖ If the submission is either a book-review, commentary or opinion piece.

Applications for exemption from the publication fee can be made to:  
Helen Buchanan ([helen.buchanan@uct.ac.za](mailto:helen.buchanan@uct.ac.za)).

Those authors eligible for payment of fees will receive an invoice from the OTASA office and payment will need to be made to OTASA within the stipulated time. The ruling regarding payment of fees will only apply to articles submitted after the 1<sup>st</sup> May 2018.

The following are included in these instructions:

1. General guidelines and instructions - procedure and presentation
2. Guidelines for authors of scientific articles
3. Guidelines for authors of scientific letters
4. Guidelines for publishing a literature investigation / review
5. Guidelines for writing an opinion piece
6. Guide to writing a commentary
7. Instructions for reviewers of books
9. Guide to submitting an article on line.

The relevant guidelines to authors (which follow) must be consulted for the layout and the format of the article, tables, diagrams and referencing.

### I. GENERAL GUIDELINES & INSTRUCTIONS – PROCEDURE AND PRESENTATION

Scripts must be submitted via the SAJOT web site ([www.sajot.co.za](http://www.sajot.co.za)); the author must retain a copy of the script. The author must submit the title page of the submission to the editor at [sajot@mweb.co.za](mailto:sajot@mweb.co.za). A username and password will then be provided to enable the author to complete the on line article submission. (See Guide to submitting an article on line on pg xxx). Users already registered as authors do not need to go through a repeat of the registration process but simply use their existing username and password. Users who are having problems with the username and password should contact the Managing Editor at [sajot@mweb.co.za](mailto:sajot@mweb.co.za).

Please insert a note in the 'footer' that gives the title of the article and the date at each submission. This is important for tracking purposes and will ensure that the correct version of the script is used for publication. This footnote will be removed at publication.

... continued on page 65



## Title Page

Each manuscript must include a separate title page.

This page must bear:

1. The title of the article, the name(s) of all the author(s), all academic degrees, present posts held, complete addresses, telephone numbers and fax numbers and e-mail addresses. When submitting the article do not include any author information on the article itself.
2. The ORCID number of each author. This number must also be recorded in the relevant place on the sajot web site when the article is being submitted. To obtain an ORCID reference number and to learn about the benefits of being registered, go to:  
<https://orcid.org>  
The ORCID number will be included as part of the metadata of your article when it goes to publication. Please note that orcid numbers must have the prefix [https://orcid.org/.....](https://orcid.org)  
Please check that the orcid number resolves.
3. Please include the ethics clearance number if applicable to the study. The ethical clearance certificate must be available if requested. The ethical clearance number must also be recorded on the article when it is submitted for publication.
4. The contribution of each author to the research must be clearly described and given on the title page or on a separate document uploaded as a supplementary file. Please attach the title page along with this information as a supplementary file during the submission process.

## References

Each reference in the text must be indicated by a number. This number should be inserted in superscript without brackets e.g.<sup>12</sup>. A reference list should be provided on a separate numbered page following the text. References must be cited in the order that they appear in the text and should adhere to the Vancouver system.

In addition all references must be linked through CrossRef ie each reference must show its DOI number (if it has one). To find the DOI number go to <http://www.crossref.org>. A window that asks "How can we help you?" will appear. Copy and paste or type in the title of the article and hit the enter button. The full information on the article will appear. Please note that the DOI ref must be spaced so that it falls on one line and is not split between two lines. It is important that the DOI's resolve and take you to the correct article. See examples of referencing below:

### Journal article

Barnard-Ashton P, Adams F, Rothberg A, McInerney P. Digital apartheid and the effect of mobile technology during rural fieldwork. *South African Journal of Occupational Therapy*. 2018; 48(2): 20-25. <http://dx.doi.org/10.17159/23103833/2018/vol48n2a4>. Please note that this format must be used NOT doi:10.17159/23103833/2018/vol48n2a4, as the number must resolve when clicked on.

[Author. Article title. Journal. Year; Volume (No): Page numbers. DOI number]

### Book

De Vos AS, Strydom H, Fouché CB, Delpont CSL. *Research at Grass Roots: A primer for the Social Sciences and Human Service Professions*. Pretoria: Van Schaik Publishers; 2011.

[Author(s). Book title. Edition. City: Publisher; Year. DOI if one is available]

### Chapter in a Book

J. Amis, M. Silk, M. Eisenhart, M. Freeman, K. deMarrais, J. Preissle, R. Roulston, E. St. Pierre, K. Howe, P. Lather, Y. Lincoln, G. C. In: Annella, D. Polkinghorne & H. Torrance. Chapter 10, Standards for Evaluating Qualitative Research. In: *Understanding and Evaluating Qualitative Educational Research*. M Lichtman, Editor. New York: Sage Knowledge; 2011: 253-260.

<http://dx.doi.org/10.4135/9781483349435.n10>

[Author(s). Chapter title. Book title. Editor. City: publisher; Date/Year published: page numbers. DOI]

### World Wide Web (WWW) sites

Uyanik M, Kayihan H. Down syndrome: sensory integration, vestibular stimulation and neurodevelopmental therapy approaches for children. In: Stone JH, Blouin M. *International Encyclopaedia of Rehabilitation*. 2010. <<http://cirrie.buffalo.edu/encyclopedia/en/article/48/>> (9 Feb 2016).

[Authors. Chapter in Book. In: Book title (or article title). City: Publisher; Year: Page numbers. If it is a journal article - Name of journal. Year; Volume and number: pages. The name of the database the article was found on [\*The URL or DOI where the article can be found] and date of access.

The following references could be consulted for details on the Vancouver method:

<http://openjournals.net/files/Ref/VANCOUVER%20Reference%20guide.pdf> or

Vancouver referencing style: Quick guide on how to use at [www.library.up.za/health/Vancouver](http://www.library.up.za/health/Vancouver)

### General requirements

Manuscripts must be clearly typed in MS Word double-spaced with a legible font (Arial size 11 is preferable).

Authors should not assume that the readers know the context in which the article is set. The content needs to be organised in a coherent and logical manner and may require concise descriptions and definitions of terms to elucidate the content. A review of the relevant literature must be provided.

The section on research methods should include: the aim of the study, the research design used, the population and manner of selecting the population sample, the research tools used, the method of data collection, the methods used to analyse the data including details of the statistical methods and details of the ethical clearance and consent obtained.

... continued on page 66

The results should be clear and must relate to the aims of the research and research methods. The discussion should summarise the main findings and explore the reasons for these. New knowledge must be highlighted and the limitations of the study given.

The conclusion must be brief, drawing the article to a close by relating the results to the aim of the research.

Tables should have the heading at the top of the table and labelled with Roman letters e.g. *Table II*.

Figures should be labelled at the bottom of the figure with Arabic numbers e.g. *Figure 2*.

Tables and figures should not be scanned but formatted and included on separate pages. Figures should be clear to the reader when photocopied.

Photographs and diagrams must be 300 dpi and saved as jpegs. They must be very sharp, taken close up, with a lightish over-all tone and without dark backgrounds. If the photograph photocopies well, it will print well. Please check this before you send photographs.

### Reviews

All manuscripts undergo an anonymous double blind peer review process. The reviewers are required to comment on the scientific worth of the article and its suitability for publication in SAJOT. (To ensure a blind review see section below). The comments are returned to the authors by the editor with a directive for further action required. Articles may be accepted without change, changes may be requested, the article may be asked to be resubmitted for review or the article may be rejected.

### Editing

Please note that the article will be checked by the Editor and the English Language editor before going to print. The article will then be returned to the author for a final check.

### Intellectual property and copyright

The author retains intellectual property rights over original material, in keeping with South African IP legislation and the policy of the employing body/training institution where relevant. SAJOT adheres to Creative Commons licensing as follows:



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### Checking the article before submission

Confirmation that the following items have been attended to will be required as part of the submission process.

- ❖ The submission has not been previously published, nor has it been before another journal for consideration (or an explanation has been provided in Comments to the Editor).
- ❖ The submission file is in Microsoft Word, or a WordPerfect document file format.
- ❖ All references have been checked to see that they comply with the requirements (see guidelines above). Where available, URLs for the references have been provided and DOI numbers have been given for each reference.
- ❖ The text is 1.5 spaced; employs italics, rather than underlining (except with URL addresses); and all illustrations, figures, and tables are placed on separate pages with their place in the text clearly indicated.
- ❖ The text adheres to the stylistic and bibliographic requirements outlined in the Author Guidelines, which is to be found under the tab "About the Journal" or under the tab Guide to submitting an article.
- ❖ The instructions for Ensuring a Blind Review have been followed. (See below).
- ❖ A colleague has read the article to provide objective peer input, inconsistencies, spelling and grammar in addition to running a spell-check with English, South Africa as the default setting. Authors for whom English is a second language should have their article edited by a professional English-language editor or editing service. During the review process, articles may be returned to the author to arrange such a service, if improvements to language and clarity are required.
- ❖ Multiple Choice Questions (MCQs) are attached in the supplementary file section of the article submission. In addition it is advisable to email these to the editor at [sajot@mwbe.co.za](mailto:sajot@mwbe.co.za). NB The article will not be sent for review until these have been received or posted on the web site.
- ❖ The details of all the authors have been included in the Step III - Entering the submissions metadata and includes the following:
  - Full names and all qualifications of ALL the authors and where these were obtained e.g. BSc OT (Wits), MSc (UP).
  - Place of employment which includes the city name and the country.
  - Contact details of all authors including email address, phone number and address.
  - The details of the contribution of each named author to the research and publication process must be provided in a supplementary file.
  - The ORCID number of each author is included in the relevant space.
- ❖ Ethical approval for the study has been sought and explained in the article and an approval number is given.
- ❖ The title of the article is on the article submission
- ❖ The abstract has been included in the submission as well as in the Submission metadata section.
- ❖ The article has undergone a plagiarism check such 'Cross Ref' or 'Turn-it-in'. This is important and the report on the article must be attached in the supplementary file section.
- ❖ Permission has been obtained from the co-authors to publish the article and to use their names.
- ❖ The contribution that each author made to the research process has been described and provided on a separate document to be uploaded as a supplementary file. This is a requirement of SciELO.
- ❖ The relevant acknowledgements have been provided.
- ❖ As a special request the author is asked to provide the names, place of work, and email contact details of two people who they believe

... continued on page 67

have the skills and expertise to review the article. These should be provided in the supplementary file section of the submission and may be either local or international expert clinicians or researchers in the field of the research. These persons may or may not be invited to review the article but the names will help SAJOT to identify suitable reviewers to add to the reviewer list.

### Ensuring a blind review

To ensure the integrity of the blind peer review of the submission to this journal, every effort is made to prevent the identities of the authors and reviewers from being known to each other.

It is the primary duty of the author to remove any possible identification from the text submitted as indicated below. The reviewer is obliged to keep his/her comments/opinions about the article confidential and communicate these only to the editor; should the reviewer have prior knowledge of or involvement with (incidental or otherwise) the author or the article in question, the editor should be informed of the situation and the situation reviewed if needed.

The editor is the only person who has access to all the information about authors and reviewers. Any issues concerning a review / edit/ authorship / copyright etc. about a SAJOT submission must be brought to the attention of the editor directly – the editor is the only person authorised to deal with these issues and will do so in a strictly confidential manner.

This process applies to the authors, editors and reviewers (who upload documents as part of their review), checking to see that the following steps have been taken with regard to the text and the file properties:

- ❖ The authors of the document have deleted their names from the text, and substituted "Author" and year used in the references and footnotes, instead of the authors' name, article title, etc. This includes ensuring that names used in the acknowledgements section have also been substituted with an X. Names will be inserted just prior to publication.
- ❖ With Microsoft Office documents, author identification should also be removed from the properties of the file.

For Microsoft 2008/2010 (Windows):

- Under the File menu select "Info".
- Click on the "Inspect Document" icon.
- Uncheck all of the checkboxes except "Document Properties and Personal information".
- Run the document inspector, which will then do a search of the document properties and indicate if any document property fields contain any information.
- If the document inspector finds that some of the document properties contain information it will notify you and give you the option to "Remove all," which you will click to remove the document properties and personal information from the document.

For MacIntosh Word 2008 (and future versions)

- Under the File menu select "Properties."
- Under the Summary tab remove all of the identifying information from all of the fields.
- Save the File.

For PDF files:

- With PDFs, the authors' names should also be removed from Document Properties found under File on Adobe Acrobat's main menu.

### Continuing education points

CEU points are accredited as follows:

- ❖ CEUs for authors of an article
- ❖ Principal author of an article (15 CEUs)
- ❖ Co-authors of an article (5 CEUs)
- ❖ CEUs for reviewers of an article
- ❖ 3 CEUs per article reviewed (which may include a 2<sup>nd</sup> review)
- ❖ CEUs for readers of an article:  
Readers obtain CEU's for answering the multiple choice questions for each article.  
3 CEUs per article. Once the article is published the MCQs can be found at [www.otasa.org.za](http://www.otasa.org.za)

CEU's can be obtained by applying to the OTASA office [otoffice@uitweb.co.za](mailto:otoffice@uitweb.co.za).

Paid up members of OTASA will receive their points free of charge

## 2. GUIDELINES FOR AUTHORS OF SCIENTIFIC ARTICLES

Articles submitted to the SAJOT must be original and must not have been published elsewhere. Articles should contain new information, add to existing knowledge, resolve controversy or provoke thought and discussion.

The content of the article must justify the length, which should be about 12-16 pages, with 1.5 spacing. Authors should consult the article "The pitfalls of "salami slicing": focus on quality not quantity of publications" by Fenseca M. Editage Insights. Nov 4; 2013. <https://www.editage.com/insights/the-pitfalls-of-salami-slicing-focus-on-quality-and-not-quantity-of-publications>

Please ensure that for all the authors contact details for the submission are in a separate document entitled 'Title Page' – see above.

### Abstract and key Words

All manuscripts submitted to the SAJOT must be accompanied by an abstract not exceeding 200 words in length.

The abstract must contain a succinct structured summary of the study.

The following headings used in the presentation of the study may also be used in the abstract.

... continued on page 68

### **Introduction**

This should provide a brief rationale for the study and an outline of the aims or questions

### **Literature Review**

This should be a critical appraisal of the current relevant literature identifying the limitations in the work already conducted on the subject and a rationale for the study. A maximum of 35 references should be included.

### **Method**

This should contain the following: Aims, study method and data collection procedures, population and sampling procedure, methods of analysis of data, information on validity, reliability, trustworthiness and credibility.

Details of the ethical clearance and informed consent must be provided.

### **Results**

The results must be presented in a way that makes them accessible to the readers and are clearly linked to the aims and methods of the research.

### **Discussion and implications of the research**

The implications for occupational therapists and or other health professionals/groups/ contexts must be outlined and the contribution that the study makes to the current state of knowledge of the profession/s stated. Limitations must also be discussed.

### **Conclusion**

There should be a clear summary of the main points of the paper, drawing the article to a close and containing no new information.

### **Illustrations**

Articles may include up to eight tables, graphs or diagrammes and should be numbered and clearly labelled with their place in the text indicated as a guide to the editor. (See General Requirements).

### **Author's roles**

NB a list of the authors and the role that each played in the research and publication process must be provided. Please note that this must be on a separate document attached as a supplementary file, it will be added to the article when it goes to publication.

## **3. GUIDELINES FOR AUTHORS OF SCIENTIFIC LETTERS**

Letters submitted to the SAJOT must be original and must not have been published elsewhere. Letters should contain new information, add to existing knowledge, resolve controversy or provoke thought and discussion.

The requirements of a scientific letter are as follows:

- ❖ The letter must have the same scientific format as an article, but should be much shorter i.e. 1500 – 1700 words, to fill only one to two pages of the Journal but does not have an abstract.
- ❖ It may have only one table of results.
- ❖ There should not be more than five references.
- ❖ It must be original research.

Peer evaluation will take place as with all other articles submitted to SAJOT.

### **Author's roles**

NB a list of the authors and the role that each played in the research and publication process must be provided in a supplementary file. This will be added to the article when it goes to publication.

## **4. GUIDELINES FOR PUBLISHING A LITERATURE INVESTIGATION / REVIEW**

Literature investigations/reviews submitted to the SAJOT must be original and must not have been published elsewhere.

The requirements of a critical review of the literature investigation/review are as follows:

- ❖ The article should provide reasons for choosing to review the topic and give the method used to conduct the survey along with the sources consulted.
- ❖ The article must cover the topic thoroughly i.e. it must include all or most of the major studies that have been conducted on the topic of interest within a given time frame. The most recent literature must be included.
- ❖ The publications referred to must be the primary source and the review should not rely on secondary sources. Articles reviewed should also not rely on opinion articles but should emphasise research articles.
- ❖ The article should not be merely a summary of past work but must critically appraise and compare the key studies as well as discuss the weaknesses and strengths of the various studies. Important gaps in the literature should be identified.
- ❖ The article must conclude with a brief synopsis of the current state of the topic and give recommendations for future work.
- ❖ The format of the review must follow that for all scientific articles i.e. it must contain the following:

- **An abstract**
- **Introduction**
- **Method.** In this instance the approach taken to search the literature, the databases searched, the search parameters and key terms used, the inclusion and exclusion criteria, and the criteria used for the appraisal and how the key information was extracted, must be provided
- **Results.** This section should present the main evidence and a summary of its quality
- **Implications.** This sections should outline the implications of the findings for occupational therapy practice, the methodological limitations of the review, identify gaps in the literature and recommend future action
- **Conclusion.** A clear summary of the main findings should be provided.

... continued on page 69

- ❖ Authors wishing to conduct a Scoping Review should consult the reference below:  
Munn Z, Peters M, Stern C, Tuafunaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. 2018 *BMC Medical Research Methodology*. 2018, 18(143). At: <https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-018-0611-x>

#### Author's roles

Should more than one author be involved in the literature search a list of the authors and the role that each played in the research and publication process must be provided in a supplementary file.

### 5. GUIDELINES FOR WRITING AN OPINION PIECE

Opinion pieces provide authors with the opportunity to express an opinion concerning any aspect of occupational therapy. They are designed to encourage topical debate and the exchange of ideas. Contributors may discuss specific aspects of occupational therapy practice or debate the impact of occupational therapy on the health of people. Opinion Pieces may also deal with health care and relevant social practice/issues in general such as consumer rights that may impact on the profession. They may also debate the impact of the current political and financial climate on the practice of the profession and its ability to meet all in need.

The following provides some guidance:

- ❖ Focus tightly on the issue or idea — in your first paragraph. Be brief.
- ❖ Express your opinion, and then base it on factual, researched or first-hand information.
- ❖ Be timely, controversial, but not outrageous. Be the voice of reason.
- ❖ Be personal and conversational; it can help you make your point. No one likes a stuffed shirt.
- ❖ Be humorous, provided that your topic lends itself to humour. Irony can also be effective.
- ❖ Have a clear editorial viewpoint – come down hard on one side of the issue. Don't equivocate.
- ❖ Provide insight, understanding; educate your reader without being preachy.
- ❖ Near the end, clearly re-state your position and issue a call to action. Don't philosophise.
- ❖ Have verve, and "fire in the gut" indignation to accompany your logical analysis.
- ❖ Don't ramble or let your piece unfold slowly, as in an essay.
- ❖ Use clear, powerful, direct language.
- ❖ Avoid clichés and jargon.
- ❖ Appeal to the average reader. Clarity is paramount.

1. Collect research to support your opinion. Make sure that your supporting statements match the topic.

You should include examples and evidence that demonstrate a real understanding of your topic. This includes any potential counterclaims. In order to truly understand what you are arguing for or against, it is imperative that you understand the opposing arguments of your topic.

2. Acknowledge the previous opinions or arguments that have been made. More than likely you are writing about a controversial topic that has been debated before. Look at the arguments made in the past and see how they fit in with your opinion in the context in which you are writing. How is your point of view similar or different from previous debaters? Has something changed in the time others were writing about it and now? If not, what does lack of change mean?

3. Use a transition statement that shows how your opinion adds to the argument or suggests those previous statements and arguments are incomplete or faulty. Follow up with a statement that expresses your opinion.

4. Next, list supporting evidence to back up your position. It is important to keep the tone of your essay professional, by avoiding emotional language and any language that expresses an accusation. Use factual statements that are supported by sound evidence.

Note: Any time you develop an argument, you should start by thoroughly researching your opposition's point of view.

This will help you to anticipate any potential holes or weaknesses in your own opinion or argument.

5. Lastly there must be a conclusion in which you restate your opinion using different words

#### In summary

Irrespective of the topic discussed, opinions should be supported by evidence or theory. They should include:

- ❖ An abstract
- ❖ Headings which give structure to the paper
- ❖ References (a maximum of 15).

Opinion pieces are subject to the same critical review process as other submissions.

The following references were consulted and the information incorporated into the above guidelines:

1. Shapiro S. 10 Rules for writing Opinion Pieces. *Writer's Digest*; July 2009. [www.writersdigest.com/writing-articles/by-writing-goal/improve-my-writing/10-rules-for-writing-opinion-pieces](http://www.writersdigest.com/writing-articles/by-writing-goal/improve-my-writing/10-rules-for-writing-opinion-pieces).
2. Astone. Ten tips to write an opinion piece people read. *Climate system science*; Australian Government, 2010 <https://www.climatescience.org.au/content/1053-ten-tips-write-opinion-piece-people-read>
3. Opinion Essays. Academic writing <http://academicwriting.wikidot.com/opinion-essays>

Opinions are not necessarily those of the Occupational Therapy Association of South Africa nor SAJOT but never-the-less may provide information for debate.

### 6. GUIDELINES FOR WRITING A COMMENTARY

These are similar to opinion pieces but are as follows:

A commentary is written on a current event or topic by a person with the background to make an informed comment and should report

... continued on page 70

on an issue or topic of interest and relevance to OT practitioners, educators and researchers.

Commentaries usually bring to the attention of the reader new ideas and advances in a particular subject or field of practice. In this case the commentary will compare past practices and new ideas and will point out any research related to it. The commentary may also present criticism of the new in relation to the old or vice versa. Personal experiences with the new can also be presented and add to the discussion. Commentaries do not include original data or the research findings of the author but are dependent on the author's perspective.

The commentary will also examine the way in which the subject or intervention can be applied to local settings and circumstances and comment on the value that the new idea may have in relation to the past.

A final statement or conclusion must be provided ie there must be a "take home" message.

Irrespective of the information being commented upon, commentaries should include:

- ❖ An abstract
- ❖ Introduction
- ❖ Coherent body with headings that give structure to the paper
- ❖ Recommendations and conclusion
- ❖ References (a maximum of 15).

Commentaries are subject to the same critical review process that other submissions undergo.

Berterö C. Guidelines for writing a commentary. *Int J Qual Stud Health Well-being*. 2016; 11:10. 10.3402/qhw.v11.31390.

doi: 10.3402/qhw.v11.31390

## 7. INSTRUCTIONS FOR BOOK REVIEWS

A book review should contain the following information:

- ❖ The full title of the book
- ❖ The full name of the author(s) and their qualifications and the position that they hold
- ❖ Details of the book:
  - Name of publisher
  - Whether it is a paperback or hard copy and the number of pages
  - The publication date
  - The ISBN number
  - The price (in South African Rand if possible)
- ❖ A review of the content, which should include:
  - The aim of the book
  - The way in which the information is structured
  - A brief summary of the content of each chapter
  - A comment on its relevance to health care generally and SA occupational therapy specifically.
- ❖ The name, qualifications and work position of the reviewer

## 8. GUIDE TO SUBMITTING AN ARTICLE ONLINE

The Guide to submitting an article on line is featured under the tab "Guide to submitting an article" / Guide for authors in the header of the SAJOT web site.

Prepare the article as described above.

The following are the steps to follow:

Go to [www.sajot.co.za](http://www.sajot.co.za). Log in using the "user name" and "password" that has been provided. Click on the tab "New Submission". The following are the steps as enumerated on the web site:

### Step 1 – Starting the submission

Journal section

Select the relevant category of the submission in this section from the drop down box.

Submission check list

Ensure that you, the author, have done **ALL** the things mentioned in the submission check list and confirm this by placing a check in the relevant box. See the section **Checking the article before submission** under the heading **GENERAL INSTRUCTIONS**. Please note that failure to comply with all the items mentioned could result in the article being returned to you and thus an unnecessary delay in the publication process.

Copyright notice – click to accept the copyright provisions as seen on the web site.

You may also send a note to the editor in the box provided.

Click save and continue at the bottom of the page, this will enable you to move on to the next stage of the submission process

### Step 2 – Upload the submission

Follow the steps for uploading your article.

**NB** it is important that you upload the file containing the complete article here. Do not include any information about the authors on the article. ... continued on page 71

**To upload** - Click on the browse button, locate the file containing the article on your computer, click on it so that the name of the file appears in the window, and then click the upload button. This is the only place where the main article can be uploaded.

Click save and continue

### **Step 3 – Entering the submissions metadata**

**Authors** – Information about all the authors must be provided here.

The bio statement box should be used to complete the details of all the qualifications of the authors (i.e. degree and where obtained.) as well as the place of work and position held. Please include each authors orcid number in the relevant box.

**Title and abstract** – Please copy / type in the full title of your article into the box provided. Paste in a copy of the abstract into the block provided.

**Indexing** –ignore this section

**Supporting agencies** – complete if relevant e.g. funding organisation.

Click save and continue

### **Step 4 – Uploading supplementary information**

You may upload tables and figures here if they have not been included within the main article. You do not have to complete this section but must click save and continue to go to the next step. Photographs should be also be loaded here. Please note that there are two steps here:

**Step 4 and Step 4a.** In step 4 the file/files containing the tables can be uploaded. Click save and continue. This will bring up step 4a where you can add any information needed to identify the supplementary information. The only compulsory window is the title window.

Click save and continue. This will bring you back to step 4 again where another file can be uploaded. Each supplementary separate piece of information is added as new file

### **Step 5 – Confirming the Submission**

Click **Finish Submission**. Please remember to do this otherwise your submission will not be recorded. It is very important to note that once you have confirmed the submission you will be unable to make changes to your main document. However, you will be able to add supplementary files. This should be done before the article is sent into the review stage by the editor

Any changes that you wish to make to the article itself will need to be done via a completely new submission.

## **RESUBMISSION OF ARTICLE AFTER REVISIONS/AMENDMENTS**

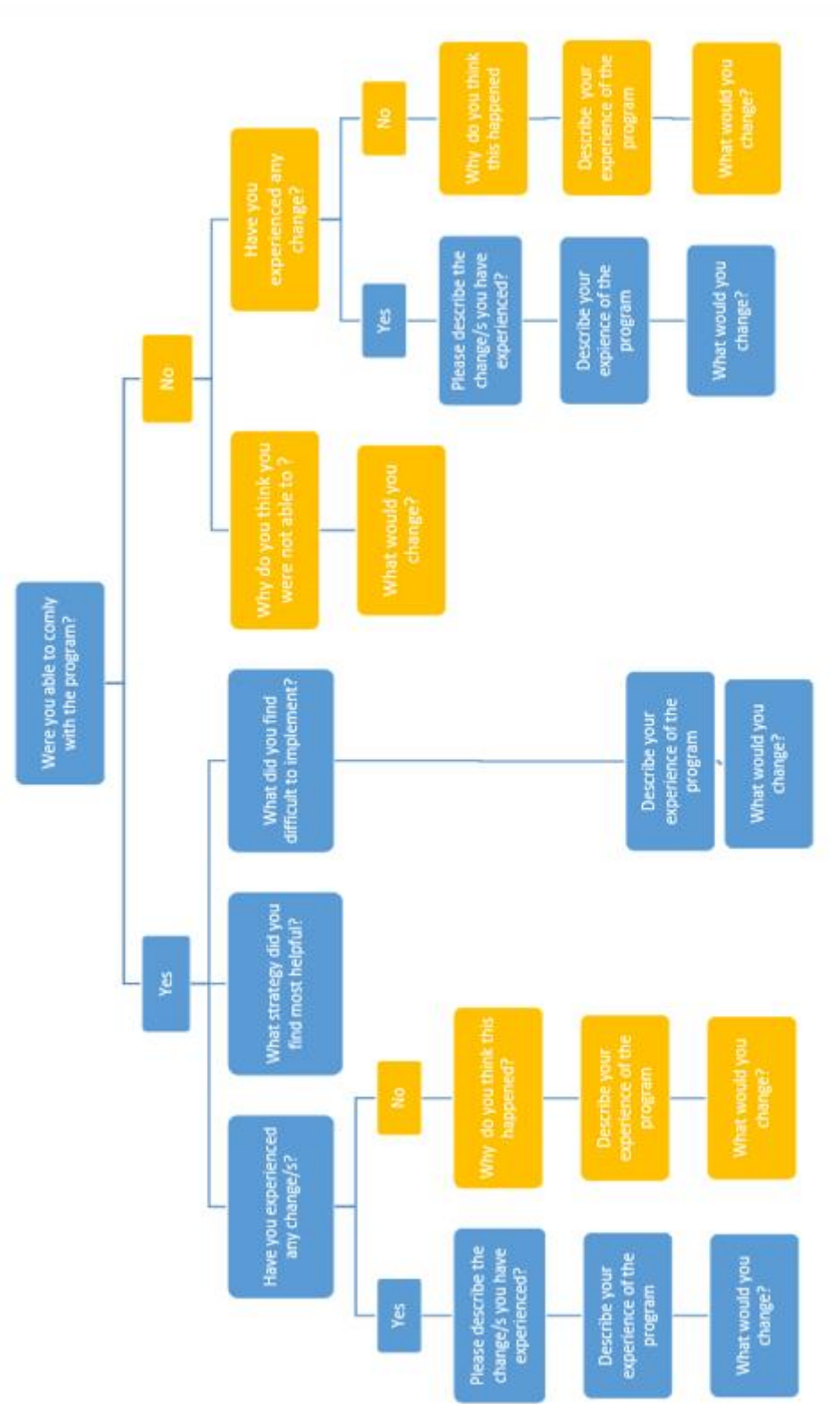
Once the author has dealt with any amendments suggested by the editor, a new version of the article must be uploaded.

Scroll to the section at the bottom of the Review page of your article to the section labelled Editor Decision. There you will see the box Upload author version. Please post your revised copy here. Please also note that the article, tables and diagrams must be included in one document at this stage in the process. Do not upload separate documents as there is no place for uploading separate documents,

Help with this submission process can be obtained by emailing the editor at [sajot@mweb.co.za](mailto:sajot@mweb.co.za)

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APPENDIX N: CHAPTER 6 - List of semi-structured interview prompts



## APPENDIX O: CHAPTER 5 – Sample of e-mail & individualised report sent to participants

Elsie Labuschagne de Jager

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Subject: Sensory Processing Additional Info  
Attachments: A Look at the Effects of Sensory Processing Disorder on each Sensory System.pdf

Good afternoon XXX,

I trust that you're well!

Thank you for your time last week and allowing me to be part of your journey.

I have attached information regarding the different senses and how they are affected by sensory processing.

Herewith the list of books recommended for further reading:

1. Making Sense: A Guide to Sensory Issues by Rachel S. Schneider  
<http://www.takealot.com/making-sense/PLID39102267>  
[https://www.amazon.com/Making-Sense-Guide-Sensory-Issues-ebook/dp/B01A1D14T0/ref=sr\\_1\\_4?ie=UTF8&qid=1531207511&sr=1-4&keywords=too+loud+too+bright+too+fast+too+tight](https://www.amazon.com/Making-Sense-Guide-Sensory-Issues-ebook/dp/B01A1D14T0/ref=sr_1_4?ie=UTF8&qid=1531207511&sr=1-4&keywords=too+loud+too+bright+too+fast+too+tight)
2. Sensory Intelligence by Annemarie Lombard  
<https://www.takealot.com/sensory-intelligence/PLID34804630>
3. Too Loud, Too Bright, Too Fast, Too Tight: What to Do If You Are Sensory Defensive in an Overstimulating World by Sharon Heller  
<http://www.takealot.com/too-loud-too-bright-too-tight/PLID1721697>  
[https://www.amazon.com/Loud-Bright-Fast-Tight-Overstimulating-ebook/dp/B00KVBX9B/ref=sr\\_1\\_1?ie=UTF8&qid=1531207511&sr=1-1&keywords=too+loud+too+bright+too+fast+too+tight](https://www.amazon.com/Loud-Bright-Fast-Tight-Overstimulating-ebook/dp/B00KVBX9B/ref=sr_1_1?ie=UTF8&qid=1531207511&sr=1-1&keywords=too+loud+too+bright+too+fast+too+tight)
4. The Out-of-Sync Child Grows Up by Carol Kranowitz  
<http://www.takealot.com/the-out-of-sync-child-grows-up/PLID41112671>  
[https://www.amazon.com/Out-Sync-Child-Grows-Processing/dp/0399176314/ref=sr\\_1\\_cc\\_2?s=aps&ie=UTF8&qid=1531207511&sr=1-2-catcom&keywords=too+loud+too+bright+too+fast+too+tight](https://www.amazon.com/Out-Sync-Child-Grows-Processing/dp/0399176314/ref=sr_1_cc_2?s=aps&ie=UTF8&qid=1531207511&sr=1-2-catcom&keywords=too+loud+too+bright+too+fast+too+tight)

The initial goal of the program is to create more self-awareness which will assist in helping you to recognise and regulate the processing of sensory input more efficiently. It should also provide you with information to explain your feelings/experiences to others and this will hopefully create increased understanding and acceptance.

The **Therapeutic brushing and relaxation** technique should further assist in improved sensory modulation and related emotional responses.

Herewith links to the progressive muscle relaxation videos:

- Short version (6-7 minutes):  
<https://www.youtube.com/watch?v=9x3ti61NW3w>  
<http://mainlinecounselingpartners.com/progressive-muscle-relaxation/>
- Longer version (14-15 minutes)  
<https://www.youtube.com/watch?v=iH002wUzpkc>

It could be useful to bookmark one or all of these on your phone.

Please try one of these relaxation techniques at least once per day, but it can also be done as often as necessary during the day or when feeling anxious.

Try and do to brushing as often as you can, allowing a 2 hour break in between.

I will send a summary report regarding your sensory processing patterns later this week.

Please let me know if you have any questions or want to bring some additional information to my attention.

Warm regards,



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Elsie Labuschagne  
B.OT. (UFS)  
HPCSA No. OT035289

## SENSORY PROCESSING – SUMMARY REPORT

(client is participating in phase 2 of masters research study)

**CONFIDENTIAL**

NAME :  
AGE :  
DATE OF REPORT :

### ASSESSMENTS

- Adolescent/Adult Sensory History – Theresa May-Benson, Spiral Foundation
- Background/demographic questionnaire
- Interview

### BACKGROUND INFORMATION

Background information was discussed but most was removed due to confidentiality.

She reported the following sensory behaviour:

- Touchy/tactile: sensitivity to certain types of fabric; gets irritated by clothing labels, light touch.
- Auditory – dislikes too much noise, speaking on the phone, dogs that bark constantly; covers her ears when someone whistles; avoids leaf blowers, drills.
- Oral/Food – avoids cooked carrots, dislikes crunchy food, sensitive to food textures, dislikes fruit pieces in yogurt, avoids trying new foods, dislikes sauces on food, prefers to keep different food separate.
- Movement (vestibular & proprioception) - has difficulty performing sport activities, especially activities requiring rhythm. As a child she enjoyed horse riding and got car sick easily. She reportedly did not crawl as a baby.

She currently modulates her sensory arousal levels by chewing gum, isolating herself, listening to music with headphones while working at the office and stroking the animals.

She likes routine and prefers to be warned timeously of changes in her schedule.

She reported that she gets irritated easily and comes across as being difficult, which has a negative impact on her interpersonal relationships. She has difficulty 'switching off' during holidays and feels driven a lot of the time.

## RESULTS

- Adolescent/Adult Sensory History questionnaire:




Sensory Section	
Visual-Spatial Processing	Definite
Auditory & Language Processing	Definite
Movement (Vestibular Processing)	Mild
Taste & Smell	Mild
Touch (Tactile Processing)	Definite
Proprioception	Mild
<b>Comments:</b> This section indicates which sensory systems may impact your performance in daily activities. It is evident that the following systems are not processing sensory input optimally: visual spatial, auditory & language and touch. Movement, taste & smell and proprioception indicate mild difficulty processing sensory input. These processing difficulties could be responsible for sensory behaviour reported previously.	
Sensory Modulation & Discrimination	
<b>Modulation</b>	Definite
Visual	Definite
Auditory	Definite
Vestibular	Mild
Taste & Smell	Definite
Tactile	Definite
<b>Discrimination</b>	Mild
Visual	Typical
Auditory	Typical
Vestibular	Mild
Taste & Smell	Typical
Tactile	Definite
Proprioceptive	Mild
<b>Comments:</b> Sensory processing difficulties are mainly reflected as modulation and discrimination problems. Modulation problems are typically reflected in defensiveness or distractibility to sensory input and can occur in several different sensory systems at the same time. Your overall score for modulation indicates definite difficulty modulating sensory input, especially input related to visual, auditory, taste/smell and tactile input. Vestibular (balance) input presents as mild difficulty. These modulation difficulties result in sensory defensiveness and accounts for avoidance of sensory stimuli and irritability when exposed to certain sensory input mentioned previously. Discrimination problems are reflected in difficulties identifying and responding to the relevant, progressive and spatial qualities of sensations and are often found in conjunction with postural or motor coordination/motor planning (praxis) problems. The scores above indicate definite difficulty discriminating tactile input and mild difficulty registering input received from the vestibular (balance) and proprioceptive systems.	
Functional Problem Sub-scores	
Sensory Seeking	Mild
Visual Seeking/ Oculo-Motor	Typical
Seekz Movement	Typical
Seek Touch	Typical
Sensory Over-Responsivity	Definite
Discomfort with Imposed Touch	Definite
Tactile-Related Hygiene	Mild
Discomfort with Water	Mild


Atypical Pain Response	Definite
Gravitational Insecurity	Mild
<p><b>Comments:</b> Sensory seeking can be present when either modulation or discrimination difficulty is present. Individuals with sensory modulation difficulty often seek sensory input to help them organise their sensory systems and to counteract negative sensory input. Individuals with discrimination problems can also display sensory seeking behaviours, but in these cases it is to register the input or to make the sensory input more meaningful. Your profile does not display any sensory seeking behaviour. It seems you prefer avoidance of sensory input in assisting with modulation of sensory input. Your profile also displays a definite over-responsivity to imposed touch, tactile input related to hygiene and pain. The profile also indicate a mild over-responsivity to water and gravitational insecurity e.g. feet leaving ground during an activity, fast rides, roller coaster etc.</p>	
<b>Motor/Social Section Sub-scores</b>	
Postural Control	Typical
Motor Coordination	Typical
Motor Planning	Typical
Sequencing	Typical
Oral Motor Planning	Typical
Fine Motor	Typical
Difficulties Driving a Car	Typical
Social/Emotional	Mild
Withdrawn/Depressed	Mild
Aggressive/Impulsive	Definite
Anxious	Typical
<p><b>Comments:</b> Difficulty in discrimination of sensory input often result in postural and motor planning (praxis) difficulties. Difficulty driving a car is common in adults with discrimination and motor coordination/ planning problems. Your profile indicates no difficulty relating to postural control and motor coordination, but will be monitored due to sensory behaviour reported e.g. difficulty performing rhythmic activities. Social and emotional difficulties are found in many individuals with sensory processing problems due to difficulty modulation and/or discrimination of sensory input and is sometimes accompanied by a mental health diagnosis, such as anxiety and/or depression. Problems in the above-mentioned social/emotional section does not necessarily reflect a mental health problem but rather reflects the way in which an individual respond to sensory input e.g. fight, flight or freeze. Anxiety is often associated with difficulties in sensory modulation, sensory defensiveness and over-responsivity to sensory input. Withdrawn/depressed or aggressive/impulsive behaviour may be associated with discrimination problems. Sensory seeking behaviours are sometimes mistaken for aggression e.g. seeking roughhousing play. Your profile indicated aggressive/impulsive behaviour and correlates with sensory modulation, over-sensitivity difficulties identified earlier. Increased aggressiveness/impulsivity could be indicative of sensory systems going into 'overdrive' and eventually resulting in sensory-overload and emotional outbursts.</p>	

**TREATMENT**

Treatment strategies are based on the following:

- Obtain insight re SPD and its impact on daily life. This often help in understanding and making the necessary adjustments in your daily routine.
- Address most concerning issue first.
- Avoid/limit/reduce exposure to sensory input you are sensitive to, to help maintain an optimal level of sensory arousal.
- Use the following sensory input to help you regulate sensory arousal levels and/or to reduce irritability if you feel you are approaching sensory overload.
  - Deep pressure e.g. brushing protocol, partner laying on top of you, massage.
  - Rhythmic linear (in a line) movement e.g. gentle rocking, prone over a ball with head lower than body and gently rocking forward and backwards.
  - Proprioception (body sense) is provided via joints and muscles when performing any resistive/hard work activity e.g. sports.
- Allow yourself to experiment with different treatment strategies – if often takes trial and error to find the most effective strategies.

SENSORY SYSTEMS (Sensory Intelligence by Annemarie Lombard)				
What is happening in the system	DEFENSIVE (Over-sensitive)	INSYNC	SEEKING (Under-sensitive)	Senses on attack
What you need to do	Low-thresholds Need less Avoid & reduce Sensory stressors Will cause sensory overload & stress.	Medium thresholds No specific input needed. Can be used for self-regulation.	High thresholds Need more of Add & incorporate Use for self-regulation.	Fluctuating thresholds Need less & more depending on situation. Difficult to manage.
Your systems	Visual Taste/smell Touch Auditory	Deep touch/brushing Slow rhythmic movement	Proprioception/movement	Auditory??
<b>GENERAL – TAKE 5</b>				
Generic strategies to assist with regulating sensory arousal levels assist to not go into sensory overload.				
<b>PUT SOMETHING IN YOUR</b>				
	<b>MOUTH</b> • Brain food – Water! • Crunchy / chewy food (the crunchier the better) • Sucking • Deep breathing	Drink from exercise bottles with spout. Nuts, veggie sticks, popcorn, pretzels, biting, dried food, chewing gum, wine gums etc. Drink shake/smoothie with straw, suck lollipops. Breathe in via nose, out via mouth.		
	<b>MOVE</b> • Take a movement break • Deep pressure via head • Hands – pull & push / press • Stretch & breath	Get up from chair and move. With both hands on head and press down via spine. Interlock hands and push & pull, press palms against one another.		
	<b>TOUCH</b> • Fiddle • Massage	Stress balls, rubber bands, paper clips, objects, materials, doodle.		

 <p><b>LISTEN</b></p> <ul style="list-style-type: none"> <li>• Music that regulates &amp; organise the brain</li> <li>• Stimulating music</li> <li>• Calming music</li> </ul>	<p>Use bilateral head phones that cover the ears. Can alert the brain in the afternoon to increase focus. Reduce arousal &amp; stress and increase focus &amp; attention.</p>
<p><b>LOOK</b></p> <ul style="list-style-type: none"> <li>• Calming visual stimuli</li> <li>• Pictures, plants, artwork</li> </ul>	<p>Fish tanks, lava lamps, oil &amp; water toys. Be careful of too much clutter.</p>

The above-mentioned recommendations are not a complete program but form part of the treatment process. It may take trial and error to establish which strategies work/are more effective and the therapist relies on your feedback to make adjustments if needed. It should also be kept in mind that change will most likely not happen overnight but it will take time to adjust your sensory modulation levels.

It is also recommended that you obtain some of the reading material recommended in previous correspondence. SPD and its impact on daily activities can often be managed by increased knowledge and insight into the condition. Your family's support is essential and it is often easier for them to support you when they have more knowledge re SPD.

Please contact me should you have any questions.

Kind regards,



Elsie Labuschagne

SPECIFIC STRATEGIES	
CATEGORIES	INTERVENTION
<p>Establish/Restore Challenge &amp; shift personal thresholds</p>	<ul style="list-style-type: none"> <li>• Willbarger Therapressure protocol – implemented. Firm deep pressure every 2 hours if possible.</li> <li>• Progressive relaxation technique – implemented.</li> <li>• Astronaut Program (Step 3 – see attachment) to increase tolerance for movement input and reduce motion sickness (NB: See strategies to Offset Sensory Overload).</li> <li>• Therapeutic listening – additional treatment option available.</li> </ul>
<p>Alter Change environmental context.</p>	<ul style="list-style-type: none"> <li>• Positioning at work: <ul style="list-style-type: none"> <li>- Move seating away from air conditioners outflows, fans, open windows.</li> <li>- Open office - Position yourself in area with least foot traffic and ideally your back towards the wall, facing the room.</li> </ul> </li> </ul>
<p>Adapt Task &amp; environment adaptations Sensory ergonomics</p>	<ul style="list-style-type: none"> <li>• Reduce clutter on work desk and in drawers – clean organised spaces.</li> <li>• Use headphones (covering the whole ear) to reduce noise levels – can listen to calming music or White noise.</li> <li>• Can use ear plugs if necessary.</li> <li>• Use blank screen saver – no moving images.</li> <li>• Use dark coloured background on computer.</li> <li>• Turn down ringer volume on telephones / or use vibrate option.</li> <li>• Ringtones – soft, calming ringtones.</li> <li>• Turn volume of sounds on computer off or lower.</li> <li>• Use visual rather than auditory instructions.</li> <li>• Use stairs if possible to limit vestibular input of escalators/lifts.</li> <li>• Use a swivel, adjustable chair for added movement while working.</li> <li>• Take regular movement breaks.</li> <li>• Lunch box – pack crunchy/chewy snacks.</li> <li>• Allow yourself to eat one type of food on your plate at a time, to minimise conflicting colours, textures, tastes. Can also use separate dishes.</li> </ul>
<p>Prevent Avoid potential overload occurrences.</p>	<ul style="list-style-type: none"> <li>• Shop at smaller shopping centres during off-peak times.</li> <li>• Shared calendar with husband to plan and manage events – limit surprises.</li> <li>• Carpets on tiled / wooden floors to reduce noise.</li> <li>• Dimmer switch – to reduce visual input.</li> </ul>
<p>Create Establish strategies within daily living to optimise performance</p>	<ul style="list-style-type: none"> <li>• Yoga – if possible.</li> <li>• Quiet space (womb space) at home / work – 10 to 20 minutes daily – practice mindfulness and recharge.</li> <li>• Place a potted plant near your computer or workspace so that you can glance at it periodically to rest your eyes.</li> <li>• Cognitive strategy during breaks/holiday: “It does not have to be ticked off the list”.</li> </ul>