AUTHORS:

Elsie Labuschagne^a https:/orcid.org/0000-0003-0575-4541 Matty van Niekerk^a https:/orcid.org/0000-0001-7505-5709

AFFILIATIONS:

^a Department of Occupational therapy, School of Therapeutic Sciences, Faculty of Health Sciences, University of Witwatersrand, South Africa

CORRESPONDING AUTHOR:

Elsie Labuschagne elsiel@absamail.co.za

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Sensory Processing Dysfunction and Genito-Pelvic Pain/Penetration Disorder: Women share their experiences of participating in a sensorybased home programme

ABSTRACT

Introduction: Sensory processing dysfunction (SPD) has only recently been described in women with genito-pelvic pain/penetration disorder (GPPPD). However, female sexual pain is a virtually unknown area of practice for occupational therapists providing intervention for adults with SPD.

Aim: To describe the experiences of women with GPPPD with identified sensory processing dysfunction (SPD) who followed a sensory-based home programme. **Methods:** Purposive, non-probability sampling was used to recruit participants for the qualitative arm of the study after they presented with SPD in the quantitative part of the study. Semi-structured individual interviews were used to gather information and 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 sensory-based home programme, 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 and 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 programme, catering to specific sensory profiles is beneficial as a non-invasive occupational therapy intervention approach (based on sensory integrative therapy) for women with both SPD and GPPPD.

Implications for occupational therapy:

- SPD in the context of sexual pain is an emergent field in occupational therapy, thus occupational therapists need to expand service-delivery to this population and other practitioners such as gynaecologists must be alerted to occupational therapy as a non-invasive, and non-pharmaceutical intervention option for patients.
- · Contribute to the knowledgebase of sensory integration in the adult population.
- Improve the occupational therapist's role in sexuality.
- Emphasize the importance of insight as part of a treatment programme.

INTRODUCTION

Atypical sensory processing has been found to continue into adulthood, impacting significantly on quality of life (QoL)¹⁻⁵ and sexual function. Sensory processing dys-function (SPD) has only recently been described in women with genito-pelvic pain/penetration disorder (GPPPD)⁶, a diagnosis related to female sexual dysfunction which usually includes pain, described in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5)⁷. Very little is known about the co-occurrence of these two conditions in women. Several studies have reported an increased sensitivity to pain in women suffering from sexual pain disorders such as GPPPD⁸. Pain percep-

tion, which is central in women who suffer from GPPPD⁹, is not only part of the focus of sensory integration (SI), but is also influenced by SPD^{3,10} Increased pain sensitivity in women with vulvovaginal pain has also been associated with psychosocial aspects, such as anxiety and depression¹¹. Some commonalities have been described between GPPPD and SPD, including pain perception¹⁰, predisposition for developing affective conditions¹² and negative impact on QoL¹³.

Women with both GPPPD and SPD may therefore require occupational therapy intervention in addition to other therapies. However, sexual aspects¹⁴ are a virtually unknown area of practice, for occupational therapists who use a sensory integrative approach with adult clients. Occupational therapists who treat atypical sensory processing, or sensory processing dysfunction (SPD), in adults have mostly addressed the interpersonal and relationship aspects affected by SPD, seldom considering female sexual pain.

Even if the small number of occupational therapists with postgraduate SI qualifications who also work with adults are willing to provide intervention for GPPPD, this may result in clients having to travel great distances to get the necessary treatment rendering them unable to see occupational therapists on a regular basis¹⁵. A home programme used as part of the treatment plan is often a pragmatic solution to address this concern¹⁶. It can assist with overcoming logistical problems, including limited time for appointments and/ or distance from HCPs¹⁷ such as occupational therapists. Home programmes have previously been used effectively in persons with sensory processing difficulties and various other conditions^{5,18}.

There is a gap in the literature regarding the use of sensorybased home programmes (SBHP) as an intervention option for women SPD and GPPPD because little is known about the co-occurrence of these two conditions. This study aimed to describe the experiences of women with GPPPD diagnosed with SPD who followed an occupational therapy SBHP. The importance of this study is that it could improve the understanding of the role of occupational therapy in sexual activity and sexuality^{14,19,20} and more specifically, female sexual pain and elucidate the role of occupational therapy SBHPs in treating SPD co-occurring with GPPPD.

Literature review

Genito-pelvic pain/penetration disorder is described as a sub-category of female sexual dysfunction in the DSM5⁷. 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 TR⁸. According to the DSM⁵ GPPPD refers to four commonly co-morbid symptom dimensions: 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 are present, and have a significant impact on the lives of women of all ages²¹.

The literature regarding the aetiology of female sexual pain disorders suggests complexity, indicating biomedical,

psychological and relationship factors^{21,22}. A recent review of GPPPD not only emphasised the complex aetiology, assessment and treatment of the condition, but also emphasised the devastating impact GPPPD has on interpersonal relationships, psychosocial health and QoL⁸. Sexual activity is often adversely affected and women with sexual pain avoid affectionate and sexual contact as they are afraid that it will lead to painful intercourse²³. Importantly, women with vaginismus and dyspareunia experienced more negative emotions, anxiety and fear related to sexual functioning²².

Formal diagnosis of, and intervention for female sexual pain are often delayed. This is due to initial confusion about symptoms, attempts to self-manage the condition²⁴ and help-seeking barriers such as embarrassment about the problem, lack of confidence in a healthcare solution, relationship characteristics, professional approachability, awareness of services and perception about the problem²⁴. Healthcare professionals therefore play a major role in the treatment or non-treatment of women with sexual dysfunction²⁵ and need to be more sensitive to these issues.

Best evidence intervention protocols to address female sexual pain conditions require a holistic (bio-psychosocial) and multi-professional approach²¹. Conventional treatment of GPPPD includes topical treatments, injections, vestibulectomy, laparoscopic surgery, physical therapy (including electromyographic biofeedback, electrical stimulation, vaginal dilators), cognitive behavioural therapy (including coping strategies, desensitization, relaxation techniques, mindfulness, education, communication skills training), sensate focus (including light touch), couples therapy, acupuncture and hypnosis²⁶. Alarmingly, pain is the only sensory aspect that has been investigated in women suffering from sexual pain⁸, despite the involvement of other sensory systems in the best evidence treatment protocols, utilising, among others, soft touch.

Sensory processing dysfunction which has a complex interrelationship with, and may be a predisposing factor for, the development of psychiatric conditions has been described in women with genito-pelvic pain/penetration disorder (GPPPD)⁶. These conditions may include affective conditions, especially anxiety and depression²⁷, adult attachment and coping²⁸, attachment and emotional distress, anxiety levels in adults²⁹ and psychological health complaints³⁰. Thus, both SPD and GPPPD play a role in anxiety, attachment and emotional distress. The impact of SPD on sleeping³¹, substance abuse³², impulsivity³³, parenting and attachment styles³⁴ has also been documented, but the literature is largely silent on sexuality and sexual activity in relation to SPD, beyond merely commenting on interpersonal relationships.

As in the case of GPPPD, persons with SPD have a tendency to self-manage the condition and employ various coping strategies to deal with the impact of SPD^{3,13}. These coping strategies may include active and passive strategies³. Active strategies involve mechanisms such as coping selfstatements, 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^{3,13} Sensory avoidance, an active coping mechanism, may result in avoiding relationships, while persons with sensory sensitivity may experience increased anxiety related to relationships²⁸. Furthermore, sensory sensitivity (low neurological thresholds) could affect social participation through avoiding social situations, resulting in perceived introversion³⁰. 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^{16,35}. Individuals with sensory sensitivity displayed greater pain sensitivity affecting their QoL negatively¹, while a recent study highlighted the association between sensory processing and pain coping strategies³.

Treatment approaches for SPD in occupational therapy have mostly focussed on children and adolescents^{18,32}, however, of late, the focus has also shifted to the adult population^{4,18,36}. Interventions for sensory processing difficulties include therapeutic use of self, sensorimotor activities (individual and group), sensory-based modalities, sensory diet, environmental enhancements,³⁵ (p.CE-4)</sup> environmental modifications^{4,37}, cognitive and occupation-based interventions³⁸, education and coaching³⁹ and Ayres Sensory Integration[®] (ASI[®])⁴⁰.

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^{35 (p.CE-4)} and to encourage participation in purposeful activities and roles⁴. Components of self-regulation, namely attention, response to sensory stimuli, feelings and learning, can be addressed in both occupation-based and cognitive interventions³⁸. Occupation-based interventions at home, work and in the community⁴¹, are fundamental to occupational therapy and are based on the principle that engagement in activities of daily living (occupations) results in improved participation, QoL, and general well-being^{38,41}. 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 e.g., 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 routine³⁶ and is compiled in collaboration with the person with SPD⁴.

Environmental adaptions aim to either increase, decrease or avoid certain sensory input in the physical environment throughout the day^{4,42}, affecting sensory arousal levels with the goal to improve self-regulation⁴³. These adaptations are important when treating persons with SPD and include adjustments to sensory input such as lighting, sounds, touch and movement in occupations (activities of daily living) in the home, work, leisure and social environments^{42,44}. Environmental adaptations also include psychosocial support and strategies to develop and maintain social support networks³⁵.

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^{4,18,36,45,46}. An example of such an intervention

described in the literature was based on a home-programme treatment protocol, and included three components, namely patient insight, regular daily sensory input and participation in physical activities (providing proprioceptive, tactile and vestibular input) chosen by the patient³⁶. Home programmes have been used to increase the frequency of therapy, or to provide intervention when a break is taken from therapy¹⁶. A study by Novak & Berry¹⁶ found home programmes 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.

There appears to be some commonality in symptoms and difficulties between GPPPD and SPD, specifically related to pain sensitivity, impact on relationships and QoL. There also appears to be some overlap in the treatment approaches that can be used for GPPPD and SPD, specifically from a cognitive-behavioural and sensory perspective. However, the absence of investigations into sensory modalities in the GPPPD literature, means that an occupational therapy sensory integration approach has not been investigated in targeting the needs of the client with GPPPD, in relation to their specific sensory processing patterns which could be accommodated in a holistic intervention that includes occupational therapy.

METHODOLOGY

Study design

A qualitative study design, using semi-structured individual interviews was used to gather information regarding participants' experience of participating in an occupational therapy sensory-based home programme(SBHP)⁴⁷. A descriptive approach was used to describe participants' experiences^{47,48}.

Ethics

Ethical clearance was obtained in 2017 from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand (HREC-M) (Certificate Number M170829).

Participants/Sampling

The incidence of GPPPD is not known and sexual dysfunction is a sensitive topic, necessitating a more focused, nonprobability sampling strategy to recruit this hard-to-reach population. Participants who were diagnosed with SPD via the Adolescent/Adult Sensory History (ASH) questionnaire in a previous study⁶ using purposive, non-probability sampling⁴⁹ were asked to volunteer to participate in the SBHP. The inclusion criteria included females from the age of 18 who have a diagnosis of GPPPD who lived in Gauteng or KwaZulu-Natal (KZN) for logistical reasons, but at the conclusion of the study the sample included only participants from Gauteng. 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.

Participants from Gauteng were selected due to logistical reasons as initial interviews were conducted face-to-face. This was necessary to establish a good rapport with participants, especially since the sensitive topic of sexual pain was to be discussed, as well as to gather sufficient information about participants to design a client-centred intervention strategy. Initial face-to-face interviews further helped to ensure treatment techniques (where applicable) were demonstrated adequately to the participants. These interviews also served to confirm eligibility for inclusion.

The model of information power⁴⁹, 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 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' population⁴⁹. Information power was further increased as the current study is supported by some theoretical background, even though most research regarding home programmes have been conducted in the paediatric population¹⁶. The current study could therefore combine existing knowledge and contribute to new knowledge regarding the use of home programmes in this specific population, resulting in a smaller sample size required. 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.

Intervention

First, an initial, face-to-face semi-structured individual interview which lasted approximately 11/2 hours was conducted. When making appointments with participants, two hours were allowed for initial interviews to prevent rushing participants, which could potentially have negatively affected the depth and quality of data⁵⁰. 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 in layman's terms 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) programme (via a video link), yoga, mindfulness, and therapeutic brushing (TB). 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 necessary¹⁶.

Data Collection

Follow-up interviews (either face-to-face or via Skype) lasted between 30 and 60 minutes. Information regarding partici-

pants' experience of participating in a SBHP was obtained during the follow-up interviews. Open-ended questions included have you experienced any change?, what strategy did you find most helpful? and what would you change? The follow-up interviews took longer than expected to arrange due to logistical challenges and most were done between eight and 12-weeks post implementation. 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 anxiety⁵¹.

One participant's interviews were 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 and to maintain the privacy of the participant. Interviews also allow for psychoeducation⁵², which is important not only because SPD is an unfamiliar condition, but also due to the sensitivity of the topic of sexual pain/difficulties⁵³. The quality of the interview dialogue was important and strong, clear, open communication allowed for maximum data gathering in a non-threating environment⁵¹. All interviews were audio-recorded and transcribed, and the researcher took field notes during the interviews. The researcher was aware of potential power imbalances during the interviews⁴⁷, and care was taken to show respect to participants whilst also protecting professional and research ethics, and building rapport with participants^{50,51}. Researcher bias was a possibility as the researcher did the intervention and conducted the interviews, but parameters of trustworthiness were implemented to reduce the possible impact thereof⁴⁸.

Data Analysis

Only data of the follow-up interviews were analysed, in keeping with the study objectives. Descriptive data analysis, specifically inductive thematic analysis^{50,54} 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)⁵⁵. Once checked, transcribed interviews were entered into Atlas.ti⁸ (a computer-assisted qualitative data analysis software programme), and coded systematically⁵⁰. In vivo coding was used where possible, but due to the large number of Afrikaans participants, this was not necessarily possible. Themes were constructed via thematic analysis from across the data sets⁵⁴, and visually represented via a thematic network diagram⁴⁷. After analytic reflection, in vivo codes were added to specific categories and themes, adding another dimension as participants' words⁵² were used to report their personal experiences.

Trustworthiness

Various parameters of trustworthiness^{49,50,52,56-59} were applied to ensure rigour and are displayed in Table I (page 35).

Table I Parameters of trustworthiness

CRITERIA	STRATEGY	APPLICABILITY	
Credibility	Information power ⁴⁹	Quality of data more important than number of participants.	
	Member checks56	Done via an e-mail to participants to ensure data were interpreted accurately ⁵⁶ .	
	Peer examinations/debriefing		
	Confidentiality	Transcripts were anonymised and audio recordings were stored using a participant number. Identifying information was stored separately.	
	Interview protocol ⁵⁰	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 in vivo codes derived from participants' words.	
Transferability	Providing thick descriptions ^{57,58} of research, participants, methodology, interpretation of data.		
	Purposive sampling		
Dependability	Create an audit trail of procedures and processes ⁵⁹	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.	
	Peer coding	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.	
	Coding & recoding of data ⁵²	Enhanced accuracy of the coding process.	
	Sceptical peer review	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.	
Confirmability	Practice reflexivity	Continuous self-examination was done to ensure that researcher-subjectivity did not interfere with data collection.	
	Audit trail of data analysis process.	Kept records of field notes, raw data and transcripts. Stored raw data in organised archives.	

RESULTS

Five women ranging in age from 35 years to 42 years 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 met the inclusion criterion of having SPD, since their Total score on the ASH fell in the definite category and they presented with atypical sensory modulation, sensory discrimination and/or social/emotional functioning⁶. Tactile processing was most affected, and a significant number of participants had an atypical pain response and presented with aggressive/impulsive behaviour. Two themes related to participants' experience of a SBHP specifically related to the SI content 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 (page 36).

Theme one: Changes experienced after participating in a SBHP

Two categories emerged in theme one. 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 after participating in the SBHP.

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

"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 because 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 adjust at work, thus indicating the impact of increased awareness reached beyond sexuality. 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. 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, or even moments, are better than others:

"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 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

Table II Summary of themes and categories

ТНЕМЕ	CATEGORY	SUB-CATEGORY	CODE
			Express SPD related issues
			Able to identify triggers
	Increased awareness/insight		Identify fluctuations in daily functioning
			Identify sensory difficulties in others
Changes experienced after	Intra-personal changes		Increased tolerance for sensory stimuli
			Feeling more in control
			I can breathe again
			Feeling safe & secure
			not as clumsy as I used to be
	Problem-focused coping		Seeking touch/tactile input
		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
Coping strategies employed by			Avoiding personal contact with others/ increased personal space
women with SPD and GPPPD			Creating order at home/work
	Emotion-focused coping	Positive reinterpretation/	Aware of changes within self
			Self-talk used as tool to calm or motivate self
		0.0.0	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

that she is much more attentive to the way other people process sensory information e.g. a child that does not like being touched.

"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)

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.

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

"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 chilled (relaxed)." **(P3)** Participants felt more in control of themselves and the environment. Not only were they able to identify sensory triggers (discussed above) but they could also 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:

"The programme helped me, because I could...the minute when I got into a situation that pushed my revs into the red [i.e., sensory overload], I was almost..., I was able to control myself." (**P5**)

Participants (P1 & P5) reported less clumsiness.

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. "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. Two categories, namely: 1) Problem-focused coping, 2) Emotion-focused coping and five sub-categories, 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 (see Table II page 36) emerged from the second theme

Category 1: Problem-focused coping

Sub-category: Active coping: Increased sensory seeking

Touch, especially deep tactile input, was sought by participants, who specifically reported that they preferred the TB to be done very hard (P1, P3), and vigorously (P3). One participant (P4) mentioned that she would have preferred a deep massage to the TB. Nonetheless, all participants found the deep touch comforting.

"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)**

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

All participants mentioned increased movement activities including 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 starting to fiddle with a pen when having to speak to colleagues.

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

"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 me, just to stroke them." (P5)

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

"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 queue, that I can zoom out..., you know, to remove myself from a 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)

"That is one thing, I hate, absolutely hate make-up." (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 (music with a prominent bass drum rhythm).

"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, 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, 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)

"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 which increased feelings of being out of control.

"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)

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:

"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. Understanding why she is different, helped a lot. She (P5) also mentioned that she realised she is fine and that she is not really such a 'witch' or bad person, as she previously perceived herself to be. Participants P2 and P5 explicitly expressed gratitude for the study, but this sense of gratitude was reflected in field notes and expressed by other participants after the formal interviews.

"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... [...] 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 who can benefit, but do not come forward, because it is a sensitive, you know, topic." **(P2)**

"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 nothing wrong with me. It's just, I am just different... 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 strategy⁶⁰ was prominent in three of the participants (PI, 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.

Sub-category: Acceptance "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**)

"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)

Subcategory: Support

Support from partners was vital and participants reported their partners to be understanding, supportive and nonjudgemental.

"[My husband] could see a difference. So, he's like, But you're not bouncing off the walls, you're not like freaking out." **(P1)**

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

DISCUSSION

The present study sought to describe the experiences of women with GPPPD and SPD who participated in a SBHP. The 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 a addressing SPD in adults¹⁸. Insight enables persons with SPD to better manage atypical processing patterns by assisting with identification and implementation of coping strategies⁴² 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 SBHP during the initial interview, as it empowers people by increasing health literacy⁶¹. Insight, gained via information, empowered participants to experience self-growth and selfregulation (incl. sensory processing, emotional regulation, cognitive regulation and social perspective taking⁶²).

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 occupational therapy intervention for children with SP difficulties, in which improvements in adaptive behaviour, withdrawal and inattention; a reduction in aggression, anxiety, depression; a decrease in sensory symptoms and improvement in motor skills were noted post-treatment⁶³. Like our study, 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^{18,36}. Importantly, the literature review¹⁸ 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 environment¹⁸. This has not been established in the current study and future research should consider collecting additional data to determine participant experiences in the longer term.

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, also related to using active coping strategies, which is supported by findings in the literature. Problem-focused coping typically involves activities/strategies (occupation) employed to improve coping in stress-inducing situations by either changing the stressor or oneself⁶⁴. The use of activities related to daily living makes this an occupation-based intervention, which have been found to support social, sensory and emotional outcomes in children SPD³⁸. Active coping strategies, such as exercise, social comparison and positive self-statements (coping statements), have also been found to reduce distress in healthy adults³, to be adaptive coping strategies in persons with pain^{3,64}, and improving mental QoL in persons with emotional disorders¹³.

Notably, 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^{3,13,28}. 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, may have contributed to participants not mentioning passive coping strategies.

Participants actively sought 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 selfregulation strategy, improves emotional regulation and contributes to positive affect²⁹ and improved socio-emotional functioning in children with sensory craving (sensory seeking), post-treatment⁶⁵. Sensory seeking has also previously been found to be an active pain strategy³. A recent systematic review suggested deep touch pressure improves the effectiveness of interventions in children and youth with SPD⁴⁶, while another study involving young people with autism, found deep pressure to be beneficial if it is adapted to the needs of the person⁶⁶. 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 to reduce/eliminate obnoxious sensory stimuli and participants actively seeking out quiet spaces. Avoidance of sensory input has been associated with persons with emotional disorders¹³, resonating with the current study's participants who also presented with atypical social/ emotional functioning on the ASH. Even though avoidance is sometimes seen as a maladaptive response¹³, 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 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 the 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 environment³⁷. Furthermore, organising and ordering (decluttering) the environment is often used to reduce sensory stimuli⁶⁷, while a multi-faceted approach that includes environmental changes/modifications has been recommended as interventions for children with SPD^{46,68}

Emotion-focused coping

Participants used positive/coping self-statements, through self-talk, to self-motivate and self-regulate, possibly contributing to a willingness to try new sensory experiences (sensory seeking) which are closely related to active coping strategies discussed above.

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 adults⁶⁹, while collaborative sexual communication between women with sexual pain and their partners has been associated with improved outcomes related to sexual and psychological functioning⁷⁰. Communication is facilitated by a trusting, balanced relationship as it creates a safe space in which critical/negative information can be shared⁷¹ and strong relationship goals can be established, which has been linked to greater sexual satisfaction in women with sexual pain⁷².

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 literature²⁸. This may happen when participants experience irritability/sensory overload, resulting in fight-andflight reactions, leading to avoidance of interpersonal contact and increased personal space²⁸. Avoiding personal contact may further impact negatively on intimate life as physical contact and touch are crucial to intimate relationships⁷³. However, the potential negative impact on relationships may be mitigated by improved communication, sharing information and explaining the reason for certain behaviours to others⁷⁰.

Limitations of the study

The current study needs to be considered in light of the following limitations: Only persons who had access to the internet and mostly private healthcare for sexual pain could volunteer to participate in this qualitative study. While we endeavoured to describe our sample in detail, transferability of the results to populations who do not have access to e-mail/internet or private healthcare may be limited.

CONCLUSION

Occupational therapists specialising in sensory integration are increasingly getting involved with adults with SPD, either as clinicians or in the evolving role as consultant⁷⁴. Literature regarding the impact of SPD on sexual activity, intimate relationships, sexual expression, and sexuality are limited to non-existent. Furthermore, sexual activity (specifically sexuality), is also expressed through other occupations such as caring for a partner, grooming, dating and intercourse²⁰. However, these occupations are often negatively affected in persons with SPD, further affecting emotional well-being, relationships and ultimately QoL¹³. Participants' experiences suggest/reflect that an individualised, client centred SBHP contributed to improved QoL of women with GPPPD and SPD. Importantly, previous studies^{16,40,42} recommend intervention strategies to be individualised and based on the needs of the client.

Most of the participants were newly diagnosed with SPD and were therefore unfamiliar with SPD although they might have been aware of some of their own sensory issues. Information regarding SPD facilitated insight and self-growth. Insight gained through education lead to intra-personal changes and increased awareness and insight. Better insight facilitated self-growth, improved coping in the environment, increased activity (sensory seeking) and increased socioemotional support.

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 clientcentred 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, would contribute to occupational therapy knowledge in this specialised field. From a treatment perspective, goal setting (i.e. goal attainment scaling⁷⁵), should be included in the SBHP as it will enhance practitioners' and patients' ability to track improvement, also enhancing a client-centred approach. Interpersonal goal setting, involving partners, has been linked to improved sexual and relationship satisfaction⁷². A relational approach, including assessment of partners' sensory integration/processing, should be considered in treatment. The inter-relationship between individual, potentially conflicting, sensory profiles within intimate relationships, should be explored as part of the intervention strategy. Both in the clinical and research context, information, and strategies, based on priority goals, should be introduced via a staggered approach in follow-up sessions, to minimise potential information overload.

Author contributions

Elsie Labuschagne was involved in data collection, formal analysis, and writing of the original draft and secured funding. Elsie Labuschagne and Matty van Niekerk designed the study. Matty van Niekerk reviewed and revised the manuscript. Both authors read and approved the final manuscript. The study was conducted by the first author for higher degree purposes, supervised by the second author.

Conflicts of interest

The authors have no conflicts of interest to declare

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