

Clinical utility of three sensory modulation measures for the child with ASD in South Africa: A Practitioners' Perspective

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Introduction

The prevalence of Autism Spectrum Disorder (ASD) appears to be increasing worldwide. The United States Department of Health estimates that there has been a 500% growth in the incidence of ASD over the past five to ten years¹. According to the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5)² ASD is a neuro-developmental disorder and for children to meet the criteria for ASD, they should present with persistent deficits in two main domains namely abnormalities in social communication and social interaction, and restricted, repetitive patterns of behaviours, activities or interests. Additionally, the individual may present with at least two of the four behavioural symptoms listed in the DSM-5, one of which is unusual interest in sensory features of the environment or reactivity (hypo- or hyper) to sensory stimulation². Sensory reactivity or modulation (reactivity/modulation), being the level of a behavioural response to a sensation as well as the ability to adjust and organise one's own behavioural and emotional reactions to stimuli, is the term that best describes this and is therefore the focus of the study.

There is extensive research which has attempted to estimate the number of children with ASD who experience unusual responses to sensory experiences³⁻⁵. Some literature estimates that 95% of ASD children experience sensory processing difficulties⁴. Since individuals of all ages with ASD present with significantly different sensory symptoms compared to age peers⁶ using Ayres Sensory Integration (ASI) as a framework for assessing and treating children with ASD is an ever growing area of work and research in South Africa (SA) and internationally⁷⁻⁹.

Sensory processing disorders (SPD) are a group of disorders which result in challenges in reactivity/modulation, integration, organisation and discrimination of sensory input. Sensory Reactivity/ Modulation Disorders (SMD) are a sub-type of SPD. Children with SMD have problems regulating and organising the degree, intensity and nature of their response to sensory input, in a graded manner¹⁰. Since sensory differences are often predictive of maladaptive behaviours in ASD⁸, accurate assessment and appropriate intervention of sensory reactivity/modulation may have a profound impact on the functional performance of children with ASD in SA.

Occupational therapists (OTs) plan an intervention with an evaluation which includes gathering information and interpreting data from assessment tools¹¹. Of SA's 55 million people, there are 11 official languages and a wide range of cultures. In 2015, eight out of ten households in SA were headed by black Africans (80, 41%)¹² who are likely to be second language English speakers. This raises issues of bias and equivalence when using measures developed in the US, but used with children with ASD in SA.

There is an identified gap in the provision of culturally sensitive, language appropriate sensory reactivity/modulation measures for ASD children in SA^{9, 13}. Developing such measures would be very costly and time consuming, hence this study focussed on exploring the practitioners' perspective on whether the three self-report, sensory reactivity/modulation tools appraised in this study have any clinical utility for a child with ASD in SA.

Literature Review

A search of the literature using the following databases was carried out: OTSeeker, Google, Google Scholar, Deepdyve and OT specific websites including OTASA (and SAISI) and AJOT. Colleagues also sent relevant articles. The search strategy included the terms "ASD" and "sensory or sensory processing" and "assessment or evaluations" OR "sensory integration"; "assessment"; "clinical utility"; "cultural"; "linguistic equivalence". Search dates were not specified however articles published after 2000 were favoured. Relevant books and chapters in books were also used.

A systematic review of assessment tools currently available for identifying different patterns of sensory processing in children aged 3 – 11 years was carried out in 2017¹⁴. This review revealed that the most commonly used tools included the SIPT (Ayres, 1989), The Sensory Profile (SP) (Dunn, 1999), The Sensory Processing Measure (SPM) (Parham & Ecker, 2007). These two main tools for assessing reactivity/modulation are available in different languages. Specifically, they are six versions of SPM (English, Danish, Finish, Swedish, Norwegian, and Chinese) and six different versions of SP (English, Spanish, Arabic, Turkish, Indian, and Chinese).

Baranek and colleagues⁵ report that caregiver report instruments are ecologically valid for obtaining information about children's behaviour. In the SA context they are a good choice from a cost and time feasibility perspective. This study investigated the clinical utility of the SP¹⁵, SPM¹⁶ and Sensory Experience Questionnaire (SEQ)¹⁷ which have been developed and normed on a US population of children. An argument exists for investigating the relevance and clinical utility of these sensory reactivity/modulation measures with the ASD child in South Africa.

Culture and Language

The culture within which a child is raised, influences values, interactions, social customs, and family structures which help organise their environment¹⁸. This may impact their social, emotional, intellectual and behavioural development. One's culture may determine what behaviour is considered to be acceptable or not acceptable and differences between cultures

may exist. Cultural fairness stipulates that items on tests must not prejudice the performance of children of same ability from different backgrounds due to the unfamiliarity of tasks¹⁹.

The issue around whether cultural differences can influence caregivers reporting on self-report sensory reactivity/modulation measures was investigated by Caron and colleagues¹⁸ in Israel by comparing the frequency of Israeli and US parent-reported responses to the sensory experiences of their children. The results indicated possible cultural differences in the Israeli and US samples and recommended that therapists be mindful of the influence of culture on sensory processing when planning an intervention programme¹⁸.

The Spanish version of the Short Sensory Profile (S-SSP) was developed using a “typical back translation process”²⁰. The authors recommended that guidance be provided to the respondent when completing the questionnaire, which results in the instrument not being used as a self-report measure. Attention to language issues can make a difference in terms of the validity of the information they had collected by these measures.

In an Arabic study in 2013²¹ The Adolescent/Adult Sensory Profile (A/ASP) developed in the US by Brown & Dunn (2002) was back translated into Arabic and the linguistic equivalence and psychometric properties reported. The authors found the sensory processing skills of the study sample, to be significantly different to the US.

Bias and Equivalence

The Psychology Board at the HPCSA²² advise that when tests are to be used within multicultural groups, interpersonal sensitivity and a good cross cultural understanding and communication skills are needed in order to minimise potential bias in the administration of the test. Bias and equivalence of tests used in cross cultural assessment is an important consideration, as its unclear as to whether scores on tests administered to different cultural populations than those it was normed on, can be interpreted in the same way, and therefore whether the test has validity in the SA context if it originated elsewhere²³. Research done in SA by Malda and colleagues²⁴ highlights the importance for the test group to be familiar with the content when testing children from two distinct cultures. They carried out cognitive testing with white Afrikaans and black Tswana children and found that the children from either cultural/ethnic group performed better with the version designed in their own home language.

Clinical Utility

Clinical Utility refers to the ability of a screening or diagnostic test to prevent or ameliorate adverse health outcomes²⁵. Law and colleagues²⁶ carried out validation studies on a newly

developed Canadian Occupational Performance Measure (COPM). Settle & Holm²⁷ investigated the utility of three activity of daily living (ADL) assessments in their ability to guide and plan occupational therapy intervention. Clinical utility research is therefore not unknown to occupational therapists.

Insert table 1 here

Smart²⁸ suggested a multi-dimensional model to assess the clinical utility of a test. His model uses dimensions of: appropriateness, accessibility, practicability and acceptability, as indicated in Table I. Clinical utility, for the purposes of this study, was the extent to which the identified sensory reactivity/modulation instruments assist occupational therapists in SA to accurately diagnose the sensory profile of a child with ASD, and thereby prescribe appropriate therapy plans for them, within the cultural, social and developmental needs of the child.

Methodology

The aim of this study was to establish the practitioner's perspective on the clinical utility of three sensory reactivity/modulation measures for the SA child with ASD. This study utilised a cross sectional descriptive survey design to establish the perspectives of occupational therapists on two well-known measures already in use in SA and one lesser known one still in development. The participants (n=31) met the inclusion criteria as they completed South African Sensory Integration Course (SASIC) 3 on the SAISI SI course, as well as having assessed five children with ASD in their career.

Population and sampling

Purposive sampling of the national database of SAISI registered occupational therapists in SA was carried out. It is housed electronically by SAISI (the gatekeeper). An invitation letter was distributed to these members and those that agreed to participate, provided they met the inclusion criteria, were sent the survey. Those that returned the completed survey and consent form became the final sample (n=31).

Methods of Data Analysis

The first seven questions required demographic information from the participants, and once coded, the raw data was entered onto a Microsoft Excel 2007 spreadsheet. Descriptive statistics were used to analyse the frequencies of responses. Participants were also asked whether or not they had used self-report sensory reactivity/modulation measures in their clinical practice, and if so what challenges they had encountered. The challenges underwent

thematic analysis²⁹ were analysed for their content, in order to establish the main themes and the frequency of these was analysed using descriptive statistics. The next section included 16 questions, in four dimensions of clinical utility²⁸. A four-point likert scale (1= strongly disagree, 2= disagree, 3=agree, 4= strongly agree) was utilised to obtain the participants positive or negative responses towards each statement. These were transferred to a spreadsheet and descriptive statistics used to establish which sensory reactivity/modulation measure held the most clinical utility, according to each of the four dimensions, as well as an overall measure. In this parametric study, t-test comparisons were then used to compare all three measures and to establish whether relationships existed between overall clinical utility and the years of experience, setting and language of the clients. T-test analyses were selected as most appropriate in analysing the results as the aim of the study was to compare the clinical utility of each instrument. Using the t-test established whether the mean scores of each instrument were statistically significant from each other ie to make a comparison³⁰. The level of significance was $p < 0.5$. The final, voluntary section of the questionnaire enquired as to the items on the sensory reactivity/ modulation measures which were problematic.

Reliability and validity

Reliability of the survey questionnaire was established through the pilot study where eight expert³¹ occupational therapists reviewed and commented on the questions and the rating scale used. Content validity was achieved by carefully describing the ASD child in the SA context and writing items that represented the issues raised in the literature review and subjecting those domains to expert scrutiny³⁰ through the pilot study. Construct Validity was observed by combining ASI and clinical utility theory to inform the design of the survey questions, so the domains of acceptability, accessibility, practicability and appropriateness were validated. The survey questionnaire was thereby designed to access both theoretical constructs through its scaled scores, to derive clinically relevant information from the subsequent data.

This study used a cross section descriptive survey design, in order to survey SAISI OT members from a nationwide sample to increase representativeness of the results. Validity was increased by ensuring the respondents had sufficient knowledge and experience on the subject matter of ASD and ASI, through the selection criteria.

Ethics

Full ethical approval was obtained from xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx. HPCSA guidelines for ethical good practice were observed during all aspects of this study³². A process of informed consent was followed during piloting and data collection.

Results

The majority (67%) of participants consulted English- speaking clients. Furthermore these participants mainly worked in private practice settings (80%), with 83% of them being based in urban areas. Sixty five percent (65%) of the participants reported having over 10 years clinical experience.

Insert figure 1 here

The first objective was to establish clinical utility of the measures. Overall mean scores of the SP, SPM and the SEQ demonstrated no statistically significant difference ($p > 0.5$). The mean rating was a '3' on the likert scale which indicated *agreement* with the three measures' clinical utility. The three measures were then analysed for statistical significance ($p < 0.5$) over each of the dimensions of clinical utility, which included appropriateness, accessibility, practicability and acceptability (Figure 1).

Insert table II here

The results in the *appropriateness* section of the survey highlight a clinically significant difference between the SP and SPM, in favour of the SPM ($p < 0.007$). This was consistent when compared to experience of participants, and setting (urban/rural, private practice/public). However, with the group of non- or second language English speakers, the SEQ held significantly higher utility than the SP ($p < 0.01$) and SPM ($p < 0.02$) (Table II).

Insert table III here

The results in the *accessibility* section (Table III) of the survey indicate statistically significant differences between the three measures with the SP being most accessible, followed by the SPM and then SEQ. The SP was more accessible than the SPM ($p < 0.002$), and the SEQ ($p < 0.001$) and the SPM was more accessible than the SEQ ($p < 0.03$). The results reflect that 90% of participants have the SP in their work place. Is available in the US and not SA as yet.

Insert table IV here

The results in the *practicability* section of the survey show no significant difference between any of the measures. The mode rating in this dimension was a '2' which is a *disagreement* with clinical utility in this dimension (Table IV). Thirty two percent of participants ($n=10$) commented that the cost of the measures was a concern.

Insert table V here

The results from the *acceptability* section of the survey show no significant difference between the three (Table V). Twenty two percent of participants (n=7) commented that these measures are not relevant for the child with ASD in SA. T-test comparisons found that the SPM was favoured over the SEQ for the English speaking group ($p<0.02$). The SEQ was favoured over the SPM in the non English speaking group ($P<0.045$).

Insert table VI here

On analysing total mean values for the English speaking (n= 21) versus the non- or second language English speakers (n=10) a statistically significant preference for the SEQ ($p<0.02$) over the SPM was seen amongst the non- or second language English speakers (Table VI). Practitioners seeing English speaking children in their practices demonstrated a significant preference of the SPM over the SEQ ($p<0.009$).

Insert figure 2 here

The second objective was to ascertain what the challenges are when using self-report sensory reactivity/modulation measures in clinical practice with children with ASD in SA. Self-report sensory reactivity/modulation measures were used by 90% (n=28) of the participants, with 68% (n=19) of them using the SP, 18% (n=5) using the SP and SPM, and 14% (n=4) using only the SP2. Of the 28 participants, 27 (97%) reported challenges in using sensory reactivity/modulation measures in their clinical practice with children with ASD. The themes that emerged (figure 3) included parents lack of insight into their child's behaviours (40%, n=11), parents having difficulty understanding the measure due to ambiguity (74%, n=20), language barriers to using the measure (22%, n=6), the measure being too long (30%, n=8) or misused (over – or understate the child's difficulties)(26%, n=7), denial of the child's diagnosis(18%, n=5) and that interviews with the parents and/or observation of the child (37%, n=10) are often needed to supplement the information given in the sensory reactivity/modulation questionnaire (Figure 2).

The third objective was to establish which items on the measures the participants found problematic and to create guidelines for OT's using sensory reactivity/modulation measures in their clinical practice (objective four). This was a voluntary section of the survey

questionnaire and 22 participants provided information. These included suggestions for changes in wording, phrases, task items, cultural and environmental specific changes as well as ASD core deficit comments.

The fourth objective was to use the suggested changes as above, to formulate guidelines on the use of the SPM when used in the SA population of ASD children. The other measures are not represented as the SPM is the recommended measure to use with ASD children in SA, at this time.

Discussion and Implications of the Study

The results of this study are significant and will influence how sensory reactivity/modulation measures are used when assessing children with ASD in SA.

The participants were largely from English speaking (n=21) private practices (n=25) in urban areas (n=26) which has skewed many of the results. The overall results for clinical utility were similar for these three areas, during the t-test comparisons. For example, no one test held overall higher clinical utility than the others, and the overall rating was '3' indicating agreeability with the clinical utility of the measures as assessed across the four dimensions in this study. However, on analysis of each dimension and comparing them to the data from different demographic groups, some significant findings emerged.

In the Appropriateness dimension, results showed the SPM was more favoured than the SP ($p < 0.007$). This was consistent when compared to number of years' qualified, urban/rural, private practice/public. However, with the group of non- or second language English speakers, the SEQ held significantly higher utility than the SP ($p < 0.01$) and SPM ($p < 0.02$). The comments made about the SPM in this section of the survey questionnaire, and reflected in these results indicate that the SPM was felt to be more appropriate for an ASD population due to the social participation section, communication items and focus on ADL's. The SEQ held higher utility in appropriateness in the non- or second language English group as it was short and concise and also focused on ASD related questions.

Regarding the Accessibility dimension, the SP held higher clinical utility over the SPM ($p < 0.002$) and SEQ ($p < 0.001$). The SPM held higher utility than the SEQ ($p < 0.03$). Accessibility is related to how accessible the measures were in one's work place and to different language/cultural groups. The SP was the most utilised measure (n=19) of those that use measures in their workplace (n=28), which explains why it has the highest utility in this dimension. The SEQ is not yet widely known or available in SA and therefore held the least accessibility; however it was noted that it was easy to understand and would be used if available and reasonably priced.

Practicability was related to the cost of the measure and the length of time taken to complete the measures, the layout and the rating scale. The Practicability results remained consistent

between all three measures, across all four dimensions. These were generally the lowest scores indicating disagreement with all of the measures for their practical use. Thirty two percent reported the cost was too high, 13% found the questionnaires to long, 10% found the rating scales challenging to use and 10% found the layout was poor.

Acceptability explored whether the practitioner would use the measure in their workplace. They answered questions about the relevance of the measures culturally, environmentally and diagnostically. The Acceptability dimension remained consistent for all groups of participants, except for the non- or second language English speaking group. The SPM was favoured over the SEQ for the English speaking group ($p < 0.02$). The SEQ was favoured over the SPM in the non English speaking group ($P < 0.045$).

These findings were similar to those seen in other cross cultural studies with sensory reactivity/modulation measures. Israeli¹⁷ Spanish¹⁹ and Arabic²⁰ studies found that language barriers as well as cultural and environmental differences impacted on the validity of the sensory reactivity/modulation measures in cultures that differed from the US. The Australian study³³ did find validity in the SP in their country, which is likely due to the official language being English. Their cultural differences were considered minor, in the study, and catered for by using suggested alternative phrases/words in a few places when administering the measure in Australia.

Since SA not only has 11 official languages, but vast diversity in culture, socio-economic status and environments, full scale translation and psychometric testing of sensory reactivity/modulation measures is not feasible. Literacy levels and language differences in SA present challenges with using self-report measures despite their other benefits highlighted in this research.

It is clear that self-report sensory reactivity/modulation measures are considered valuable by the number of participants already using them (90%, $n=28$), but challenges are experienced by all but one (97%). Many participants commented that an electronic measure which can be emailed to parents, was easy to understand, translatable, not too long, scored automatically, and was reasonably priced would be favoured. Ten ($n=10$) of the participants used a sensory reactivity/modulation measure as a guide to parent interviews, and used a parent interview as well as observation of the child as part of their assessment in ASD, before planning an intervention. Despite the SP being the most utilised (68%) of the sensory reactivity/modulation measures in this sample, therefore holding the highest clinical utility for 'accessibility' the SPM and SEQ demonstrated higher clinical utility than the SP in the 'appropriateness' and 'acceptability' dimensions, for the child with ASD in SA. Comments included finding the SPM more suitable for ASD due to the social participation, and ADL questions. The SEQ was favoured also due to the fascinations sections of the questionnaire which many felt was appropriate for ASD, and it was described to be shorter and easier to complete compared to

the SP and SPM. The SP had many more negative comments including being lengthy, daunting to parents, having complex questions, taking a long time to score and having too many gaps in ADL for the ASD child.

Limitations were present in this study, in that 80% of the research sample was practitioners in private practice. Since the inclusion criteria required the practitioner to have training to SASIC level 3, it highlights that this training may only be accessible to those in private practice. It may also highlight that training is inaccessible geographically as there is one course per year and usually in an urban setting that many rural OTs may not be able to access. Since 70% of participants were based in urban areas, this may hold true. Sixty seven percent of the sample saw English speaking clients only, in their practices. The results therefore showed that these practitioners practising within these parameters found clinical utility in the measures, for use with that population.

Recommendations

It is suggested that further research should be done particularly focusing on rural and second language settings. A sensory reactivity/modulation measure should be developed and made available in additional languages with terminology and phrases suitable for the culture in that language group. The measure should be concise and readily available at low cost and used thereafter to guide a parent interview and intervention. This study highlights that the US developed sensory reactivity/modulation measures do not hold validity in second language speakers in SA. Since 90% of participants already use sensory reactivity/modulation measures as part of their ASD assessment, it is clear that they hold value, and therefore this guidance will be important in their clinical practice. Additionally, since 32% were challenged by the cost of the measures, developing a measure that is low cost, and reproducible, is an important consideration. Tertiary educators and trainers in SI, should consider teaching the SPM with recommended adaptations until such time an SA tool becomes available. Those currently practicing OT-SI with ASD children who have non- or second language English caregivers, should administer the SPM with some adaptations. Organisations such as OTASA should review the process of culturally and linguistically fair OT assessments in SA and support the research and development of such tools.

Conclusion

Practitioners in this study commented that sensory reactivity/modulation measures are more beneficial in one's home language, that instruments should be culturally and environmentally applicable and that an SA measure is required. The literature is clear on the need for ASD assessment to be fair and just, culturally sensitive and environmentally suitable, in order for

any such assessments to hold validity. The results indicate that whilst the measures hold clinical utility for some of the SA population, this is the minority. Specifically, the sensory reactivity/modulation measures normed in the US hold no clinical utility for non- or second language English speaking parents of ASD children, particularly those in rural areas. A sensory reactivity/modulation measure for children with ASD in SA thus needs to be developed.

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PAGE 13

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PAGE 15

PAGE 16
