

Chapter 6

CONCLUSION

The paediatric occupational therapist provides therapeutic interventions aimed at improving a child's occupational performance (e.g. play, self-care and school functional skills). Occupational therapy services for pre-school children with ASD predominantly include sensory and motor treatments within the context of a more holistic intervention plan, which emphasises family centred occupational goals. An occupational performance questionnaire (OPQ) to be used as an outcome measure for all areas of occupational performance was developed, but before the outcome measure could be used to evaluate the effectiveness of occupational therapy it had to be tested for validity and reliability in this study.

This study therefore represented the first phase of test or instrument development which included the following steps.

- Defining the test
- Preparing and formatting items
- Item checks – content validity
- Reliability determination
- Obtaining data – intervention study
- Validity checks – construct and consequential validity, response to change and sensitivity
- Dissemination of results (Kielhofner, 2006)

The need for the test and the construct of occupational performance to be assessed was defined. It was established that no other suitable test was available. A number of sub-constructs including "Personal management", "Social interaction", "Communication", "Play" and the "Family Impact" of the occupational performance behaviour of a child with ASD were identified. Preparation of the items was based on a literature review and item checks occurred over a number of processes to determine whether they represented the construct and sub- constructs to be measured. Various pilot studies were done to submit the items to interrogation by expert occupational therapists as well as parents who were

to fill in the outcome measure. Items were checked for ambiguity and the format, number of items and scoring was finalised. This completed the content validity stage and the reliability of the OPQ was then established. The test-retest reliability was found to be high but internal consistency was identified as a problem using Cronbach α for “Social interaction: Group” and all sub-constructs of “Play”. The items in these sections need to be checked for difficulty and serial dependency using Rasch analysis.

Once the test content validity and test-retest reliability had been established an intervention study to investigate construct validity was carried out.

A relatively small sample of 19 subjects was used for the intervention study which involved using the OPQ three times over a 12 month period while the subjects received OT-SI. Rigour was applied in the methodology of this study to accommodate the small sample. It was a prospective longitudinal study, with a pre-post test design, multiple baseline measures and well-defined cohorts. Strict inclusion and exclusion criteria and documentation of the reasons for loss to follow-up were included.

The subjects were their own controls. A no-treatment control group was not considered due to the ethics around withholding treatment to a vulnerable group at a critical stage of their development. The OPQ was filled in by parents, who were considered as objective evaluators of the treatment effect. However the subjective nature of parental report data may be construed as a methodological limitation. Parents were the pre- and post-treatment evaluators who knew their children intimately, so subjectivity could have made the validity of findings questionable. However although neither objective nor blinded to the expected outcomes, change in the child’s ability to function in their occupational roles within the family can really only be truly assessed by their parents.

Initially two groups were identified, that had significant differences in terms of various demographic and medical factors as well as external factors like access to therapy and schooling. However the subjects in these groups were homogeneous in terms of milestone delay.

To evaluate construct validity the scores on the OPQ were compared to the scores on two other outcome measures:

- A. One that measures an internal performance component of the subjects – sensory processing, measured on the SSP and

- B. one that measures a component external to the children with ASD – parent stress, measured on the PSI-SF.

Both these constructs had been shown in previous research to be associated with occupational performance behaviour, in children with ASD. The data for these two measures was collected at the same time as the data for the OPQ.

The uni-dimensionality of the OPQ in measuring occupational performance and its consequential validity to investigate whether it was measuring other factors and constructs was established by comparing the scores of the two subject groups. This was essential in preventing interference from other demographic and social factors. Overall the OPQ was adequate in this aspect but some sub-constructs showed significant differences indicating they may be influenced by factors identified as different between the groups. The sections that need attention in terms of this are “Personal management”, “Play” and “Family impact”.

Convergent validity for the occupational performance areas was established by correlating the scores on the OPQ sections covering “Personal management”, “Social interaction”, “Communication” and “Play” with scores on the SSP. A low correlation consistent with the literature (Jasmin et al. 2009) was found for the constructs overall at baseline. The correlation strengthened over the 12 month period to a moderate association while the subjects were receiving OT-SI. Reasons for this can only be deduced from further research but both the input from the therapy and the involvement of the parents in the therapy may have had an effect. It appears that as subjects gained control in terms of sensory modulation, and parents understood the role of sensory processing in their child’s occupational performance, the constructs of sensory processing and behaviour in occupational performance were better aligned.

When sub-constructs on the two outcome measures were correlated the same trend was evident with all occupational performance areas, except “Communication” moving from negligible correlation to a moderate correlation by the end of the study period.

“Social interaction” had the strongest convergence validity to of all the sub-constructs on the OPQ when correlate to the overall SSP but the convergence was not consistent with sub-constructs on the SSP. Further investigation of the possible association between all the sub-constructs will have to be researched further and the item construction of the OPQ still needs to be reassessed in terms of convergence.

The scores of the “Family impact” section of the OPQ were compared with the scores on the PSI-SF. Acceptable, moderate convergence was found between the two outcome measures indicating this section of the OPQ has construct validity. Sub-construct analysis of the “Family Impact” on the OPQ and the various sections of the PSI-SF showed some variation over the 12 month study period especially for parent-child interaction. A strengthening of the inverse association to the sub-construct of difficult child was seen for the OPQ family impact at 12 months.

Although all the correlations reported as moderate were statistically significant it is possible that measurement error due to the small sample may account for some of the fluctuations seen between the sub-constructs of the OPQ and the other two outcome measures.

The last of the psychometric properties of the OPQ to be considered was response to change in occupational performance over time and sensitivity. Differences in scores collected at six monthly intervals for 12 months on all three outcome measures were compared to establish the response to change. Significant improvement was found overall on all three measures with a statistically significant improvement occurring in the first and second six months in the OPQ and PSI-SF. The SSP only showed statistically significant improvement in the last six months. The response to change in the OPQ overall was therefore similar to the other two measures, and it can be accepted that this aspect of the measure is valid. The rate of the OPQ response to change was not as equitable over the 12 months as that for the other measures, however, with greater change being seen in the last six months for occupational performance.

When the sub-constructs of the OPQ were considered; “Social interaction”, “Communication” and “Family Impact” were the aspects of occupational performance areas that did not record a significant change over the 12 month period. “Family Impact” has already been identified under internal consistency and consequential validity as having items that are problematic.

“Social Interaction” does have convergent validity so this section will need to be reassessed for person fit in terms of Rasch analysis. “Communication” presents with convergent validity and response to change problems and needs to be totally reassessed.

The sensitivity of the OPQ to change was established by correlating the changes in the scores collected on the OPQ to those from the SSP and the PSI-SF at six monthly

intervals for 12 months. A moderate positive association to the SSP and moderate negative association to the PSI-SF were found in all analyses indicating the OPQ is sensitive to improvement as it was assessed by the other outcome measures. None of the child subjects with ASD in the study showed deterioration in any measure.

Only the sub-constructs of “Social Interaction” had moderate associations to the overall SSP, with “Family Impact” having moderate association to the PSI-SF. Thus the sub-constructs that were not as responsive to change over time indicted association with change measured in terms of sensory processing and parent stress. They are therefore more sensitive to change in other constructs than sections that were responsive to change like “Personal Management” and “Play”.

This indicates that these aspects will have to be addressed before this outcome measure can be used in further research to assess the effectiveness of therapy.

This will involve intensive retesting of all the items once they have been analyzed in detail to establish which ones are affecting the validity of the test. The test will also need to be used with a larger sample if it is to be generalized to the ASD population

6.1 Generalised findings to phenomena not directly related to present research

The development of this outcome measure is important in view of the situation in South Africa. In developed countries the incidence of ASD is now in the region of 1:150 (Rutter, 2005). In South Africa, we have no idea of the magnitude of the problem we are facing. What we do know is that the incidence of ASD is increasing across all socio-economic strata (Jacklin, 2006).

In the last two decades, research and programme development in the area of educational intervention has focussed on very young children with ASD. Developments in research have resulted in earlier identification of children at-risk for developing ASD. Early intervention capitalises on neuroplasticity, which is optimal in the first 5 years of life (Eliot, 1999). Multidisciplinary early intensive intervention, results in substantially better outcomes for the individual’s integration into the society (Myers & Johnson 2007). Providing therapy that deals with lifestyle change and occupational performance issues early in life changes the developmental trajectory of individuals with ASD. This approach

is more cost effective than funding intervention, welfare support or incarceration of people with disturbed or disrupted lives later (Parham, 2002).

Early intervention and educational services for children with ASD in South Africa are inadequate to meet the growing need. Occupational therapy has multiple opportunities to contribute to improved individual and community health of children with ASD through areas of practice in preventive therapy. Occupational therapy practitioners also have expertise in addressing person and environmental barriers to performance and in the adaptation of occupations and environments that have a positive impact on physical, emotional and social health and may provide valuable services to community planning agencies (Bass-Haugen , 2009).

A multidisciplinary model for early intervention for young children with ASD needs to be developed, that can be replicated in all communities in South Africa. Sensory Integration is recognised as one of the key elements Occupational therapy provides for young children with ASD. It has the capacity to provide answers to the questions of best practice, not merely cost effectiveness or ease of implementation, and has the capacity to change the developmental trajectory of these children (Bass-Haugen , 2009).

A reliable and valid occupational performance outcomes measure will enable occupational therapists to justify their therapy and show the differences they can make to the lives of children with ASD. It is hoped that this research has started occupational therapy in South Africa on the path to addressing some of these needs.

6.2 Recommendations for future studies

Longitudinal outcomes studies of occupational performance in children with ASD need to be of at least one year's duration and include a follow-up to ascertain whether children are able to sustain the modified developmental trajectory.

Multidisciplinary longitudinal studies are also required as it is virtually impossible to separate the effects of the various interventions.

The OPQ needs to be validated further in terms of the sub-constructs and then to be standardised for a large population of typically developing children, and children with ASD who do and do not receive OT-SI as part of their intervention.

“The true revelation of a society’s soul is the way in which it treats its children”

Nelson Mandela

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