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Sensory processing, praxis and related social participation of 5-12 year old children with Down syndrome attending educational facilities in Bloemfontein, South Africa***

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ABSTRACT

Background: *Down syndrome is one of the most investigated and well discussed syndromes related to intellectual disability, yet little can be found in literature of the impact that sensory processing difficulties or disorders have on the functioning of individuals with Down syndrome. This study investigated the sensory processing, praxis and related social participation of children with Down syndrome with the purpose of contributing to a better understanding thereof and heightening awareness of the importance of including sensory integration therapy as part of intervention.*
Methods: *The study was conducted by using a cross-sectional, quantitative, descriptive study design. The Sensory Processing Measure (SPM) Home Form was used to collect information regarding the children's sensory processing, praxis and related social participation. The questionnaire was completed by a parent or caregiver of a child with Down syndrome (n=15).*
Results: *The majority of the children with Down syndrome included in the study experienced vulnerabilities in social participation (53.3%) and praxis (80.0%), whereas 100% of the children experienced vulnerabilities in sensory processing.*
Conclusion: *The results of this study contribute to the emerging understanding of the sensory processing, praxis and related social participation of children with Down syndrome. The findings may be taken into consideration by occupational therapists delivering services to children with Down syndrome to ensure optimal intervention. It is recommended that further studies on larger samples investigate this topic to corroborate these findings.*

Key words: Sensory processing; social participation; praxis; Down syndrome; sensory processing measure

INTRODUCTION

Available literature provides evidence that children with Down syndrome experience difficulties with functions that are largely dependent on sensory integration. Low muscle tone, poor balance and motor planning difficulties have been identified by researchers as factors contributing to poor motor development and performance in children with Down syndrome[1]. Chen and Fang[2] found that children with Down syndrome experience sensory deficits, particularly in the areas of visual acuity and contrast sensitivity, tactile perception and peripheral hearing. Literature further describes that children with Down syndrome can behave in socially unacceptable manners[3], the cause of which may be related to difficulties in sensory processing, praxis and related social participation. However, to date, this association has not been investigated.

Deficits in sensory processing, praxis and related social participation influence an individual's engagement in everyday occupations such as eating, dressing, grooming, playing, social interaction and schooling[4]. This together with the already mentioned difficulties children with Down syndrome experience lead to the question of whether they struggle with sensory processing, praxis and related social participation which in turn, can interfere with their engagement in activities of daily living.

The possible implications of sensory processing difficulties do not only have relevance for individuals with Down syndrome, but also for occupational therapists' intervention for this population, if best practice is endeavoured in terms of service delivery. The researchers therefore attempted to address a gap in the literature regarding the sensory processing, praxis and related social participation of children with Down syndrome[5]. Limited studies have been done on sensory processing and children with Down syndrome in the United States[1] but no such research on South African children with Down syndrome could be found.

***Article commemorating the UFS Anniversary

LITERATURE REVIEW

Down Syndrome

According to Down Syndrome South Africa, the incidence of Down syndrome is estimated to be one in 1000 live births in developed countries, one in 650 live births in developing countries, and approximately one in 500 live births in South Africa[6].

Down syndrome is a chromosomal disorder most commonly associated with an additional copy of chromosome 21 (trisomy 21)[7]. Hypotonia, facial and hand features, such as a depressed nasal bridge and a single deep crease across the centre of the palm of the hand, are typical physical characteristics of children with Down syndrome[8]. Congenital heart disease, immune and endocrine system abnormalities are medical complications that occur in these children[8]. In addition, children with Down syndrome may exhibit developmental delays with regards to motor, sensory, cognitive, language and social developmental milestones, as well as stunted physical growth[9–11]. It has been noted that children with Down syndrome experience challenges with adaptive behaviour, such as social skills, and therefore struggle to adjust their behaviour and/or responses[12]. Motor delays are also of particular importance for occupational performance in areas such as school and play[6].

Sensory processing

Initially the paradigm of sensory integration was constructed by Dr. Jean Ayres[13], ased on her work on patterns of perceptual-motor dysfunctions. According to Ayres (cited by Schaaf and Smith Roley[8:2,3]), sensory integration is a neurological process that allows for "the organisation of sensations for use" and thus the integration of sensations from one's body and from the environment makes it possible to use the body effectively in the environment. A group of occupational therapy researchers proposed a paradigm shift in 2007 regarding the terminology, suggesting that *sensory integrative dysfunction* be referred to as *sensory processing disorder*[13]. Another description of sensory processing is that it involves the neural processes of receiving, registering, modulating, organising, and integrating sensory input in order to execute successful adaptive behaviours for daily activity[14]. Therefore, sensory processing can be used as an umbrella term for the processes of sensory discrimination, sensory modulation and praxis.

Although not all occupational therapists and authors may agree, it has been suggested in recent years that sensory processing and sensory integration may be used interchangeably[13]. For the purpose of this study, the terms "sensory integration" and "sensory processing" have been viewed as equivalent and as such, "sensory processing" will be used throughout.

Sensory processing and function

Difficulty with sensory processing negatively influences a wide variety of basic skills, resulting in problems with everyday activities such as self-care, play, social participation and school[15].

Interactions between the sensory systems such as auditory, vestibular, proprioceptive, tactile and visual provide integrated information that contributes to progressively more complex behaviour[8]. An example of such an interaction is the contribution of the vestibular and proprioceptive systems to the ability to develop effective postural balance, gravitational security, and muscle tone[8]. These sensory systems simultaneously interact with the tactile system to support the development of body awareness, bilateral co-ordination eye-hand co-ordination and praxis[8]. Consequently, these abilities enable the opportunity for engagement in meaningful and purposeful activities that require motor actions.

The term modulation, also referred to as self-organisation, is a brain process of increasing or reducing neural activity in order to maintain balance between all functions of the nervous system[15] and allows for an individual to be in an optimal state of arousal for engagement in activities. Sensory discrimination and perception contributes to refined organisation and interpretation of sensory stimuli[16] that in turn allow for a more refined use of the body during engagements in activities.

Praxis is a term used to describe the ideation (planning), execution, and sequencing of novel motor actions[16]. Praxis is a prerequisite for participation in activities of daily living such as dressing and playing[16]. Although the literature indicates that individuals with Down syndrome have motor deficits[1], there is a lack of detailed information regarding their praxis abilities. The social environment and social demands are constantly changing and involve unpredictable human interaction and unspoken rules[17]. Children with sensory processing difficulties are more often challenged by social participation, which influences the child's ability to engage with others[5,16].

The authors are of the opinion that the sensory processing difficulties experienced by children with Down syndrome do not always receive the necessary acknowledgement – and therefore limits sensory integration intervention for this population. With this study an attempt is made not only to focus on children and the sensory processing dysfunctions/difficulties they experience but also to add to the limited body of knowledge regarding the specificity thereof.

AIM

The aim of the study was to describe the sensory processing, praxis and related social participation of a selected sample of children with Down syndrome 5–12 years of age, attending educational facilities in Bloemfontein.

METHODOLOGY

This research study made use of a cross-sectional quantitative, descriptive study design[18] to investigate the sensory processing, praxis and related social participation of a selected sample of children with Down syndrome

Population and sampling procedures

The population that was considered for this research was children with Down syndrome aged between 5–12 years, attending educational facilities in Bloemfontein and whose parents or caregivers were willing to participate in the study. The Sensory Processing Measure (SPM) Home Form that was used to collect data was developed for completion by parents or caregivers of children[5]. In the case of caregivers, the child had to be known to them for more than one month as specified in the SPM[5].

A non-randomised convenience sampling method was used as the overall study population was relatively small. Therefore, all consecutive study participants that provided consent were included.

The inclusion and exclusion criteria for the study participants were as follows:

Inclusion criteria

- Children with Down syndrome aged 5 to 12 years and their parents or caregivers attending identified educational facilities in Bloemfontein. The SPM Home Form was standardised for this age group[5].
- Parents or caregivers who were verbally proficient in English. The SPM is currently available only in English and may not be translated due to copyright. Time limitations did not allow for the lengthy process of obtaining permission from the publishers and then translating the questionnaire if permission had been granted. The researchers were, however, available throughout the completion of the questionnaire to explain any words which caused confusion or needed clarification.

Exclusion criteria

- Children with co-morbid diagnoses such as attention deficit disorder and hyperactivity (ADHD) and autism were excluded due to possible influences on the results. (Congenital heart defects and mental retardation were not excluded as these conditions are common among individuals with Down syndrome).
- Children that at the time of the study received or had previously received sensory integration therapy from a trained

Ayres Sensory Integration (ASI) occupational therapist were also excluded due to the influence thereof on the results.

Data collection instrument and procedures

The Sensory Processing Measure (SPM) was developed to obtain a profile of how a child processes sensory information, plans, executes and sequences motor actions, and how they participate in social circumstances[5]. Although this instrument was standardised on an American population, no such instrument has been standardised on a South African population, making it the best available option for this study. The SPM was regarded by the authors as the most valid and reliable instrument for use in this research.

For the purpose of this study, the researchers only made use of the Home Form, as the other two forms, namely the Main Classroom Form and Environment Difference Form, contain questions that are not relevant for all the children with Down Syndrome in the South African context as some of the children are in schools for children with special needs or have received school exemption.

Each of the 75 test items represents a question related to a variety of behaviours and characteristics that are evidence of the child's sensory processing, praxis abilities and related social participation[5]. Each item is rated on a 4-point Likert scale according to the frequency at which the behaviour occurs. The 4-point scale includes the following response options[5]: "never", "occasionally", "frequently" and "always". These responses are numerically represented from 1 to 4 depending on the wording of the test item, with 4 always representing a most definite dysfunction. However, for the purpose of interpretation of the results, the SPM manual specifies that a score of both 3 and 4 demonstrates a problem or vulnerability.

The SPM Home Form yields a total of eight[4] norm-referenced standard scores, namely 'social participation' (SOC), 'vision' (VIS), 'hearing' (HEA), 'touch' (TOU), 'body awareness' (BOD), 'balance and motion' (BAL), 'planning and ideas' (PLA) and 'total sensory systems' (TOT). It is important to note that 'planning and ideas' is used in the SPM as the lay term for praxis[4]. The standard scores of the SPM make it possible to classify a child's functioning into one of the following three ranges[4]: 'typical', 'some problems' or 'definite dysfunction'. Sensory processing was measured through the use of five system scales, namely vision, hearing, touch, body awareness (proprioception), balance and motion (vestibular). A total score of these five system scales was calculated into the total sensory system score.

The questionnaire was completed by the parents or caregivers, or verbally answered where one of the researchers then filled in the form. A suitable time was arranged with parents or caregivers for completion of the SPM questionnaire at the relevant facilities, as these settings were familiar, accessable and convenient for them.

Analysis of data

The scoring of the response forms was completed by coding the data, combining the total results for each section of the questionnaire and then plotting these raw scores on the Home Form Profile Sheet to obtain the percentiles and *T*-scores, as well as the interpretive range for each of the eight mentioned areas. The coded demographics questionnaires as well as the coded SPM Home Forms were then analysed.

Descriptive statistics namely medians and ranges, were calculated for continuous data. Frequencies and percentages were calculated for categorical data. The Statistical Analysis software (SAS) version 9.2 was used for analysis. The analysis was done by the Department of Biostatistics, University of the Free State.

Table 1: Methodological errors

Possible errors	Ways to address
1. Incorrect interpretation of the questions in the SPM due to uncertainty regarding terms used in the Home Form.	The questionnaire was developed in USA, therefore there could have been terms in the test that were unclear to the participants in South Africa. Although the questionnaire could not be altered in any way as it is a standardised instrument, the researchers were present when the participants completed the form in order to clarify and elucidate on any uncertain terms as this is allowed for clarity according to the administration process of the SPM. This potential methodological error was further addressed by excluding individuals who were not proficient in English.
2. The inability of the test to effectively identify sensory processing difficulties in the South African population since the test was standardised on children from an American population.	The only other similar instrument that is available was also developed in the USA, but it does not assess social participation and praxis. The researchers decided to use the SPM as the preferred measuring instrument, and were therefore not able to control this factor.
3. Parents' own perceptions of questions.	The nature of the standardised instrument requires parents or caregivers to complete a form regarding the child's behaviour, thus all answers are the parents' or caregivers' own perceptions of the child's behaviour, which could not be controlled.
4. Incorrect transfer of data.	When making use of a questionnaire data are required to be transferred to a coding form. Consequently, the risk of errors exists during the transfer of data. This was avoided or decreased by including coding blocks on the scoring sheet of the questionnaire that are in line with each question. Data were therefore less likely to be incorrectly captured during coding. A biostatistician then entered and analysed the data.

Reliability of the study

The reliability of this research study lies in the use of a standardised questionnaire and the fact that the researchers were all formally trained in the administration, scoring and interpretation of the questionnaire. One of the researchers is also an occupational therapist well versed within the field of sensory integration.

Methodological errors

Possible methodological errors were identified and are summarised in *Table 1*.

Ethical aspects

Permission was obtained from the Ethics Committee of the Faculty of Health Sciences at the University of the Free State to conduct this research.

All other relevant ethical procedures were followed by obtaining permission from the Free State Province Department of Education, the relevant authorities of the educational centres, and the participating parents/caregivers.

Avoidance of discomfort

Due to the sensitivity of the topic under investigation, emotional discomfort could have been endured by the parents or caregivers during the completion of the SPM Home Form and the feedback session. The researchers arranged with a qualified occupational therapist, trained in sensory integration, to be on call during all data collection sessions in case counselling was necessary.

Voluntary participation

Participation in the study was voluntary and participants were informed upon giving consent for participation that they could withdraw from the study at any time without being penalised in any manner.

Informed consent

The proceedings of the research were explained in detail to all participants by means of an information sheet. It was ensured that individuals agreed to participate and signed an informed consent form. All consent documents were made available in the three most predominantly spoken languages in Bloemfontein, namely English, Afrikaans and Sesotho to ensure that potential participants had a clear understanding of what participation in the study would require of them.

Misleading participation

The participants were provided with an information document prior to providing consent for participation in the study. This document included all information necessary for the participant, such as that compensation would not be provided for participation and that the study included assessment only and did not imply that treatment would be provided by the researchers or any other qualified occupational therapist. This information document indicated that information obtained from the study would be used for research purposes only. Consent was also obtained to publish the findings in a relevant journal and present the results on relevant research platforms.

Privacy, anonymity and confidentiality

To ensure confidentiality, each participant was allocated a participant number which was indicated on their demographics questionnaire, as well as a participant name and number form, and only this number was indicated on the SPM Home Form, which substituted the participant's name. The name and number form was handled by only one researcher to ensure confidentiality. The researchers had to be able to identify which questionnaire correlated with which participant, in order to provide accurate feedback to the parent or caregiver on completion of the study.

Since the research involved human beings and was required to be conducted in line with ethical guidelines, it was important that the researchers not only provided the parents or caregivers with information regarding the results of their particular child, but also to inform them on the results of the entire study. Scheduled feedback sessions were held, one at each individual institution, after the results were obtained. In instances where a child presented with sensory processing issues, it was in the participant's interest that the researchers informed the relevant educational facility's occupational therapist for further attention. This allowed for the issues to be addressed should the parents or caregivers have chosen to do so. A list of names and contact details of qualified occupational therapists practicing in Bloemfontein, was made available to parents or caregivers during the feedback session should they have wished to consult a private occupational therapist trained in Ayres Sensory Integration.

Compensation

Participation in this study was voluntary and the participants were informed before consenting to participation that they would only be provided with compensation for travelling costs to and from the relevant institution, in the case that the travelling was for the sole purpose of the research and not for another appointment/visit. Study participants were also informed that compensation would have a maximum cut-off point.

Table 2: Demographic information of participants (n=15)

Demographic variable	Participants (n=15)	
Gender	Male:	9 (60.0%)
	Female:	6 (40.0%)
Median age (range)	8.27 years (5–12 years)	
Home language	Sesotho:	6 (40.0%)
	Afrikaans:	6 (40.0%)
	Zulu:	1 (6.7%)
	English:	1 (6.7%)
	Setswana:	1 (6.7%)
Relation to the child	Parent:	14 (93.3%)
	Caregiver:	1 (6.7%)

Table 3: Results of the subscales of the SMP for children with Down syndrome 5–12 years of age (n=15)

Scales of SPM	Interpretive range			Total of vulnerabilities n (%)
	Typical n (%)	Some problems n (%)	Definite dysfunction n (%)	
Social participation	7 (46.7)	7 (46.7)	1 (6.7)	8 (53.3)
Vision	2 (13.3)	7 (46.7)	6 (40.0)	13 (86.7)
Hearing	1 (6.7)	6 (40.0)	8 (53.3)	14 (93.3)
Touch	1 (6.7)	14 (93.3)	0 (0)	14 (93.3)
Body awareness	2 (13.3)	11(73.3)	2 (13.3)	13 (86.7)
Balance and motion	5 (33.3)	8 (53.3)	2 (13.3)	10 (66.7)
Planning and ideas	3 (20.0)	10 (66.7)	2 (13.3)	12 (80.0)
TOT* scores	0 (0)	11 (73.3)	4 (25.7)	15 (100)
*TOT = total sensory systems				

RESULTS

Fifteen parents or caregivers who met the inclusion criteria participated by completing the SPM Home Form questionnaires, and all the questionnaires were eligible for analysis. *Table 2* summarises the demographic information of the participants.

Of the 15 study participants, 14 were parents and one was a caregiver. The children had a median age of slightly over eight years, with nine of them being male.

All children scoring in the 'some problems' and 'definite dysfunction' range were regarded as experiencing vulnerabilities[5], and although the results of the SPM Home Form of all participants are reported in *Table 3*, only those scores indicating vulnerabilities will be discussed.

Results regarding social participation indicated that seven (46.7%) of the children scored within the typical range, while eight (53.3%) presented with vulnerabilities regarding social participation.

It was found that 13 (86.7%) of the children experienced vulnerabilities with regard to vision, and 14 (93.3%) children presented with vulnerabilities related to hearing. Fourteen (93.3%) children also presented with vulnerabilities with regard to touch, while 13 (86.7%) children experienced vulnerabilities with regard to body awareness. Vulnerabilities with regard to balance and motion were observed in 10 (66.7%) of the children.

The praxis (planning and ideas) results indicated that three (20.2%) of the children scored within the typical range, while the remainder (n=12; 80.0%) experienced vulnerabilities pertaining to planning of motor action and the generation of ideas regarding body use.

DISCUSSION

Visual input is essential for the integration of various sensations and appropriate functioning at every level of the brain in order to 'see' meaning in the environment, especially on a two-dimensional level, for example, the pages of a book[15]. The study found that the majority of the children (n=13; 86.7%) experienced vulnerabilities with vision. One question in particular indicated that they enjoyed looking at movement, such as spinning objects, which could be interpreted according to the SPM Home Form as 'sensory seeking behaviour'. This seeking behaviour can at times appear inappropriate to those around them[5]. Although no other studies could be found on sensory processing of visual stimuli as such, the literature does indicate that children with Down syndrome experience difficulties with regard to vision, in terms of visual acuity, refractive errors, strabismus ("squint") and accommodation[19].

The auditory system contributes to the functions of hearing, speech and language[16]. The majority of the children in this study (n=14; 93.3%) presented with vulnerabilities in terms of hearing. Although it was reported that some sounds were disliked and could cause distress to individual children, the participants tended to repeatedly engaged in activities that produced certain sounds, such as flushing the toilet, indicating sensory seeking behaviour. These findings are supported by both Chen and Fang[2] who reported that an estimated two-thirds of children with Down syndrome present with hearing loss and Kumin (cited by Chen and Fang[2]) who found that children with Down syndrome experience difficulties in the processing of auditory stimuli.

Tactile input is processed at lower levels of the brain and also influences emotions due to adjustments taking place in the reticular arousal system[15]. Fourteen (93.3%) children experienced vulnerabilities with regard to touch, and preferred touching rather than to be touched. The only comparable study that could be found was conducted by Bruni et al.[1] on the sensory processing of children with Down syndrome aged 3–10 years, who found that children with Down syndrome responded either typically, enjoying sensory play, or with seeking behaviour in terms of tactile input by touching people and objects.

The functional purpose of the vestibular and proprioception systems is to develop effective posture, balance, gravitational security and muscle tone[15]. In previous studies where the SPM was used, muscle tone and flexibility were identified as common problems among children with Down syndrome, and therefore the results of the body awareness and balance and motion scale items should be interpreted with caution[5]. Taking this into consideration, we found that 10 (66.7%) children presented with vulnerabilities in the area of balance and motion. Contrastingly, Bruni et al.[1] reported that movement sensitivity was common in 64% of their study population, and over-sensitivity to movement was experienced by only 13% of children with Down syndrome.

Body awareness, otherwise known as proprioception[5], is a manner through which the muscles and joints receive sensory stimuli[12] to provide information regarding the position and movements of the body and limbs. Eleven (86.7%) of the children in our study experienced vulnerabilities in this area. Common behaviour that was identified, indicating vulnerability, was that the children tended to hold items/objects too tightly or too loosely, contrary to Bruni et al.[1] who found that only 39% of study participants held items too tightly or too loosely.

Praxis is necessary for executing new and novel activities and also for engaging in activities of daily living independently, such as eating, dressing and brushing teeth[6]. With regard to praxis, an area in which 12 (80.0%) of the children in our study showed vulnerabilities, these children found it challenging to build a replica of a model and coming up with new ideas (ideation). Our findings are in accordance with a study by Fidler et al.[6], who also found that children with Down syndrome generally experienced definite dysfunction within this area.

Lastly, social participation forms a part of everyday activities such as play and schooling, and is an important performance area for all children, including those with Down syndrome[15]. The results indicated that the children who participated in this study interacted appropriately with adults, easily joined others in play without causing disruption, and maintained eye contact. It was also reported that they participated acceptably during family outings and gatherings. Comparably, Sadock and Sadock[9] indicated that language had been identified as a relative weakness in children with Down syndrome, whereas social relations had been identified as a strength.

CONCLUSION

This study aimed at determining the sensory processing, praxis and related social participation of children with Down syndrome. Results of this study revealed that 100% of children with Down syndrome experienced vulnerabilities in sensory processing, 80.0% of the children with praxis and 53.3% with social participation.

This study is the first of its kind done on a South African population, and the results contribute to the emergent understanding of the sensory processing, praxis and related social participation of children with Down syndrome within the South Africa context. These results need to be taken into consideration by occupational therapists delivering services to children with Down syndrome to ensure optimal intervention. Further research on larger samples is recommended.

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