

*How do children's challenges to function
and participation impact maternal stress?
A survey of mothers of children with
suspected developmental co-ordination
disorder*

Article

Accepted Version

Allen, S. and Knott, F. ORCID: <https://orcid.org/0000-0002-5334-7206> (2016) How do children's challenges to function and participation impact maternal stress? A survey of mothers of children with suspected developmental co-ordination disorder. New Zealand Journal of Occupational Therapy, 63 (2). pp. 29-37. ISSN 1171-0462 Available at <https://centaur.reading.ac.uk/69294/>

It is advisable to refer to the publisher's version if you intend to cite from the work. See [Guidance on citing](#).

Publisher: Occupational Therapy New Zealand-Whakaora Ngangahau Aotearoa

All outputs in CentAUR are protected by Intellectual Property Rights law, including copyright law. Copyright and IPR is retained by the creators or other

copyright holders. Terms and conditions for use of this material are defined in the [End User Agreement](#).

www.reading.ac.uk/centaur

CentAUR

Central Archive at the University of Reading

Reading's research outputs online

How do children's challenges to function and participation impact maternal stress?

A survey of mothers of children with suspected Developmental Co-ordination Disorder

Susan Allen, MSc, BSc(Hons), SROT.

Fiona Knott, PhD, DCLinPsy, BSc,

Corresponding author:

Susan Allen

Email: sueallenot@gmail.com

Abstract

Mothers of children with suspected developmental coordination disorder qualitatively report high levels of parenting stress. The parent-child relationship impacts on opportunities for participation available to the child and family. This study used standardised measures to quantify maternal stress and to examine factors that may be associated with parenting stress (social support and coping child diagnosis, motor skills and sensory processing). Maternal stress was high but not associated with child motor impairment. Instead, stress was correlated with child sensory processing problems, maternal social support and coping. Mothers are at risk and concerns about the child should be considered in the context of family need.

Key words

Autistic disorder, mothers, motor skills disorder, stress

Occupational therapists consider environmental factors in their holistic assessment of children with developmental motor concerns and their families. This usually includes environmental factors that impact the child's ability to participate in everyday activities (College of Occupational Therapists 2008). Such factors encompass the physical characteristics of the environment as well as relationships with significant caregivers. The International Classification of Function, Disability, & Health, Children and Young

People (World Health Organization, 2007) identified physical and emotional support along with the attitudes of immediate family as key factors in a child's environment. A lack of physical or emotional support or negative attitude may act as a barrier, whereas positive physical and emotional support and/or a positive attitude can facilitate the child's ability to maximise participation in daily activities. Child and family focused therapy services would consider the capacity of the mother to support the child to participate. Conversely, maternal stress would be a barrier to emotional support and positive attitude. An understanding of the mechanisms influencing maternal stress may help to optimise the environmental context of the child.

Developmental coordination disorder (DCD) is a condition marked by significant impairment in the development of motor coordination, which interferes with academic achievement and/or activities of daily living (American Psychiatric Association, 2013). The disorder affects 1.8 % of children living in the United Kingdom (UK), with an additional 3.1 % 'at risk' (Lingam, Hunt, Golding, Jongmans, & Edmond, 2009). It is well known that DCD leads to a poor social, psychological and motor outcome (Blank, Smits-Engelsman, Polatajko, & Wilson, 2012). DCD is also linked to both physical and social limits on participation (Engel-Yeger cited in Cairney, 2015) and children with this condition present significant challenges to education and health services (Cermak & Larkin, 2002). However, the impact of DCD on the family is under-researched. Parenting a child with neurodevelopmental disorder is known to be challenging and may result in ineffective parenting with fewer positive interactions and repeated attempts to discipline the child for the same behaviour, leading to feelings of frustration and low self-efficacy (Garner et al., 2011). Understanding more about stress levels and the factors that impact on mothers will assist the development of effective family support strategies and may improve the long-term participation and occupational choices of children and their families. Qualitative reports have identified that DCD has an overwhelming impact on family life and that families are required to support children and adolescents for longer, and more intensively, than is usual for typically developing children (Novak, Lingam, Coad & Emond, 2012). These previous reports concurred with clinical observation that mothers whose children were referred for motor and functional concerns exhibited distress.

Parents are crucial to the success of interventions for other developmental disorders (Schopler, 2005). In DCD, parent involvement in treatment is associated with greater improvement in the child's motor skills and there is also greater parental satisfaction with the child's functioning post-treatment (Blank, Smits-Engelsman, Polatajko & Wilson 2012). Pless and Carlsson (2000) identified home programme's of intensity 3 to 5 times per week as a feature of more effective intervention. However, parent involvement in therapy does not always have a positive impact on the parents themselves (Jansen, Ketelaar, & Vermeer, 2001) and parents who are already stressed may be unable to work effectively in such programme's (Osborne, McHugh, Saunders & Reed, 2008). This study therefore aims to quantify levels of maternal stress and to explore both the child and maternal factors that may be associated with parenting stress in order to guide family focused occupational therapy interventions.

Literature review

While parenting typically developing children can be challenging, the additional strain associated with parenting a child with disability has been demonstrated repeatedly (Hayes & Watson, 2013). Parents of children with disabilities are known to have higher stress levels than parents of typically developing children. Parents of children with Autism have the most elevated levels of parental stress (Estes et al., 2009). Similarly, increased stress has been found in parents of children with a range of disabilities. For instance, intellectual disability (Hastings & Beck, 2004), and physical disability (Cherry, 2004). Parenting stress may contribute to the poorer mental health reported by parents of children with disabilities such as, depression (Singer & Floyd, 2006). As well as the impact on parents themselves, stress negatively affects parental ability to carry out interventions with their children (Osborne et al, 2008). Equally, children of mothers who are depressed and anxious demonstrate increased cortisol levels (Azak, Murison, Wentzel-Larsen, Smith & Gunnar, 2013), thus demonstrating a negative physiological impact on the child's stress response. With regard to DCD, although parental stress has not been quantified, Stephenson and Chesson (2008) and Novak et al. (2012) argued in their qualitative studies,

that additional demands are placed on mothers in particular. Mothers strongly described feeling the need to fight the system. Reports of a frustrating struggle to be taken seriously and obtain a diagnosis are common. Stephenson and Chesson (2008) advocated for increased attention to the impact of DCD on the family. They suggested that family resources were a key factor in remediation. Furthermore, they questioned how professional support could improve outcomes for families. However, Novak et al. (2012) identified professional support as important and suggested that professionals need to be better at advocating and facilitating early recognition and access to intervention. The theme of maternal stress driven by the child's needs, and challenges in accessing support, is prevalent in both of the above studies but has not been formally measured.

Child and maternal factors associated with parenting stress

Understanding the factors that contribute to maternal stress is important and will help shape the provision of appropriate services. One cluster of factors relate to characteristics of the children themselves. This population is primarily defined by motor impairment therefore the data on motor impairment will be explored. However, in previous studies factors such as challenging behavior were thought to be more strongly related to stress than ASD symptoms (Lecavalier, Leone & Wiltz, 2006). Sensory processing is known to be a factor that limits family participation in work, family and leisure activities in families of children who have autism (Schaaf, Tooth-Cohen, Johnson, Outten & Benevides 2011). This paper advocates reducing stress to increase life satisfaction for children and their families. Therefore it is appropriate to consider sensory processing in this population.

The second cluster of factors relate to maternal stress, social support and coping variables. It has been consistently found that parents who report higher satisfaction with social support generally have lower stress levels. For instance, Ekas, Lickenbrock and Whitman (2010) argued that social support was both directly and indirectly associated with maternal stress in ASD. Similarly, maternal coping has been shown to be related to maternal wellbeing in a variety of other conditions. For example, cerebral palsy (Guilamon et al., 2013). 'Coping' refers to the actions taken to deal with stress, which them-

selves stem from the way a problem situation is appraised. Parents of children with disabilities have been shown to use a larger number of coping strategies overall than parents of children with no disability. Strategies include problem-focused solutions such as seeking social support, planning, and emotion-focused problem solving (Paster, Brandwein, & Walsh, 2009) even though the latter is associated with increased rates of depression and isolation. Similarly, Lai and Oei's (2014) comprehensive review of coping, showed that the most effective strategies used by parents of children with ASD are social support and problem focused coping such as, planning and seeking instrumental support. We therefore examined both the role of social support and coping strategies in mothers of children with DCD.

Method

A cross sectional descriptive design was used to explore levels of maternal stress and its possible correlates. Suitable measurement tools were identified by reviewing literature and clinical utility. Participants were recruited through referrals to occupational therapy DCD pathway over a 24 month period. Ethical approval was granted by the National Research Ethics Committee (08/H050/37) and the University Research Ethics Committee. Data was collated and anonymized by clinical staff. Confidentiality was maintained at all times.

Acceptance for referral required a report of functional impairment in either school skills or self-care. All children in the study were referred by a general practitioner or psychiatrist. They either fell in the probable motor difficulty or below range according to the Developmental Coordination Disorder Questionnaire (Wilson, 2007), or a community paediatrician thought they were at risk of motor difficulties following a developmental assessment. Standard clinic assessment included Movement Assessment Battery for Children - 2 [MABC-2] (Henderson & Sugden 2007), and Short Sensory Profile [SSP] (Dunn, 1998). Children with intellectual disabilities, as reported by a class teacher, were excluded from assessment of DCD in this service as they have higher than average risk of motor difficulties. There were no other exclusion criteria and in keeping with Diagnostic

and Statistical Manual V (American Psychiatric Association, 2013), children with co-occurring diagnoses of ASD or ADHD were included.

Birth mothers of children aged between 6 and 12 years 11 months who were seen for initial assessment by an occupational therapist during the study period were invited to take part. Those who were eligible were given an information sheet and invited to participate in the study. Written consent was obtained before the mothers completed additional questionnaires relating to stress, coping, and social support. Mothers were offered help to complete questionnaires if required. They were offered access to psychological support for any issues arising. Findings were shared with participants.

Child measures

Movement Assessment Battery for Children-2 (MABC-2) (Henderson & Sugden 2007) is a referenced assessment of motor impairment. This tool was selected as it was normed on a large national sample and has excellent psychometric properties (Smit-Engelsman, Fiers, Henderson & Henderson, 2008). A standard score of 5 or below reflects a severe movement difficulty and equates to a score at the 5th percentile or below. A standard score of 6 or 7 equates to a score above the 5th and below the 15th percentile and reflects borderline movement difficulty (Henderson & Sugden, 2007). Children who gained a standard score of 7 or below in total, or sub scale scores, were identified as having movement difficulties to encompass both those with borderline and severe motor impairment (Spironello, Hay, Missiuna, Fought, & Cairney, 2010). This is recommended by the European Academy of Childhood Disabilities (Blank et al, 2012).

Short Sensory Profile (SSP) (Dunn, 1999), is a 38 item caregiver questionnaire that evaluates children's sensory processing in everyday situations. The SSP was developed by selecting the items that demonstrated the highest discriminative power of atypical sensory processing among all the items from the long version of the Sensory Profile [SP]. The full SP, from which the norms were established, was standardised on 1,200 children age three to 10 years. Psychometric properties of both long and short form are reported to be good (Dunn, 1999). The SSP was selected over other tools as it is quick (10 minute ad-

ministration) and easy for parents to use. Maternal measures were selected based on clinical utility and speed of use. The goal was to gather data whilst minimising demands on mothers.

Parent Stress Index - Short Form [PSI/SF] (Abidin, 1995), is a derivative of the full length Parent Stress Index and measures stress in the parent-child system and was selected as a quick and easy to use tool with good measurement properties. Internal consistency of the PSI/SF is very good to excellent (Reitman, Currier, & Stickle, 2002) and it was identified as having better clinical utility with 36 items over the 120 item full form. The PSI/SF has strong psychometric properties and has been used successfully in a variety of settings including children with developmental disabilities (Quinn, Carr, Carrol & Sullivan, 2007). The PSI/SF requires parents to respond to statements on a five point Likert-type scale (strongly agree to strongly disagree). Three factors, Parental distress, Parent-child-dysfunctional interaction and Difficult child are summed to provide a total score. Parents who gain a score at the 90th percentile or above are experiencing clinically significant levels of stress

The Family Support Scale [FSS] (Dunst, Trivette, & Hamby, 1993) is an 18 item scale that measures parental satisfaction with support in various domains including informal kinship, formal kinship, informal social network, and professional services. Parents are asked to rate members of their family and community on a six point scale of helpfulness. This one sided tick box questionnaire is quick and easy to use. Results provide a number of resources for support and the level of helpfulness of those resources. Internal consistency and test-retest reliability are moderately high (Hanley, Tasse, Aman & Pace, 1998).

The COPE Inventory was developed to assess a range of coping responses, both positive (positive reframing) and negative (self-blame). It was reduced in size to develop the Brief COPE (Carver, 1997). The 28 item questionnaire asks respondents to describe the use of each coping response to child's difficulties, using a four point Likert scale. Psychometric properties of the Brief COPE are acceptable (Carver, 1997). To reduce the number of

items for statistical analysis, items from the Brief COPE were collapsed into four subscales, following Benson (2009), who examined parent stress in ASD using the Brief COPE.

Factor 1: Engagement: (use of instrument support, active coping, planning, and emotional support), reflects active involvement by the mother in addressing the stressful situation relating to the child's disability e.g. I have been taking actions to make the situation better

Factor 2: Distraction: (self-distraction, humour, self-blame, and venting), reflects attempts by the mother to distract herself from the stressor e.g. I've been turning to work or other activities to take my mind off things.

Factor 3: Disengagement (substance use, behavioural disengagement, and denial), suggests attempts by the mother to deny or distance herself from the situation e.g. I've given up trying to deal with it.

Factor 4: Cognitive Reframing: (acceptance, use of religion, and positive reframing), describes maternal efforts to positively restructure or reframe their beliefs about the stresses related to their child's difficulties e.g. I've been learning to live with it.

Statistical analysis

Examination of the data showed that coping scores were not normally distributed, and transforming the data and removal of outliers did not resolve the issue. These data were therefore analysed using non-parametric analysis. The other variables were normally distributed and parametric statistics were therefore appropriate. One way analysis of variance (ANOVA) was carried out firstly, to compare levels of parenting stress in children with and without motor impairment and secondly, to compare mean in children with and without coexisting diagnoses. Correlations (Pearson's R or Spearman's rank correlation coefficient) were used to explore relationships between variables.

Results

During the study period 210 children were assessed and 62 mothers were asked to participate in the study. A full set of questionnaires were completed by 51 mothers, giving a

response rate of 82%, representing approximately a quarter of the assessed group of children.

Participants included mothers of 40 boys and 11 girls. The mean age of children was eight years four months (standard deviation - 25 months). Referrals were made by general practitioners (n=18), community paediatrician (n=30) and psychiatrists (n=2). Most families reported functional concerns in both home and school environments (75%).

Total score and sub-sections of the MABC-2 were reviewed, 71% (n=36) demonstrated total or sub-section scores below the 15 percentile, 29% (n=15) showed no motor difficulty as measured by MABC-2. All children demonstrated, functional impairment (difficulty with school skills or self-care), age appropriate learning levels (attending mainstream school with no additional support) and no other neurological diagnoses (e.g. cerebral palsy). Exploring additional developmental diagnosis identified 25 of the 51 participants had a diagnosis of ASD either alone or with an additional diagnosis.

1. Parent stress levels

Table 1 shows that the mean total score for the Parent Stress Index was very high, suggesting that this sample were highly stressed. Thirty one of the mothers, or 67% of the sample, had a total score above the 90th percentile. There were some differences in sub scale scores. Parent-Child Dysfunctional Interaction and Difficult Child had mean scores falling above the 90th percentile, with more than 60% of mothers scoring in this range. Parent distress was lower, with only 33% of mothers reporting scores above the 90th percentile.

(Table 1 about here)

2. Child factors associated with DCD

a) Motor severity

In order to explore the relationship between DCD and parent stress, two sets of analyses were carried out. One way ANOVA showed that there was no difference in maternal

stress between children with DCD (5th percentile or below on MABC-2) (Mean maternal stress 102.3, sd 26.6), children at risk of DCD (above 5th and below 15th percentile on MABC-2) (Mean maternal stress 93.1, sd 26.2) and those whose motor skill fell above the 15th percentile on the MABC-2 (Mean maternal stress 109.8, sd 20.5) according to the MABC-2. Correlations between PSI and the total MABC-2 and each of its sub scales demonstrated that motor skills as measured by the MABC-2 were not related to maternal stress (See Table 2). Thus severity of maternal stress did not appear to be related to variables associated with motor co-ordination.

(Table 2 about here)

b) Sensory processing

In contrast, there were significant correlations between the SSP total score and PSI score, and a number of sub scales (See Table 2). Mothers were more stressed when their children had more severe sensory processing difficulties. Analysis of sub scales suggested that maternal stress was particularly strongly related to the tactile, auditory, taste / smell and visual / auditory sensitivity domains and total scores.

c) Co-occurrence

To explore the impact of co-occurrence with DCD, participants were grouped into those with and without additional diagnosis of ASD (88% and 46% respectively above the 90th centile for total stress on the PSI). Other disorders did not occur frequently enough for statistical analysis. Parents of children with a diagnosis of ASD were more stressed than those without ASD [mean 112.1 and 91.8 respectively; $f(1,50) = 9.7, p < .001$]. However, even the non-ASD group were highly stressed with a mean score around the 90th percentile.

In order to clarify differences between children with ASD and without ASD, a series of one-way analyses of variance were carried out. There were no differences in children with ASD and non-ASD in MABC-2. However, children with ASD had higher SSP scores than those without [means 122.6, and 106.1 respectively; $f(1,49) = 7.1, p < .001$].

3. Maternal factors associated with maternal stress.

a) Social support:

Maternal stress did not correlate with total number of sources of support, but there was a trend to a correlation with total perceived helpfulness suggesting that the more others were perceived as helpful, the lower stress levels tended to be (See Table 3). Exploration of sub scales revealed that particular sub scales correlated significantly with stress. Higher ratings of helpfulness related to partner / partners family, informal kinship (friends), or formal kinship (own parents) were associated with reduced stress. This finding suggests that the mother's partner, her parents, partner's parents and friends can make a difference to mothers stress levels. Although there is some cumulative effect with the level of perceived helpfulness, each of these sources on their own, had a positive impact. A partner, parents or friends can each act as a protective factor to the mother. This is important to note when considering intervention and how to best provide family-centered practice.

(Table 3 about here)

b) Coping:

Using the recoded variables and non-parametric analysis, parent stress correlated positively with factor 1 Engagement, factor 2 Distraction and factor 3 Disengaging, but not with factor 4, Reframing. Thus, higher levels of stress were associated with higher levels of engagement, distraction and disengagement. Those experiencing stress appear to utilise both positive and negative coping strategies.

Discussion and implications

Maternal Stress

The primary goal of this study was to identify maternal stress levels in families referred to a DCD pathway. Maternal stress levels were high with over 60% of the sample having clinically significant stress levels, at or above the 90th percentile. This is striking in com-

parison to parents of typically developing children where much lower rates are reported (10%). It is likely that a mother's stress levels are acting as a barrier to family participation in this client group. Given previous qualitative research that linked DCD to mothers under pressure (Stephenson & Chesson, 2008, Novak et al., 2012), it was surprising to note that in this sample, motor skills did not appear to show a relationship to maternal stress. The pattern of sub scale scores suggest that the mothers were particularly affected by characteristics of the child, rather than factors personal to themselves such as, lack of social support (Abidin, 1996). High 'difficult child' scores suggest that the mother is finding the child difficult to manage due to behaviour problems. In addition, high 'parent-child dysfunction' scores suggest that the interaction between mother and child does not support the mothers well-being. The focus of mothers stress levels appears to be on the demands of parenting the child rather than more generalised stress. This does not correlate directly with studies that have looked at maternal mental health in parents of children with disabilities that suggest both maternal factors (maternal participation in healthy activities, maternal empowerment) and child factors (child's emotional health and unmet service needs) are both important to a mothers well-being (Bourke-Taylor, Pallant, Law & Howie, 2012). Although data on children in this cohort suggested that a number of them would not meet diagnostic criteria, all had functional impairment and many of the children demonstrated challenges in sensory processing. Despite the debate on aetiology it is clear that mothers stress levels are frequently dangerously high for their own and their child's well-being. Therefore, it is important for occupational therapists to be aware and consider this when planning services that aim to increase family participation.

Child factors

Exploring child factors that may help explain maternal stress levels revealed some interesting findings. For example, there was no relationship found between maternal stress and child motor skills as measured on the MABC-2, despite all parents describing functional concerns and indeed, almost one third of children did not meet criteria for a diagnosis of DCD using the MABC-2. Measurement of motor skills does not measure function or behaviour and perhaps functional skills or behavioural responses have more impact on family life. Better understanding of functional concerns and the impact on family

life will support appropriate allocation of resources for interventions that target parent identified concerns and goals.

Sensory processing difficulties were very strongly related to maternal stress. The mechanisms underpinning this relationship need further exploration. Epstein, Saltzman-Beniah, O'Hare, Goll and Tuck's (2008) hypothesised that sensory behaviours may relate to some of the unusual behaviours that can be difficult for parents to manage. According to Lane, Reynolds and Dumenci (2012) sensory processing problems are linked with child anxiety and this may place additional burden on parents. Indeed, anxiety is reported to be high in children diagnosed with DCD (Pratt & Hill 2011). This study suggests that sensory processing and its impact on function and participation should be considered in this population.

The data also showed that parents of children with co-occurring ASD were more stressed than children without ASD. This is unsurprising, as parents of children with ASD are repeatedly shown to have higher stress levels than parents of children with other disabilities (Epstein et al, 2008). While mothers of children with co-occurring diagnosis had higher levels of stress, mothers of children referred to the DCD pathway without child co-occurrence were nonetheless still highly stressed. Whilst co-morbidity is a contributing factor to maternal stress, it cannot be assumed that where there is no comorbidity that mothers are not stressed. This calls for individual family-centred assessment.

Maternal factors

A key maternal factor related to maternal stress was, as expected, social support. In particular, mothers who rated highly the helpfulness of her partner, her friends and her own parents, had reduced levels of stress. Support from social organisations and professional services were not correlated with stress at this point of initial access to occupational therapy services. The support of friends and family appear to be important to the mother's well-being. Encouraging mothers to consider their social networks and support strategies for themselves, may act in the best interests of the child as well as themselves.

Maternal coping style was also important. Higher levels of stress were strongly associated with use of distraction and disengagement from child's difficulties, but the direction of causality cannot be implied from these analysis. Some coping styles may suggest the mother is attempting to distance herself from the child's problems. Novak et al., (2012) showed that mothers who are in denial about their child's problems are more stressed. Similarly, Benson (2009) found that distraction and disengagement predicted depressed mood in parents of children with autism. This suggests that parent education should consider supporting and developing positive coping strategies in mothers.

Surprisingly, greater use of maternal engagement, suggesting an active coping style, was also moderately related to stress. Further exploration with a larger sample is needed to understand this relationship. However, consistent with other studies (Paster et al., 2009), mothers appear to be using both positive and negative strategies in order to cope with the demands of child care. Negative coping strategies are a barrier to family participation. Occupational performance coaching that focuses on building parents capacity to design their own solutions, in families with children with autistic spectrum conditions, leads to improved participation (Graham, Rodger, & Ziviani, 2010). Dunn, Cox, Foster, Mische-Lawson, and Tanquary (2012) explored parent coaching further in children with autism and sensory processing concerns. Ten sessions of coaching intervention led to significant reduction in parental stress as well as perceived parental competence and child participation. Provision of one-to-one coaching for up to 4.9 % of the population may not be a realistic option within the National Health Service however, group parent training is already used by a number of services. Novak et al, (2012) suggested that professionals need to become better advocates to facilitate early recognition, and support access to intervention. Synthesis of the work above suggests that professionals might best support parents through facilitating the parents own goal setting and supporting identification of resources within themselves and their own environment. In addition, Engel-Yeger (2015) as cited in Cairney (2015) highlighted that when working with the DCD population, clinicians should consider what information to impart to the child's social network. Therefore, it is reasonable to suggest that reframing behaviour, promoting understanding, and supporting development of problem-focused rather than emotion-focused coping strate-

gies are likely to have a positive impact on the family's ability to function and participate in everyday life.

Finally, this study has raised a number of issues around parental involvement and child versus family need that would support further investigation. Both Missiuna, Polatajko and Pollock (2015), and Pentland et al, (2015) stressed the importance of interagency and collaborative working with parents and school staff. Occupational therapists are key players in the identification of need and the provision of services. Influencing long-term outcomes in the DCD population will have an impact on long-term health and well-being and reduced secondary consequences to physical and mental health. How those services are developed will depend on occupational therapists active participation in that process and, how collaboration is fostered across agencies. At a clinical level, occupational therapists need to continue reflecting on client-centred practice versus family-centred practice in the light of the high levels of maternal stress.

Limitations

There are a number of limitations to this study. Apart from the small sample size, a limitation relates to the timing of the study, as mothers were asked to complete questionnaires at the same time as their child's initial assessment. Maternal stress may have been exacerbated by uncertainty around diagnosis as well as the assessment process itself, and thus stress levels may have been higher at that point than at other times. This factor could have been controlled by comparative data collection with an alternative out-patient clinic. Moreover, the use of the Short Sensory Profile may not only be assessing sensory processing factors such as activity levels and anxiety may contribute to total score (Koziol, Ely Budding, & Chidekel, 2011). However sub factors of the SSP identified specific relationship with tactile and auditory sensory processing. Another limitation is that although all children presented with functional concerns in daily life, only 71% met the criteria for definite or borderline DCD. However, the study group reflected a clinical sample and demonstrates that clinical services that base criteria for intervention only on levels of motor impairment may fail to address functional occupational concerns for children and families.

Conclusion

Mothers of children with developmental motor concerns present with clinically significant levels of stress, therefore the needs of the family should be considered when designing intervention for children with functional impairment. Both parent and child factors impact on parents ability to support their child's participation. Whilst maternal stress does not correlate with motor impairment as measured by the Movement Assessment Battery for Children-2, it strongly and positively correlates with sensory processing difficulties as reported by SSP. The higher the SSP score the higher maternal stress is likely to be. Coping strategies of distraction and disengagement also correlated positively with maternal stress levels. Mothers are frequently using coping strategies that are likely to make the situation worse. Further exploration of the impact of sensory processing on family functioning and of strategies to support positive coping within families is recommended.

This study adds to our understanding of the stresses experienced by parents bringing up children with functional concerns and some of the factors that contribute to such stress. Increased awareness of the issues faced by parents may assist in therapeutic goal planning which is most relevant to the needs of families, rather than being focused solely on the child's motor impairment. Possible clinical outcomes include development of direct support strategies for parents, including a coaching approach. The well-being of mothers should be considered when planning services for children who meet screening criteria for DCD.

Key findings

1. Mothers of children at risk of DCD present with clinically significant levels of stress.

2. Functional concerns may present a greater risk factor than diagnostic category.
3. Higher maternal stress correlates with less effective coping styles, less support from family and friends, social communication and, a child's sensory processing.
4. This study has quantified the stress levels of mothers of children at risk of DCD, and identified potential hindrances to successful participation for families.

References

- Abidin, R. R. (1995). *Parent Stress Index – Third Edition*. Psychological Assessment Resources. Inc. Lutz, Florida.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*. (5th Ed.). Washington,DC, USA.
- Azak, S., Murison, R., Wentzel-Larsen, T., Smith, L., & Gunnar, M. R. (2013). Maternal stress and infant daytime cortisol. *Developmental Psychobiology*, 55(4), 334-351. doi: 10.1002/dev.21033
- Benson, P. R., (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders*. 4(2), 217–228. doi:10.1016/j.rasd.2009.09.008
- Blank, R., Smits-Engelsman, B., Polatajko, H., Wilson, P. (2012) European Academy of Childhood Disability (EACD): Recommendations on the definition, diagnosis and intervention of developmental coordination disorder (long version). *Developmental Medicine & Child Neurology*, 54(1),54–93. doi: 10.1111/j.1469-8749.2011.04171.x
- Bourke-Taylor, H., Pallant, J. F., Law, M. & Howie, L. (2012). Predicting mental health among mothers of school aged children with developmental disabilities: The relative contribution of child, maternal and environmental factors. *Research in Developmental Disabilities*, 33(6), 1732-1740. doi: 10.1016/j.ridd.2012.04.011
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100. doi:10.1207/s15327558ijbm0401_6

- Cermak, S. A., & Larkin, D. (2002). *Developmental Coordination Disorder* Delmar, Thompson Learning. ISBN 9780769300924
- Cherry, D. (2004). Stress and coping in families of children with ill or disabled children: application of a model to pediatric therapy. *Physical and Occupational Therapy in Pediatrics*, **11**,11-32.
- College of Occupational Therapists (2008). *Position Statement – Access to occupational therapy for children and young people with Developmental Coordination Disorders*. London. COT.
- Dunn, W. (1999). *Sensory Profile*. Psychological Assessment Resources, Odessa, FL, USA
- Dunn, W., Cox, J., Foster, L., Mische-Lawson, L., Tanquary, J. (2012). Impact of a Contextual Intervention on Child Participation and Parent Competence Among Children With Autism Spectrum Disorders: A Pretest–Posttest Repeated-Measures Design. *American Journal of Occupational Therapy*, 66, 520–528. doi: 10.5014/ajot.2012.004119
- Dunst, C. J., Trivette C. M., & Hamby, D. W. (1994). Measuring social support in families with young children with disabilities. In C. J. Dunst, C. M. Trivette & A. G. Deals (Eds.), *Supporting and strengthening families: Methods, strategies and practices* (Vol. 1)(pp.152-160). Cambridge: Brookline Books.
- Ekas, N., Lickenbrock, D. & Whitman, T. (2010) Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 40, 1274-1284. doi: 10.1007/s10803-010-0986-y.
- Engel-Yeger, B. (2015). Chapter 2 Developmental Coordination Disorder and Participation. In J.Cairney (Ed.) *Developmental coordination disorder and its consequences* (pp. 33-61). University of Toronto Press, Toronto. ISBN-13: 978-1442626744
- Epstein, T., Saltzman Beniah, J., O'Hare, A., Goll, J.C. & Tuck, S. (2008). Associated features of Aspergers syndrome and their relationship to parenting stress. *Child, Care, Health and Development*, 34, 503-511. doi: 10.1111/j.1365-2214.2008.00834.x
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X-H., Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with

- autism and developmental delay. *Autism*. 13, 375-387.doi: 10.1177/1362361309105658
- Garner, R. E., Arim, R. G., Kohen, D. E., Lach, L. M., Mackenzie, M. J., Brehaut, J. C., & Rosenbaum, P. L. (2011). Parenting a child with neurodevelopmental disorders and /or behaviour problems. *Child: Care,Health and Development*, 39, 412-421. doi: 10.1111/j.1365-2214.2011.01347.x
- Graham, F., Rodger, S., Ziviani, J., (2010). Enabling Occupational Performance of Children through Coaching Parents: three Case Reports. *Physical and Occupational Therapy in Pediatrics* 30, 4-15. doi:10.3109/01942630903337536
- Guillamon, N., Nieto, R., Pousada, M., Redolar, D., Munoz, E. Boixados, Gomez-Zuniga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *Journal Of Clinical Nursing*, 22, 1579-1590. doi: 10.1111/jocn.12124
- Hanley, B., Tasse, M., Aman, M., & Pace, P. (1998). Psychometric properties of the family support scale with Head Start families.*Journal of Child and Family Studies*,7, 69-77. doi:1062-1024/98!D300-0069\$15.00/0
- Hastings, R. & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 45, 1338-1349. doi: 10.1111/j.1469-7610.2004.00357.x
- Hayes, S. A. & Watson, S. L. (2013). The impact of Parenting Stress: A meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children with and without Autism Spectrum Disorder. *Journal of Autism and Developmental Disorder*. 43, 629-642. doi: 10.1007/s10803-012-1604-y
- Henderson, S. & Sugden, D. (2007). *Movement Assessment Battery for Children- 2nd Edition*. Sidcup, Psychological Corporation.
- Jansen, L. M. C., Ketelaar, M., & Vermeer, A. (2003). Parental experience of participation in physical therapy for children with physical disabilities. *Developmental Medicine and Child Neurology*.45, 58-69. doi: 10.1111/j.1469-8749.2003.tb00861.x

- Koziol, L.F., Ely Budding, D. & Chidekel, D. (2011). Sensory Integration, Sensory Processing, and Sensory Modulation Disorders: Putative Functional Neuroanatomic Underpinnings. *Cerebellum* . doi: 10.1007/s12311-011-0288-8
- Lai, W. W., & Oei T. P. S (2014). Coping in parents and caregivers of children with Autism Spectrum Disorders (ASD): A review. *Review Journal of Autism and Developmental Disorders* 1(3), 207–224. doi: 10.1007/s40489-014-0021-x
- Lane, S. J., Reynolds, S., & Dumenci, L. (2012). Sensory over-responsivity and anxiety in typically developing children and children with autism and attention deficit hyperactivity disorder. Cause or coexistence? *American Journal of Occupational Therapy*, 66, 595-603. doi:10.5014/ajot.2012.004523
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172-183. Doi: 10.1111/j.1365-2788.2005.00732.x
- Lingam, R., Hunt, L., Golding, J., Jongmans, M., & Edmond, A. (2009). Prevalence of Developmental Coordination Disorder using the DSM-IV at 7 years of age: A UK population - based study. *Pediatrics*, 123, e693-e700. doi: 10.1542/peds.2008-1770.
- Missiuna, C., Polatajko, H. J., & Pollock, N. (2015). Chapter In J.Cairney (Ed.). *Developmental Coordination Disorders and its consequences*. Toronto, University of Toronto Press. ISBN-13: 978-1442626744
- Novak, C., Lingham, R., Coad, J., Emond, A. (2012) ‘Providing more scaffolding’: parenting a child with developmental co-ordination disorder, a hidden disability. *Child: Care, Health and Development*. 38, 829-835. doi: 10.1111/j.1365-2214.2011.01302.x

- Osborne, L., McHugh, L., Saunders, J. & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for Autistic Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 38, 1092-1103. doi: 10.1007/s10803-007-0497-7
- Paster, Brandwein & Walsh (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research in Developmental Disabilities* 30, 6 1337-1342. doi:10.1016/j.ridd.2009.05.010
- Pentland, J., MacIver, D., Owen, C., Forsyth, K., Irvine, L., Walsh, M. & Crowe.,M. (2015) Services for children with developmental co-ordination disorder: an evaluation against best practice principles. *Disability and Rehabilitation*. E-pub April 22,1-8. doi:10.3109/09638288.2015.1037464
- Pless, M., Carlsson, M. (2000). Effects of motor skill intervention on Developmental Co-ordination Disorder: A meta-analysis. *Adapted Physical Activity Quarterly*, 17, 381-401.
- Pratt, M. L., & Hill, E. L. (2011). Anxiety profiles in children with and without developmental coordination disorder. *Research in Developmental Disabilities*, 32, 253-1259. doi:10.1016/j.ridd.2011.02.006
- Quinn, M., Carr, A., Carrol, L. & O'Sullivan, D. (2007). Parent plus programme 1: evaluation of its effectiveness for pre-school children with developmental disabilities and behavioural problems. *Journal of Applied Research in Intellectual Disabilities*, 20, 345-359. doi: 10.1111/j.1468-3148.2006.00352.x
- Reitman, D., Currier, R. O., Stickle, T. R. (2002). A critical evaluation of the Parenting Stress index-Short Form (PSI-SF) in a Head Start population. *Journal of Child and Adolescent Psychology*. 31(3), 384-392. doi: 10.1207/S15374424JCCP3103_10
- Schaaf, R. C., Tooth-Cohen, S., Johnson, S. L., Outten, G. & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism*, 15, 378-389. doi: 10.1177/1362361310386505
- Schopler, E. (2005) Cross cultural priorities and reclassification of outcome research methods. In F. Volkmar, R. Paul, A. Klin & D. Cohen (Eds.). *Handbook of Au-*

- tism and Pervasive Developmental Disorders*, Vol 2. (pp1174-1192). John Wiley and Sons, third edition. ISBN-13: 978-1118107034
- Singer, G.S & Floyd, F. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without Developmental Disabilities. *American Journal on Mental Retardation*, 111(3), 155-169. doi: 10.1352/0895-8017(2006)111[155:MOCSOD]2.0.CO;2
- Smit-Englesman, B.C.M., Fiers, M.J., Henderson, S.E. & Henderson, L. (2008) Interrater reliability of the Movement Assessment Battery for Children. *Physical Therapy*, 88, 286-294. doi: 10.2522/ptj.20070068
- Spironello, C., Hay, J., Missiuna, C., Faight, B. E., & Cairney, J. (2010). Concurrent and construct validity of the short form of the Bruininks-Oseretsky test of motor proficiency and the Movement-ABC when administered under field conditions: implications for screening. *Child: Care, Health and Development*. 36(4), 499-507. doi: 10.1111/j.1365-2214.2009.01066.x
- Stephenson, E. A. & Chesson, R. (2008). Always the guiding hand: parents accounts of the long-term implications of developmental co-ordination disorder for their children and families. *Child: Care, Health and Development*, 34, 335-343. doi: 10.1111/j.1365-2214.2007.00805.x.
- World Health Organization (2007) *International Classification of Functioning Disability and Health – Children and Youth version*. Geneva: WHO. ISBN: 9241547324

Table 1: Parent Stress Index total and subsection scores

Parent Stress Index -Short Form	Mean (SD)	% at or above 90th centile
Total	101.8 (25.1)	66.7%

Parent Stress Index -Short Form	Mean (SD)	% at or above 90th centile
Parent distress	32.8 (10.4)	33.3%
Parent-child dysfunctional interaction	30.3 (10.2)	60.8%
Difficult child	38.9 (10.2)	68.6%

Table 2: Correlation of parent stress to child factors

Child factors	Parent Stress total r value	Parent stress total p-value
MABC2 Total Score	0.002	NS
MABC2 Manual Dexterity	0.05	NS
MABC2 Ball skills	0.13	NS
MABC2 Balance	0.06	NS
SSP Total	0.67**	< 0.01
SSP Tactile	0.53**	< 0.01
SSP Taste/ Smell	0.37**	< 0.01
SSP Movement	0.2	NS
SSP Under	0.27	NS
SSP Auditory	0.57**	< 0.01
SSP Low energy	0.21	NS
SSP Visual/ Auditory Sensitivity	0.37**	< 0.01

MABC2 - Movement Assessment Battery for Children-2

SSP - Short Sensory profile

NS- Not Significant

Correlation significant at 0.01**

Correlation significant at 0.05*

Table 3: Correlation of maternal stress and maternal factors.

	Parent Stress r-value	Parent Stress p-value
FSS - Relative helpfulness Total	0.24	0.08 Trend but NS
FSS - Relative helpfulness Partner	0.33*	0.02
FSS - Relative helpfulness Informal (friends)	0.36*	< 0.01
FSS - Relative helpfulness Formal Kinship (family)	0.38**	< 0.01
FSS - Relative helpfulness Social	0.15	NS
FSS - Relative helpfulness professionals	0.21	NS
BriefCOPE -Total		
BriefCOPE Engagement	0.32*	0.05
BriefCOPE Distraction	0.40**	< 0.01
BriefCOPE Disengagement	0.51**	< 0.01
BriefCOPE Reframing	-0.14	NS

Correlation significant at 0.01**

Correlation significant at 0.05*

FSS - Family Support Scales