

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

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## Research note

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# 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.

## Introduction

The role of sexuality is often ignored in occupational therapy and 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 must address intimate relationships during 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 by Bar-Shalita et al. [6] found pain sensitivity to be related to over-responsivity in a person with sensory modulation disorder (SMD).

Sensory processing disorder (SPD) [7–9] is a result of difficulty grading and/or regulating responses to sensory input and consists of three diagnostic groups namely, sensory modulation disorder (SMD), sensory discrimination disorder (SDD) and sensory based motor disorder (SBMD) [7, 10]. Sensory modulation disorder consist of three sub-types, namely sensory over-responsivity (SOR), sensory under-responsivity (SUR) and sensory seeking (SS). Sensory based motor disorder consists of two sub-type, namely postural disorder and dyspraxia [7, 10].

Individuals with SOR experience non-painful sensations as abnormally irritating, unpleasant or painful [7, 11] and can result in defensive behaviour e.g. tactile defensiveness. Atypical sensory processing responses have significant implications for quality of life (QoL) [12–15], 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 and current treatment options range from medical intervention, physical therapy and psychosocial treatments and reflect the current concepts regarding the aetiology [33]. Physical touch is often emphasised in relationships [29] and 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 actually exacerbate the condition in persons with sensory processing disorder (SPD).

The possible inter-relatedness of these two conditions 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 contribute another factor in the aetiology of female sexual pain and lay the foundation for inclusion of sensory integrative OT treatment to 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 also impacts 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 [15]. A study by Abernethy [15] found treatment of anxiety through mainly cognitive strategies to be ineffective in persons with SOR. Tactile input is a very important treatment modality in the treatment of SPD and Cascio [43] suggests that tactile based therapies can be effectively used to modulate arousal, attention and sensory defensiveness.

## **Study Design**

A sequential explanatory two-phased mixed method study 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 explanatory study using semi-structured individual interviews to gather information regarding participants' perception of participating in a sensory based home program. Qualitative research designs can however evolve and may only be finalised once data collection ends [44]. Data from both phases will be integrated during the data analysis phase by merging the data using a mixed method matrix [44, 45].

# 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. Purposive sampling [46, 47] will be used and women who meet the inclusion criteria will be included. The estimated number of patients seen per annum by healthcare professionals consulted 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 (AASH) questionnaire [48]. Reliability of the AASH's total score is 0.85 and concurrent validity 0.78 ( $p < .001$ ) [48–50]. The AASH is relatively new but has already been used in a few studies [51, 52]. 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 [48] as well as functional problems related to these areas. 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 AASH 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) subscales 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 [53]. 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 [54, 55].

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 & age, sexual history, province) and online questionnaires (AASH & 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 with 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**

Nominal data and ordinal data will be assigned a numeric value to each possible answer within REDCap software. The raw data will be exported from REDCap to Excel and imported into Statistica analytics software program. Nominal and ordinal data will be analysed using descriptive statistics including ranges, means and medians for each section of the demographic questionnaire. Categorical data will be analysed descriptively, using frequency tables and percentages.

The responses to the AASH will be entered into the AASH-Scoring Program©. Individual reports providing raw scores, z-scores and interpretation of scores will be generated. Standardised scores will be divided into three categories, namely typical performance, mild (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 result in functional difficulties). A diagnosis of mild difficulty requires further investigation or assessment and a diagnosis of definite difficulty requires intervention. A combined score will be obtained for each item by combining the mild and definite difficulty percentages indicating the percentage of participants who fell outside the parameters of typical functioning.

Results obtained on the AASH and HADS (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. Data will be cleaned and imported into Statistica software program for descriptive analysis.

## **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 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**

Qualitative data will be collected during initial individual interviews during which information regarding personal experiences and impact of sensory processing, SPD, personalised interventions and possible treatment techniques will be discussed. Researcher will be available should any questions arise during the execution of the program. Semi-structured individual follow-up interviews will be conducted to obtain information regarding participants' perception of participating in a sensory based home program. The follow-up interview may be conducted via electronic media e.g. Skype. All interviews will be audio-recorded and transcribed and 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. [46] six to twelve interviews should suffice when the aim is to describe a homogeneous group's perceptions and experiences when using nonprobability sampling. Malterud et al. [56] 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[57].

### **Data Analysis**

Inductive thematic content analysis [58–60] will be used to analyse data obtained using interviews which will be recorded and transcribed. A 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 they will be grouped into themes. Horizontal analysis will be used to look for common threads [57, 61].

Various parameters of trustworthiness will be applied to ensure rigor. This includes using an interview protocol [61] to ensure a consistent style of data collection. The implementation of the sensory home based program will follow a standard framework, but include individual treatment activities based on participants' unique sensory processing profile obtained from phase one. A list of open-ended questions, which support the research question, will be used ensure all participants respond to the same questions. Furthermore, the researcher will ensure prolonged engagement in the field and 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 [62]. 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 [57, 61]. Member checking will be done to ensure data were collected accurately [63]. All records and data will be managed and maintained and 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. The data management system is crucial to rigorous qualitative research.

## Conclusion

This is to our knowledge the first study investigating a possible link between SPD and women diagnosed with GPPPD.

Although much has been written about GPPPD and SPD as separate entities, there is a paucity of literature regarding a possible link between these two conditions. Establishing whether a link exists between these two conditions may have important implications for treatment of GPPPD, for which a multidisciplinary and multidimensional approach is recommended. Assessment and treatment of SPD has not been evaluated as a possible option for GPPPD intervention, despite evidence suggesting that SPD intervention assists with pain management [18]. Current, conventional multi-disciplinary treatment methods for female sexual dysfunction e.g. sensate focus, may be rendered ineffective or actually make the condition worse in persons with sensory processing disorder (SPD).

A common theme in both these study fields is the presence of affective symptoms related to anxiety in women diagnosed with a sexual disorder [38] or adults diagnosed with SPD.

## **Limitations**

No or limited knowledge regarding SPD and could result in non-participation or biased results. Results of phase one may also be biased as data are obtained via self-report questionnaires.

Study sample size may be limited due to purposive sampling as recruitment will be done by healthcare practitioners practicing in the field of sexual health and may mostly consist of clients with access to private medical facilities and more extensive personal resources. 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 program 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.

## **List Of Abbreviations**

AASH: Adolescent/Adult Sensory History; ADL: Activities of daily living; GPPPD: Genito-pelvic pain/penetration disorder; HADS: Hospital Anxiety and Depression Questionnaire; 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.

## **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**

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

## Competing interests

The authors declare that they have no competing interests.

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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. All authors read and approved the final manuscript.

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