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Development of a questionnaire to determine change in the occupational performance of pre-school children with autistic spectrum disorders receiving occupational therapy - sensory integration

Wallace, Kerry Anne

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Development of a questionnaire to determine change in the occupational performance of pre-school children with Autistic Spectrum Disorders receiving Occupational Therapy - Sensory Integration

WitsETD

Kerry Anne Wallace

A dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, for the degree Master of Science

Johannesburg 2009

DECLARATION

I, Kerry Anne Wallace, declare that this is my own unaided work except for the help given by those listed in the acknowledgements.

Signed on this day in Cape Town

Signature

Date

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PRESENTATIONS IN SUPPORT OF THIS DISSERTATION

Faculty of Health Sciences Research day, University of the Witwatersrand August 2006

A longitudinal study investigating the change in occupational performance of pre-school children with Autistic spectrum disorders receiving Occupational Therapy – Sensory Integration: K.A. Wallace

South Africa SAACAPAP Congress, Cape Town, September 2007

Poster Presentation: A longitudinal study investigating the change in occupational performance of pre-school children with Autistic Spectrum Disorders receiving Occupational Therapy –Sensory Integration: K.A. Wallace

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PLEASE LISTEN TO MY HEART

Please listen to my heart
Please forgive these clumsy words
Just hear me from my open heart to yours
The language of my heart speaks eloquently
While my fingers grapple for the letters one at a time
My mouth has nothing to say.

- Please Listen to My Heart, Roy Bedward

"Please Listen to My Heart" triggers different responses from its readers as the lyrical words are both powerful and poignant. Yet many readers are further moved to learn that the author, Roy Bedward, age 29, from Madison, WI is an individual with autism that is non-verbal and uses facilitated communication to write.

ABSTRACT

As there are no occupation based outcome measures evaluating the effect of occupational therapy in the pre-school child with an Autism Spectrum Disorder (ASD) an Occupational Performance Questionnaire (OPQ) was developed to address this.

The OPQ was tested for content validity and reliability before a 12 month intervention study to establish construct validity and response to change in children with ASD receiving Occupational Therapy using a Sensory Integration frame of reference (OT-SI) was done.

The results of 19 subjects on the OPQ were compared with the results on two other standardised measures -the Short Sensory Profile (SSP), and Parenting Stress Index (PSI-SF) at six monthly intervals.

Convergent validity between family impact on the OPQ and the PSI-SF was moderate but for occupation performance on the OPQ and the SSP it changed from negligible to moderate over 12 months. The OPQ is responsive to change as correlations between improvements in the three outcome measures were moderate. The OPQ was found to still need attention in terms of item reliability and validity.

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ABBREVIATIONS USED

ABA	Applied Behaviour Analysis
AD	Autistic Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
AGM	Annual General Meeting
AS	Asperger Syndrome
ASD	Autistic Spectrum Disorder
CA	Chronological age
CDC	Children's Disability Centre
CMI	Children's Memorial Institute for Childhood and Family Development
CNS	Central Nervous System
COPM	Canadian Occupational Performance Measure
DC	Difficult Child subscale
DISCO	Diagnostic Interview for Social and Communication Disorders
DSM IV :TR	Diagnostic and Statistical Manual of Psychiatric Disorders – Fourth Edition Text Revision
EDR	Electrodermal Reactivity
EEG	Electro-encephalograph
FIM	Functional Independence Measure
FXS	Fragile X Syndrome
HFA	High Functioning Autism
HRQL	Health-Related Quality of Life
IQ	Intelligence quotient
NDT	Neurodevelopmental Therapy
OCD	Obsessive Compulsive Disorder
OPM	Australian Occupational Performance Measure
OPQ	Occupational Performance Questionnaire
OPQ:FI	Occupational Performance Questionnaire – Family Impact
OPQ:SI	Occupational Performance Questionnaire – Social Interaction
OT	Occupational Therapy
OT-SI	Occupational Therapy using a Sensory Integration frame of reference
MA	Mental Age
MAP	Miller Assessment for Pre-schoolers
M-COPM	Modified Canadian Occupational Performance Measure
MR	Mental Retardation

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OPQ	Occupational Performance Questionnaire
PD	Parental Distress
P-CDI	Parent-Child Dysfunctional Interaction
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder- Not otherwise specified
PEDI	Pediatric Evaluation of Disability Inventory
PSI-SF	Parenting Stress Index – Short Form
RR	Retest Reliability
SAISI	South African Institute for Sensory Integration
SI	Sensory Integration
SIPT	Sensory Integration and Praxis test
SMD	Sensory Modulation disorder
SPD	Sensory Processing Disorder
SPM	Sensory Processing Measure
SSP	Short Sensory Profile
TSI	DeGangi-Berk Test of Sensory Integration
VABS-2	Vineland Adaptive Behavior Scales – second edition

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OPERATIONAL DEFINITION OF TERMS

Pre-School Child

Children who have received occupational therapy intervention before the age of seven years, who have been diagnosed during the period two to seven years as having an autism spectrum disorder by a specialist medical practitioner.

Autistic Spectrum Disorders (Pervasive Developmental Disorders)

Autism is considered to be a spectrum of neurobiological disorders also known as the Pervasive Developmental Disorder group (PDD). The spectrum encompasses the diagnoses of Autism, Pervasive Developmental Disorder - not otherwise specified (PDD-NOS), Asperger syndrome; the less commonly seen Rhett syndrome, and Childhood Disintegration Disorders (American Psychiatric Association, 2001).

Autistic Disorder

A. (1) Qualitative impairment in social interaction,

(2) Qualitative impairments in communication,

(3) Restricted repetitive, stereotyped patterns of behaviour, interests and activities, (American Psychiatric Association, 2000)

(4) Delays in functioning in at least one of the following (social interaction, social communication with language, symbolic or imaginative play) (American Occupational Therapy Association, 2008).

B. Restricted or abnormal functioning in social interaction, language as used in social communication or symbolic or imaginative play with onset prior to three years of age (American Psychiatric Association, 2001).

C. The Multisystem Developmental Disorder diagnosis (MSDD) (Emde, Egger, Guedeney, Emmons, Wise & Wolkowitz, 2005) includes the following additional diagnostic criteria in the evaluation of infants and toddlers less than two years old:

(1) Significant dysfunction in the processing of visual, auditory, tactile proprioceptive and vestibular sensations, including hyper-reactivity and hypo-reactivity to sensory input.

(2) Significant dysfunction in motor planning (sequencing movements) (Emde et al. 2005).

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Occupational Performance

"The act of doing and accomplishing a selected activity or occupation; resulting from the dynamic transaction between the client, the context, and the activity" (p 83) (Law, Baptiste, McColl, Polatajko & Pollack,1990). Improving or enabling skills and patterns in occupational performance leads to engagement in occupations or activities. For the pre-school child this includes: the assessment of personal management, (toileting, sleeping, eating); social ability; constructive use of free time, which for this age group is play; and work ability, which would be participation in age-appropriate schooling (Crouch & Alers, 2005).

Play

"Any spontaneous or organized activity that provides enjoyment, entertainment, amusement, or diversion" (p 252) (Parham & Fazio, 1997). Play is a childhood occupation crucial for adaptation, well being and participation in society and is thus of primary concern to practitioners working with young children with developmental disabilities such as autism.

Occupational therapy

The practice of occupational therapy means the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, workplace, community, and other settings. Occupational therapy services are provided for the purpose of promoting health and wellness and to those who have or are at risk for developing an illness, injury, disease, disorder, condition, impairment, disability, activity limitation, or participation restriction. Occupational therapy addresses the physical, cognitive, psychosocial, sensory, and other aspects of performance in a variety of contexts to support engagement in everyday life activities that affect health, well-being, and quality of life (Smith-Roley, 2008; American Occupational Therapy Association, 2004).

Sensory Integration

Sensory integration is "the organization of sensation for use" (p 5) (Ayres, 2004). It is a complex set of processes in the central nervous system including modulation, perceptual and practice functions. Sensory Integration refers to a clinical frame of reference for the assessment and treatment of persons who have functional disorders in sensory processing. It originated in the work of Dr. A.J. Ayres whose clinical insights and original

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research revolutionized occupational therapy practice with children (Parham & Mailloux, 1996).

Parenting Stress

Parenting a child with a chronic disability is often highly stressful. Stress is attributed to intrinsic parental issues, the extra physical and emotional demands placed on parents due to a difficult child and parent-child relationship issues (Abidin, 1995).

Quality of life

A clients' dynamic appraisal of life satisfactions (their perceptions of progress toward identified goals), self-concept (the composite of beliefs and feelings about themselves), health and functioning (including health status, self-care capabilities), and socioeconomic factors (e.g., vocation, education, income) determine quality of life (Smith-Roley, 2008; Radomski, 1995; Zhan, 1992). It is the role of occupational therapists to ensure that the larger population of at-risk children and infants, who survive in the 21st Century, will have the satisfaction of a life worth living. This implies meaning "in the stream of life" of rest, self-care, play/work and leisure. The skills required for success in the work place are founded in the nursery school and on the playground of childhood, in the social as well as the physical interactions (Yerxa, Clark, Jackson, Pierce & Zemke, 1989).

Outcomes

The outcomes are what occupational therapy actually achieves for the consumers of its services (Fuhrer, 1987). This implies the change desired by the client; and can focus on any aspect of the client's occupational performance (Kramer, McGonigel & Kaufman, 1991). Selecting types of outcomes and measures, includes but is not limited to occupational performance, adaptation, participation, prevention of occupational deprivation, parent's health and wellness, prevention of parental occupational imbalance and alienation, and preservation of quality of life (Smith-Roley, 2008).

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