

Chapter 5

DISCUSSION

The objectives of this study were to develop and test an occupational performance outcome measure (OPQ) to be used by occupational therapists with children with ASD. The development of the items for the test and the validity and reliability studies were described in Chapter 3 and 4. This discussion will consider the reliability findings as well as those of the intervention study carried out to establish construct validity and responsiveness of the OPQ was to change in relation to two other tests measuring related constructs. Limitations in terms of the research design and further validity and reliability testing will be considered as recommendations.

5.1 Study Sample and Research Design

Nineteen subjects participated in this study. Their mean age was four years and six months at the start of the study and 21% were females and 79% were males. They were all diagnosed with an ASD by independent medical practitioners using DSM IV :TR criteria. All the children received an individualised programme of OT-SI for 40 minutes to an hour a week for a school year, from an occupational therapist trained in OT-SI who met the fidelity criteria stipulated in the “Sensory Integration Fidelity Measure” (Parham et al. 2007a).

Difficulty in recruiting sufficient subjects reduced the anticipated power of the study. However studies of individualised interventions on subjects with specific diagnoses do commonly have smaller samples. Petersen however indicates that such small sample research is important as it provides data that would otherwise not be available and lays the groundwork for useful future research (Petersen, 2008).

The longitudinal design of this study, over a year in a mobile population, resulted in higher than expected drop-out rates. This 20.8% loss to follow-up was mainly from subjects in Group 1, who were attending private OT-SI, where the parents bore the costs of their child’s treatment. From the results it was noted that the stress levels in Group 1 were higher at baseline, before the drop-outs occurred. The reasons they dropped out of the study were related to other extraneous factors such as financial and “Parental Distress” (PD) factors.

Since the sample was small, stringent inclusion and exclusion criteria were used to ensure rigour of the study (Petersen, 2008). In this longitudinal study, a diagnosis of ASD was essential before the commencement of OT-SI and parents were required to provide baseline data during the first month of OT-SI treatment. This requirement further limited the sample size as in many instances parents were reluctant to label their children as there is a stigma associated with a diagnosis of ASD. Parents frequently seek therapy before they have a definitive diagnosis.

Typically developing pre-school children in the age band three to six years (Case-Smith 2001; Stewart-Lord & Kotkin, 1998; Bayley, 1993; Solarsh et al. 1990) commonly achieve the milestones and developmental goals in the occupational performance areas of “Personal management”, “Social interaction”, “Play” and “Communication” as described in the OPQ. Therefore the expectation was that typically developing children in these age groups would achieve maximum scores on the milestone section and all items on the OPQ outcome measure. The demographic section of the OPQ showed that in this study the subjects had only achieved between 28.5% and 85.7% of the milestones in the occupational performance areas investigated. This result (Table 4.2.5 and Table 4.3.1), confirmed the findings of Jasmin et al. (2009) that children with ASD have significant deficits in daily living skills, compared with their typically developing peers. Occupational performance was therefore deficient in the entire sample, indicating the sample was homogeneous in this respect. For research rigour an important requirement is for a sample to be as homogeneous as possible (Petersen, 2008).

Another rigorous standard applied in this study was adherence to the “Sensory Integration Fidelity Measure” (Parham et al. 2007a), which limited the number of therapists eligible to recruit and treat subjects during the study period. In order to ensure that the intervention was carried out appropriately, therapists participating in the study were included only if they met the stringent fidelity criteria which stipulated therapist qualifications, the availability of equipment, environmental preparation, record review and peer review of therapist’s adherence to OT-SI intervention criteria (pg 53) (Appendix D).

The resultant small sample size resulting from the stringent inclusion criteria may influence the external validity, limiting the extent to which the results can be generalised.

5.2 Development and the Uni-Dimensionality and Consequential Validity of the Occupational Performance Questionnaire

The first two objectives of the study were to develop and establish the content validity and reliability of an occupation based questionnaire that measured the subjects' behaviour in the occupational performance areas of "Personal management", "Social interaction", "Communication" and "Play". A second section considered the impact of the child with ASD's occupational performance on the family.

Content validity and test retest reliability was established at ($r = 0.90$) (Table 3.3.4.2) achieved acceptable levels however some of the items did not reach the required level for internal consistency. Cronbach α was used to determine internal consistency of the OPQ fell below ($\alpha = 0.75$) (Table 3.3.4.3) for items in "Group interaction", "Communication" and "Play". Therefore the items in these three sections will need to be re-examined and changed to improve the internal validity of the OPQ. These items are further discussed under section 5.4 under response to change and sensitivity.

The subjects in the longitudinal study were identified as belonging to two separate groups, one of which received OT-SI from private practitioners and the other attending the school at CDC, receiving intervention from the researcher. There were some significantly different demographic variables between Group 1 and Group 2. Group 2 was based at a school where the only supplemental therapy they all received was speech therapy. They were also all diagnosed as having autism and the majority of them were on medication. There were also clear significant socio-economic and family differences. The school is funded and therefore largely provides a service to children from lower socio-economic backgrounds and parents are not required to pay for additional health services. Group 1 all had parents who were working and could afford private health care which presents an extra financial burden to these parents. This meant that it was more difficult for them to keep the child in therapy for a year.

At baseline the total raw score of all three outcome measures, demonstrated no significant difference between the two groups: OPQ ($p = 0.13$) (Table 4.2.3), SSP ($p = 0.25$) (Table 4.3.2) and the PSI-SF ($p = 0.69$) (Table 4.3.3). This indicates all three

measures are uni –dimensional and were not affected by the demographic or social differences between the groups. They measure constructs that are related to ASD.

The only significant difference between the two groups on the SSP ratings was a higher incidence of subjects who were “Under-responsive/seeking sensation” in Group 2 (Table 4.3.2). Thus it was accepted that the diagnostic differences between the two groups, the type of therapy and schooling did not significantly influence the scores of the subjects in terms of their sensory processing. The high incidence of sensory processing deficits in this sample with all z scores falling below (-1.7), concurs with the growing body of literature that report on the prevalence of sensory dysfunction in autism at 90% -100% frequency of sensory symptoms, in both low and high functioning ASD groups, in all the main modalities including multisensory processing (Leekam et al. 2007; Kern et al. 2007; Baranek et al. 2006, Liss et al. 2006). Consistent with research by Rogers et al. (2003); in this study, levels of sensory symptoms are unrelated to the child’s specific diagnosis (AS, PDD-NOS or AD) in children with autism. Since no significant differences were found between the groups for the PSI –SF either (Table 4.3.3), it was assumed in terms of this construct (as with sensory processing) that the two groups could be combined for analysis.

The stress levels of the parents who participated in this study was extremely high for both groups at the baseline assessment, with $z = +3.35$ (104) (Table 4.3.4). Any score over 90 is considered to be clinically significant and warranted referral for further investigation (Abidin, 1995). Other studies that have used the PSI-SF with caregivers of children with ASD, and made use of the Parent Stress Index and the PSI-SF respectively also reported excessively high levels of parenting stress in the parents of children diagnosed with ASD (Fisman et al. 2000; Wolf et al. 1989), with all three domains elevated. This is similar to the findings in this study where Parent Distress was reported at (85%), but Difficult Child (95%) and Difficult Interaction (95%) were found to be a more significant source of parenting stress. The lack of differences in parenting stress between the two groups also indicates the PSI-SF measures one construct i.e. stress levels of parents of children with disabilities and as in studies by Weiss (1991) and Dyson (1991), neither marital status nor socio-economic circumstances had a bearing on this. Personal factors related to parenting e.g. a sense of parenting competence, stress associated with restrictions placed on other life roles, conflict with the other parent, lack of social support and the presence of depression are also important .

The uni-dimensionality and consequential validity of the OPQ was considered to establish whether this instrument measured only the occupational performance of subjects with ASD and the impact this has on the family, without being affected by other variables. The two groups were compared on their baseline scores of the OPQ and although the total score indicated no significant differences; a number of differences between the groups was found when analysing the sub-constructs (Table 4.3.1). "Personal management", "Play" and "Family impact" items may have been influenced by differences between the groups. Although not significantly different, the positive/negative and intended/unintended consequences of some items on the OPQ must be considered in the light of differences in the sub-constructs.

Since the OPQ was designed to measure the construct of behaviour indicating age appropriate occupational performance without taking any social consequences such as culture or environment into account ; it must be considered that the significant difference found in the scores between the two groups suggests negative or unintended consequences in the instrument. Interestingly Group 2 had significantly lower scores for "Personal management" and "Family impact", but higher scores for "Communication".

The higher proportion of subjects with a diagnosis of autism in Group 2, may account for the lower "Personal Management" score at baseline. The severity of autism is a factor that has been shown to affect the outcomes of studies of sensory modulation symptoms in individuals with ASD (Ben-Sasson et al. 2007). Sensory modulation symptoms are associated with daily living skills (Jasmin et al. 2009). Therefore it is to be expected that Group 2 would have a lower mean "Personal Management" score at baseline, because a higher proportion of Group 2 had a diagnosis of an Autistic disorder.

A higher mean "Communication" score at baseline in Group 2 is puzzling considering the higher proportion of subjects with autism in Group 2. Perhaps higher "Communication" scores at baseline reflect a far greater access to speech therapy which was the only other therapy provided to this group of subjects.

Another factor affecting the scores obtained at baseline may be that the questionnaire was originally designed for parents of children from middle to high socio-economic strata, as the study was planned for children who were receiving OT-SI in private practices. However it was expanded to include subjects from the CDC. Demographic information regarding the parent's educational level was not collected, but Group 2 reflected a large proportion of families from a lower socio-economic group. Some of the items like "going to

restaurants” may need adjustment so that they are not sensitive to the significant socioeconomic, educational and marital differences found between the parents in the two groups (Table 4.2.4). The differences found need to be critically analysed and the OPQ needs to be reconfigured so that the effects other variables may have on the scores are excluded. Some sections need to be re-worked and a Rasch item analysis may be helpful to critically analyse each item.

Although a limitation with “Personal management”, “Play” and “Family impact” items on the OPQ exist, all three measures were considered valid in terms of measuring the constructs they were designed to measure and thus further analysis of the OPQ was also done to compare the relationship between them to establish the construct validity of the OPQ.

5.3 Construct Validity of the Occupational Performance Questionnaire

The third objective of the study was to assess the construct validity of the OPQ. The construct validity was determined by correlating the OPQ scores with scores using other instruments to determine whether the constructs measured by the OPQ were associated with sensory processing and parents’ stress or not. In order to establish whether behaviour in occupational performance measured by the OPQ was related to other constructs addressed by occupational therapists in the management of the child with ASD, the scores on the OPQ were correlated with scores from the SSP and PSI-SF. These distinct constructs that are assumed to be similar to the occupational performance measured will be convergent if they correlate with the OPQ scores or divergent if no correlation is found. This correlation allowed the convergence of these constructs to be examined.

Abnormal sensory reactivity has a strong relationship with overall adaptive behaviour in young children with ASD (Rogers et al. 2003). The cerebellum is one of the most consistent sites of neural abnormality in autism (Allen, 2006). Sensory sensitivities and motor difficulties affect virtually all aspects of adaptive functioning (Dawson & Watling, 2000), including the mastery of daily living skills (Jasmin et al. 2009). Although motor planning difficulties make dressing, grooming and bathing real challenges for pre-school

children with ASD (Jasmin et al. 2009) they were beyond the scope of this study and were not covered in the OPQ.

An additional correlation was measured to establish the relationship between parenting stress levels and sensory processing. A low negative correlation at baseline indicated that parents experience higher stress levels when the child's sensory processing was dysfunctional and the child's SSP score was lower (Table 4.4.1). However there was a fluctuation over the study period, which suggests that changes in the child's sensory processing did not have a clear association with parenting stress. Thus this aspect was not reviewed further in this study.

5.3.1 Sensory Processing and Occupational Performance Areas

The constructs of sensory processing and behaviour in occupational performance areas of "Personal management", "Social interaction", "Communication" and "Play" were compared, because pre-school children with ASD present with atypical sensory responses (Ben-Sasson et al. 2008, Rogers et al. 2003). This results in poor functional independence in occupational performance (Jasmin et al. 2009; Watling & Dietz, 2007). However no relationship between the two constructs was found at baseline (Table 4.4.1) indicating that they were not convergent. During the 12 month study period the correlation changed with constructs becoming positively correlated over the period that the subjects received OT-SI. By the end of six months there was a moderate correlation which was carried through to the end of 12 months indicating convergence between sensory processing and the occupational performance areas.

The lack of convergence between occupational performance and sensory processing seen at the beginning of the study needs to be compared with other studies because of the contradiction in other literature. The only two OT-SI outcome studies reported in the literature were both of short duration and were single-subject research designs that have limited generalisability (Case-Smith et al. 1999; Linderman & Stewart ,1999). No correlations between constructs were presented in either study and Case-Smith et al. (1999) reported no significant change in functional communication which is reflected by the result for "Communication" ($p=0.31$) this study (Table 4.5.1) indicating little overall effect of OT-SI treatment on this aspect of function within the time frame.

Improvements reported in both studies in the domains of social Interaction is reflected in the positive change in "Social Interaction: Individual" ($p=0.1$) (Table 4.5.1) found in this study. Improvements in engagement in "Social Interaction: Individual" could be compared with the minimal improvement in the frequency of interactions in pre-school "Play:Group" ($p=0.15$) reported by Case Smith et al. (1999). Gains similar to those found in this study for mastery of "Play" ($p=0.01$) (Table 4.5.1) under the approach to new activities were found by both authors.

In the single case study by Linderman & Stewart (1999) an improvement in response to hugging and holding, and response to movement concurred with a positive change in the modulation of "Tactile sensitivity" ($p=0.00$) and "Movement Sensitivity" ($p=0.06$) (Table 4.5.2) reported in this study. Thus supports the assumption that when children can modulate and regulate sensory information, they can more easily reach and maintain an optimum behavioural state to engage in social interaction in particular and participate in developmentally appropriate activities (Ayres, 1972).

Two studies which presented a correlation between occupational performance personal management, as measured by the WeeFIM, and the SSP with this population (Jasmin et al. 2009, Msall, DiGaudio, Rogers, LaForest, Catzano, & Campbell, 1994) found a low correlation between the constructs (0.31) similar to the findings of this study (0.26). No detail of the therapy received by the subjects in this study was provided although the group was selected from a clinic specifically aimed at children on the autistic spectrum. Thus the longitudinal results of this study cannot be compared to their study. No other longitudinal study could be found where occupational performance areas and sensory processing were compared so the trend towards convergence of these two constructs while subjects are receiving OT-SI has not been found in other research.

Thus, convergence of the sensory and occupational performance constructs, which are realistic in terms of OT-SI theory and supported by observations reported by parents and teachers lend substance to the validity of the OPQ. This change in convergence may be explained by adaptation that takes place when the child is receiving OT-SI. The relationship between adaptive behaviour and sensory symptoms reported Baker et al. (2007) and Rodgers et al. (2003) indicates that sensory responsivity has more influence on adaptive behaviour scores than the severity of the condition, mental age or IQ in young children with ASD. It seems in the current study, adaptive behaviour was influenced by a

change in sensory processing, bringing their occupational performance into line with their sensory profiles. This is a positive result in terms of OT-SI as it appears to play a role in achieving this. Further research will need to be done to determine the actual effects of the intervention.

The other reason for the change in convergence after a period of twelve months could be the involvement of the parents. Occupational Therapy–Sensory Integration is associated with a decrease in parents' stress which may be related to their understanding and management of difficult behaviour. In addition to being invited to observe therapy sessions, parents of the CDC group were invited to a support group organised by Autism South Africa, and two research group meetings, where topics like the ASD child's need for routine and clear boundaries and the general principles of OT-SI, were discussed. Occupational therapists played a vital role in helping parents to understand their own children through individual parent-therapist six-monthly consultations, followed by written progress reports. Seventeen parents reported that they felt empowered by having sensory strategies to use when their child's behaviour was difficult, e.g. a tantrum in a shop or a taxi; which enabled them to feel better about their efficacy as a parent.

All the sub-constructs in both the SSP and OPQ were correlated at baseline, six months and 12 months to establish if the pattern of emerging convergence was true for all aspects of both tests. The trend was true for "Personal management", "Social interaction" and "Play" but not for "Communication". A review of the changing correlations between specific sub-constructs for both the OPQ and SSP, that were statistically significant, is considered in relation to literature to see if the change can be supported by sensory integration theory.

5.3.1.1 Personal management

The overall correlation for Personal management compared to the SSP changed from negligible to moderate over the 12 month period with a moderate correlation found on both Toilet training and Sleep; and Visual/auditory sensitivity.

Visual and auditory sensitivity in pre-school children have been associated with maternal stress (Crepeau-Hobson, 2009) and sub-acute stress is reported to affect the modulation of the endocrine, nervous and immune systems resulting in temporary auditory

hypersensitivity in animal studies (Mazurek, Haupt, Tino, Szczepek, 2009). Sleeping disorders are linked with stress (Stein, Mendelsohn, Obermeyer, Amromin & Benca, 2001). Time taken to fall asleep and night waking is more frequent in studies on touch deprivation among typically developing pre-school children separated from their mothers (Field, Harding, Soliday, Lasko, Gonzales & Valdeon, 1994). Touch deprivation, associated with “Tactile sensitivity”, and avoidance of touch at baseline changed during the course of intervention in this study, and improvements in “Tactile sensitivity” was associated with “Sleep” in this group of subjects with ASD after 12 months of OT-SI (Table 4.4.4).

The fact that variability of “Low energy” also moved to a moderate correlation with “Sleep” (0.45) may relate to improvements in processing of proprioceptive stimuli. Increased engagement in physical activity improves sleep cycles because exercise affects metabolism and reduces arousal levels (Edelson, Edelson, Kerr & Grandin, 1999), thereby affecting sleep (Edelson, 2008). It is also possible that a child who is sensory avoidant and has low muscle tone, would not have enough daily physical activity. This could interfere with their circadian rhythms and sleep. Perhaps children process proprioceptive information better, with vigorous exercise / OT-SI intervention increasing their activity levels which would assist with regulation of arousal and sleep states.

Therefore, a reduction in night time waking associated with convergence between the sleep construct and related to decreased sensitivity on the SSP at 12 months; including Taste/smell sensitivity (0.51), Tactile sensitivity(0.42), and Movement sensitivity (0.41) (Table 4.4.4) were significant. A maturational deficit of the CNS, specifically a dysfunction of the brainstem mono-aminergic neurones, resulting in a disturbance of serotonergic and dopaminergic pathways, is thought to be responsible for the sleep disturbance in individuals with ASD. In normal development it is hypothesized that, during non-REM sleep unused neural connections are eliminated by a pruning process. Frequent night time waking implies a maturational deficit that is still present in autistic subjects in adulthood (Diomedi, Curatolo, Scalise, Placidi, Caretto & Gigli, 1999). The possibility of excessive neurogenesis and defective synaptic plasticity associated with inefficient pruning during the first year of life in children with autism, is hypothesised to result in brain overgrowth (Courchesne, Carper & Akshoomoff, 2003). Strongly connected sub-regions are not appropriately delimited and differentiated, and computationally meaningful long range connections fail to develop (Courchesne & Pierce, 2005). Both are associated with

the defective modulation of neural systems, including sleep, feeding, bonding and sensory processing, potentially leading to the defects in language, social behaviour and sensory processing seen in individuals with autism (Anderson, Hooker & Herbert, 2008).

Integrity of multisensory processing improves all other regulatory systems that include sleep-wake cycles. The concept of intersensory integration (Parham, 2002) is helpful in understanding the correlation between improved sleep and reduced sensitivity to incoming stimuli from all systems. It is possible that the arousal system contributes to deeper sleep and less night time waking. This provides a window of opportunity for early treatment and prevention for children under the age of one year, who are starting to present with the behavioural and social interaction symptoms that define the disorder.

Perhaps improved sleep, (due to less night time waking) in these subjects, could be linked with OT-SI.

A moderate correlation between "Taste and smell sensitivity" and "Feeding" (0.57) (Table 4.4.4) at 12 months reflected a convergence in these sub-constructs. Oral motor activities during OT-SI were important in improving tactile sensitivity in and around the mouth, and activating muscles in the oral structures for food manipulation and speech. A reduction in the need to smell food prior to deciding whether to eat it and a decrease in chewing clothes concurrent with an increase in chewing food was reported by parents and teachers.

A moderate negative correlation between "Toilet training" with "Tactile sensitivity" ($r = -0.46$) (Table 4.4.2) may be explained by half the subjects who had poor tactile registration. These subjects would be unaware that their nappy was full, and therefore unmotivated to pre-empt a bladder or bowel movement and display readiness for toilet training. Sixty four percent of the children were toilet trained during the day at baseline and 43% at night. On termination of the study and 76% were toilet trained in the day and 51% at night. The improvements in day time readiness is statistically significant ($p=0.01$), but the improvements at night do not reach significance ($p=0.37$). These results apply mostly to Group 1 where the most significant improvement was seen. It is hypothesised that as tactile and interoceptive awareness increased with increased readiness for toilet training in 12% of the subjects who were not displaying readiness at baseline (Table 4.2.5).

5.3.1.2 Social Interaction

“Social interaction: Individual” had the highest convergence with sensory processing throughout the 12 months of the study. A moderate positive correlation between “Social interaction” and “Visual-auditory sensitivity” was found at baseline and retained throughout the study (Table 4.4.2 - 4.4.4). This is in keeping with research done by Liss et al. (2006) where children with a low sensory threshold (sensitive, yet seeking of visual and auditory input) were over-reactive; demonstrated poor social imitation which affected play. They tended to have narrow interests on which they over-focused, pre-occupation with parts of objects was observed and perseveration was common. High fidelity visual memory and idiosyncratic language resulted from a tendency to over focus on visual and auditory stimuli.

At six months “Social interaction: Individual” (Table 4.4.3) was found to have a stronger association to “Visual-auditory filtering” and the “Unresponsive/sensory seeking” category. The association with the latter was even stronger at 12 months. “Social Interaction: Group” correlated moderately with the same sub-constructs at 12 months (Table 4.4.4).

The improvement in convergence of “Social interaction: Individual” and “Social interaction: Group” was possibly a reflection of a reduction in self-stimulatory behaviour as the subjects’ sensory needs were met. Linderman and Stewart (1999) found similar improvements in social interaction following OT-SI, with children being more affectionate following weekly OT-SI sessions.

No correlations with “Social Interaction: Peer interaction” after six and twelve months was recorded. This finding is similar to that of the study by Case-Smith and Bryan (1999), where individual social behaviours improved, but changes in peer interaction were not significant after 10 weeks of OT-SI for 30 minutes per week (Case-Smith, et al 1999). Peer interaction is the most complex relationship for any child, as peers are more unpredictable (Miller-Kuhaneck 2004). Peer relationships demand joint attention, turn taking and sustaining circles of verbal and / or non-verbal communication which are all very challenging long term goals for the child with ASD (Greenspan & Weider 1998). The items for the assessment of this aspect need further investigation in terms of what expectations children with ASD can achieve at this age, and may need to reflect smaller changes in behaviour.

The results for “Communication” showed fluctuating correlations with sub-constructs of “Low energy”, “Visual/auditory sensitivity” at six months and “Under-responsive / seeking sensation” at 12 months on the SSP. The moderate correlation of “Communication” to the “Under responsive” may have included a few subjects, who changed from using non-verbal to verbal means to communicate, with improved listening being cited by parents as a more frequent outcome. The subject’s receptive language gains, including responding to their name, increased understanding of verbal and non-verbal cues and in some cases, the emergence of vocalisation of sounds. The subject’s increased ability to communicate non-verbally, by pointing, or being able to express their needs, resulted in others outside of the family understanding the child.

It is clear from the fluctuating correlations for this section that it needs further investigation. Since social and communication skills are the greatest deficits in ASD, the items need to be re-analysed, especially for Communication. Rasch analysis to interrogate item scoring may be useful.

5.3.1.3 Play

At baseline the level of Play correlated moderately with “Taste/smell sensitivity”(r=0.40) (Table 4.4.2). Perhaps oral/olfactory sensitivity inhibited oral and manual exploration of unfamiliar media. The mouth is the centre of the infant’s world, and oral-motor learning is primary (Oetter et al. 1988). If children with ASD are avoidant in their oral/motor exploration of their environment, does this affect manual exploration and learning? Could this be associated with limited development of play? The associations of these sub-constructs are not clear.

“Play” correlated moderately with the SSP after 12 months and particularly in the case of children who were “Under-responsive / seeking sensation” (Table 4.4.4). Children with ASD typically engage in repetitive stereotypical and apparently aimless behaviour, considered maladaptive. These behaviours may be related to sensory seeking which may be reduced by OT-SI which helped to develop more occupationally relevant ways of achieving pleasurable proprioceptive sensations through appropriate activities.

In this study, some parents reported that instead of withdrawing in groups, their children were learning to play in parallel with their peers. Attempts to play with other children were

noted. At school, teacher's reported that subjects became noticeably more confident in the playground, enjoying swinging, climbing and riding scooters and tricycles. In one case a subject was able join in with the neighbourhood children in a soccer game in the street. A longitudinal study that is longer than a year would probably be necessary to observe more significant gains in Play.

5.3.2 Parent Stress and Impact of Occupational Performance on the Family

It has been recognised for some time that parenting a disabled child is very stressful (Fombonne et al. 2001) especially the influence of the behaviour of the child with ASD on the family. Therefore, the parent stress questionnaire (PSI-SF) was correlated with the "Family Impact" section of the OPQ to establish if there was any convergence between the subjects' occupational performance behaviour and parent stress. The overall and sub-construct scores were considered.

At baseline there was a moderate negative correlation between the PSI-SF and the OPQ (0.61) with the convergence of the "Family Impact" section of the OPQ having the highest convergence with "Parenting Distress" (PD). Low non-significant correlations were found in terms of "Difficult child" (DC) and "Parent-child dysfunctional interaction" (P-CDI). This indicates that the items on the "OPQ:Family Impact" were convergent with the parents' distress and did not relate to their interaction with their child. These items need to be reconsidered as the highest stress scores were for the P-CDI suggesting that the subjects' occupational performance improved which resulted in the child's behaviour changing the parent's perception of their child as difficult.

At 12 months the convergence with PD had become lower and the association between the "OPQ:Family Impact" and the DC showed convergence with a moderate correlation. The fluctuation in the convergence between the "Family Impact" section of the OPQ and the PSI-SF over the 12 months was another indication that the items need attention as they are not uni-dimensional.

5.4 RESPONSE TO CHANGE AND SENSITIVITY OF THE OCCUPATIONAL PERFORMANCE QUESTIONNAIRE

The researcher needed to determine whether the OPQ was able to measure change in the occupational performance of pre-school children with ASD over time. The ability of the tool to discriminate change in the subjects' occupational performance was established showing that the tool does respond to change in some occupational performance areas. Positive statistically significant change in occupational performance, on the total OPQ score over a 12-month period during which the subjects received OT-SI, was statistically significant after six months ($p < 0.05$) and highly significant after 12 months ($p < 0.001$) (Table 4.5.1).

To further test the responsivity of the OPQ to change, the difference in the scores for occupational performance over six and twelve months was correlated with the change in the SSP and the PSI-SF. Since significant positive change was found at 12 months on the SSP overall (Table 4.5.2) and significant negative change was found at both six months and 12 months on the PSI-SF overall (Table 4.5.3), it can be assumed that participating subjects had improved sensory processing and the parents experienced less stress, unrelated to maturation as parenting stress increases with age in children with ASD (Sabih & Sajid, 2008; Konstantareas et al. 1989).

The change in the OPQ scores correlated moderately with the changes in the SSP and PSI-SF scores indicating that the measure of change in occupational performance is similar to the change in sensory processing and parent stress. This was a positive finding which showed the OPQ measured response to change adequately in relation to other constructs. It can be seen from Figure 4.5.1 that the rate at which the OPQ measured the change was not as even as the standardised measures as greater change was measured in the second six months. This is another indication that both person and item responses need to be analysed and refined before the outcome measure can be used with confidence. When correlating the change in the sub-constructs (Table 4.5.4) only "Social Interaction" on the OPQ had a significant moderate correlation with the change in the SSP. This further reflects the problems with construct validity of the OPQ where all the sections other than "Social interaction" need attention.

When sub-constructs of the OPQ were considered, significant positive change was seen in the areas of “Personal management” ($p < 0.01$) and “Play” ($p < 0.01$). The OPQ was responsive to change in all areas but sensitivity to change in “Social Interaction” was not adequate in indicating significant change. Items in this section were more uni-dimensional and had better convergent validity with sensory processing indicating this section of the test has higher validity. This section of the OPQ has the greatest number of items which may account for this. However the ability of the items to measure small changes over time needs to be addressed if the sensitivity of this section is to be brought in line with the other sections.

The sensitivity of the sub-constructs of the OPQ was considered in terms of significant changes in the sub-constructs of the SSP and PSI-SF. In terms of sensory processing significant improvements in “Tactile sensitivity” ($p < 0.001$) “Taste and smell sensitivity” ($p < 0.01$), “Auditory filtering” ($p < 0.01$) and a decrease in “Visual/auditory sensitivity” ($p < 0.05$) were found. This was reflected in a reported reduction in the frequency of the maladaptive behaviours like rocking, hand flapping, mouthing which may be reflected in the initial significant change in “Social interaction: Individual” (Table 4.5.1).

The significant change seen in all the aspects of “Feeding” and “Sleeping” in “Personal Management” may relate to decreased “Taste and smell sensitivity” and “Tactile sensitivity” (Table 4.5.2). Toilet training did not improve significantly (Table 4.5.1) but half the subjects were already toilet trained at baseline. The OPQ was perhaps not sensitive enough to measure the subtle behavioural changes that underlie readiness for toilet training.

While there was a significant change for the sub-construct of “Level of Play” ($p < 0.05$), “Individual Play” and “Group Play” did not improve to a significant level (Table 4.5.1). As deficits in sensory processing interfere with the ability to interact with people and objects, it is logical that autistic children have difficulty playing (Bundy et al., 2007). This relates to the improvements in subjects who became less Under-responsive/sensation seeking and those whose “Visual/auditory sensitivity” decreased.

When the “Family impact” section of the OPQ was compared to the sub-constructs of the PSI-SF, all three sub-constructs showed a significant change over the 12 month period. There was a moderate correlation with change in the “Difficult Child”, “Parent-child

dysfunctional interaction” and “Parent distress” subscale- constructs. Therefore the sensitivity of the “Family impact” section of the OPQ to change is inversely associated with change measured by all the sub-constructs of PSI-SF. This was reflected in this study when some parents reported that improvements in their children’s behaviour paved the way for the beginnings of a process of socialisation with parents were more comfortable taking their ASD child to participate in family activities, visiting extended family and going to a wider variety of unfamiliar places.

In terms of response to change and sensitivity the OPQ proved adequate in measuring change over time (that was related to other constructs at an acceptable level of association). As with the uni- dimensionality, consequential validity and the construct validity, attention needs to be paid to various sections and particularly those items in the social interaction section in order to improve the sensitivity.

5.5 IMPLICATIONS AND RECOMMENDATIONS

Gathering cumulative information of relatively low frequency sensory behaviours across place and time is a challenge. The advantage of using parent questionnaires is to collect information from an observer who has great familiarity with the child compared with an observational study. However the use of parent questionnaires for studying sensory symptoms raises several questions. Dahlgren and Gillberg (1989) caution that parent responses to questionnaires can be powerfully influenced by the symptoms they know to be associated with their child’s diagnosis.

There are several concerns about the external validity of parent questionnaire studies of sensory functioning in autism. Miller, McKintosh, McGrath, Shyu, Lampe, Taylor, Tassone, Nietzel, Stackhouse & Haggerman (1999) addressed many of the questions concerning validity and psychometric qualities of the SSP. Miller et al. (2001) also found abnormal scores on the SSP converged with abnormal psycho-physiological responses to a series of sensory challenges in children who were developing typically, and those with ASD. Studies on the SSP have traditionally used small samples which may account for this.

Though parent report measures are the best standard measures available and are cost effective, clinically and empirically there is a need for the development of other types of measures, especially for sensory processing in children with ASD. When using parent report versus objective reporting by informed professionals; false positives are not uncommon. With education and exposure to therapists and therapy, the accuracy of their reporting increases (Reznick et al. 2007). In this study, parents were the only possible option to provide information relating to the child's occupational performance in natural environments. Rater bias is one of the limitations of this study, which could be addressed by having a parallel or convergent instrument completed by the child's occupational therapist.

During the research project it became apparent that some parents' understanding of the OPQ may have been a problem. In two cases where objective outsiders (teachers and therapists) reported progress, the change reported by parents in social interaction, communication, following instructions and participation in family activities did not reflect the same progress. Although the changes reported by one mother that her child is a completely different person, that family life is much easier, and although her child is shy he wants to play with others are measured, the understanding the mother developed about her child and the gift of enabling her child to achieve things the family never thought possible are in contrast to the objective data obtained on the OPQ. This is one of the limitations in the OPQ that became apparent.

To a great extent parents found the assessment forms relevant, but completion was time-consuming. Parents of children at the CDC attended six-monthly follow-up meetings, during which time assessment forms were filled in. In a few instances assistance from the therapist or their child's teacher was required. In the case of some parents who were unable to attend the meetings, forms had to be sent home with their child and in one case a teacher assisted the researcher by contacting a parent telephonically, in order to complete the forms.

In contrast, independent validation by qualified professionals of parent reports of sensory symptoms, found that parent reports correlated with clinical observations of sensory (Davis & Carter 2008) and repetitive behaviour symptoms (Rogers et al. 2003). Although this validates the use of parent report measures in this study, it appears that as parents

gained an understanding of the issues behind the behaviour, they were able to make a more accurate assessment of their child's sensory processing abilities. Therefore the scores at six months were perhaps more accurate than the parent reported baseline scores as seen by the change in convergence between the OPQ and SSP. The development of the convergence seen can be explained in terms of the influence OT-SI may have had on the various sensory modalities and thus the occupational performance behaviours monitored by the parents.

The study has confirmed that outcomes studies for children with ASD need to be longitudinal and measure change at six-monthly intervals, preferably over a period of longer than twelve months, for significant changes to be found. The high incidence of sensory processing problems, occupational performance problems and the high level of parental stress found at baseline indicate these are all concerns in terms of pre-school children with ASD. This is irrespective of their socio-economic, ethnic backgrounds, marital status, and the severity of the diagnosis.

After a year-long study, a statistically significant change in occupational performance was attained that correlated moderately to the change in sensory processing and parent stress. This indicated the sensitivity of the OPQ to assess change is adequate but the rate at which change is measured still needs attention.

Previous outcome measures were not sensitive enough to detect meaningful changes over a period of the specific treatment. In this study the OPQ was sensitive enough to detect change over a year period and in some sections even after six months. However the sensitivity of the OPQ for measuring changes in "Play: individual", "Play: group", "Social interaction: peer interaction", "Social interaction: group interaction" and "Toilet training" needs to be addressed. Further development of the psychometrics would be required to support using OPQ for its intended purpose of evaluating occupational therapy services for ASD children in relation to changes in occupational performance. Therefore further validation on a large normative sample would be necessary. The number of items in each subsection of the OPQ requires a better balance between the sections so their impact on the child's occupational performance as a whole would be reflected. A Rasch analysis on the "Level of Play", "Toilet training" and "Communication" sections would assist in making these sections more sensitive to change (Andrich, 1988). The mean change in the total OPQ indicates that the questionnaire is appropriate to the population

and may be useful for occupational therapy clinicians to use as a tool to measure change in the pre-school child with ASD's independence in everyday activities.

The use of the longer Sensory Profile Caregiver Questionnaire would enable researchers to group the subjects according to their neurological thresholds and behavioural responses, in accordance with Dunn's four quadrants, which would enable researcher to determine which groups of children with ASD respond best to specific interventions.

Qualitative research may help elucidate the problems experienced by different groups of caregivers and the particular needs of mothers, fathers and grandparents.

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