

Coping strategies and implications of disability in parents of children with autism versus down syndrome – Two different sides of the same coin?

Daniella Goldberg, M.A, McGill University

Laura Fontil, M.A., McGill University

Ingrid Sladeczek, Ph.D., McGill University

Nancy Miodrag, Ph.D., California State University

ABSTRACT

Parenting a child with a developmental disability is stressful. Psychological impairment among parents and siblings is more apparent in families where there is a child with emotional, behavioural, and communication problems, such as autism (Dabrowski & Pisula, 2010). Researchers have found that parents of children with autism are more distressed compared with parents of children with other developmental disabilities, such as Down syndrome (DS; Sanders & Morgan, 1997). This study compared beliefs about the implications of having a child with a disability with the different types of coping strategies used by parents of children with autism spectrum disorders (ASD) and DS. The sample included 41 parents who had a child with DS and 33 with ASD. MANOVA was used to compare these two groups on coping strategies and beliefs. Results elucidated that parents with a child with ASD had more negative beliefs about the implications of their child's disability on family life than parents with a child with DS.

RÉSUMÉ

Élever un enfant ayant une déficience développementale est une activité stressante. Les perturbations psychologiques chez les parents, les frères et les sœurs sont plus apparentes dans les familles où l'un des enfants a des problèmes émotionnels, comportementaux ou de communication, comme c'est le cas des enfants autistes (Dabrowski et Pisula, 2010). Les chercheurs ont constaté que les parents d'enfants autistes sont plus perturbés que les parents d'enfants ayant d'autres types de déficience comportementale, comme la trisomie (syndrome de Down; Sanders et Morgan, 1997). Cette étude a comparé les croyances concernant les conséquences d'élever un enfant qui a une déficience avec différents types de stratégies de réponse mises en œuvre par les parents d'enfants ayant un trouble du spectre de l'autisme et ceux d'enfants trisomiques. L'échantillon étudié

était constitué de 41 parents d'enfants trisomiques et de 33 parents d'enfants autistes. L'analyse de la variance à plusieurs variables a été utilisée pour comparer ces deux groupes tant sur le plan des stratégies de réponse que des croyances. Les résultats ont fait valoir que les parents d'un enfant autiste ont plus de croyances négatives au sujet des répercussions que la déficience de leur enfant peut avoir sur la vie familiale que les parents d'un enfant trisomique.



Introduction

Parenting a child with a developmental disability can be taxing for parents because of the increased financial and emotional costs involved (Baker, Blacher, & Olsson, 2005). Numerous empirical studies have found that parents of children with developmental disabilities (e.g., Autism Spectrum Disorder (ASD), Down syndrome (DS)) report more mental health difficulties than parents of typically developing children (Siklos & Kerns, 2006; Tunali & Power, 2002). Baker, Bruce, Blacher, Crnic, and Edlerbrock (2002) suggest that stress is related to parents' ability to cope with the many challenges involved with raising a child with a disability, such as the financial, personal, and social stressors.

Trute and Hiebert-Murphy (2002) found that one of the ways that parents of children with developmental disabilities cope with parental stressors is related to their conceptualization and understanding of their child's diagnosis and its impact on family life. These appraisals determine how the family will cope in the face of misfortune. Some families will seek out community services and others will rely on familial or spiritual support (Van Riper, 2007). Sanders and Morgan (1997) found that mothers of children with developmental disabilities who had more positive beliefs about their child's diagnosis, reported less depressive symptomology and scored higher on measures of psy-

chological well-being. These mothers were more likely to seek out services and have more positive interactions with their children.

Researchers have found that although stress is higher in parents of children with developmental disabilities compared to parents of typically developing children, these rates are higher in mothers of children with ASD than in mothers of children with DS (Abbeduto et al., 2004; Dabrowska & Pinsula, 2010). Griffith, Hastings, Nash, and Hill (2010) attributed the high psychological distress of parents of children with ASD to the specific characteristics of ASD. For example, ASD compared with DS, is diagnosed at a later age (around six years of age), is characterized by fewer physically identifiable features and more behavioural problems, as well as a lack of social and communication skills. The lack of social and communication skills and increased behavioural problems contribute to greater physical and psychological distress for parents (Abbeduto et al., 2004; Baker et al., 2005). There are tend to be more personal and financial costs associated with raising a child with ASD, which can result in greater familial stress and life changes (Jabrink, Fombonne, & Knapp, 2005).

Few studies have compared the differences in how parents of children with ASD and DS conceptualize the impact of their child's disability on their family life, and their ability to cope with related stressors. This study examined the relationship between stress, appraisals, and coping in families with children with developmental disabilities in order to elucidate how the type of diagnosis relates to the stress families experience. It was hypothesized that parents of a child with ASD would experience more negative beliefs compared with parents of a child with DS. It was expected that parents of a child with ASD would use less adaptive coping strategies compared to parents with a child with DS.

Method

Participants

Families with a child who met the criteria for ASD or DS were taken from a larger study, the National Early Intervention Research Initiative Project, as well as a community sample. The National Early Intervention Research Initiative Project looked at the trajectories of children with developmental disabilities and their families receiving early intervention services. Participants in the community sample were recruited using flyers, advertisements on Canadian websites, and through parent newsletters. The study received approval by the Human Subject Research Ethics Board at the university level and community center where participants were recruited. From the large sample, children diagnosed with either ASD or DS were se-

lected. Eligible participants consisted of 39 children with ASD and 42 with DS out of the larger sample of 177 children. Children with comorbid diagnoses were excluded from the final sample.

Diagnoses were determined by clinical chart reviews conducted by research assistants affiliated with this project and were based on DSM-IV criteria (DSM-IV, APA, 2000). Of the original 177 children in the larger National Early Intervention Project and community sample about 22% ($n=39$) met the DSM-IV criteria for ASD, and 23% ($n=42$) met the DSM-IV criteria for DS.

Children with ASD averaged 6.15 years old ($SD=2.34$), and children with DS averaged 5.94 ($SD=3.62$) years old. Most of the children with ASD were male (79.5%) while in the DS group about half (54.8%) were male. 28 mothers completed the psychological, social, and demographic questions in the ASD group. In this group, mothers on average were 37.97 years old ($SD=6.040$) and 35.7% had a university education. In the DS Group, 38 mothers completed the psychological, social, and demographic questionnaires, and averaged 40.08 years old ($SD=5.049$) and 47.4% had a university degree.

Measures

Coping with life stressors. The Family Crisis Oriented Personal Evaluation Scale (F-COPES) is a self-report measure used to assess how families cope with life stressors (McCubbin, Olson, & Larson, 1981). Mothers were asked to rate their use of particular coping skills. Five coping mechanisms are measured in this questionnaire. These include acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and receive help, and passive appraisals. Test retest reliability for each scale was found to be .78; .61; .95; .78; and .75, respectively, in a study by McCubbin et al., (1981). A total coping scale was computed by summing up scores from the six subscales.

Beliefs about disability. The Family Impact of Childhood Disabilities Scale- 2nd Edition (FICD) was used to determine families' beliefs on the positive and negative effects of disability on a family's daily life (Trute & Hiebert-Murphy, 2002). Mothers were asked to rate items (both negative and positive) on the degree to which their child's disability affects family life. Higher scores on the positive subscale indicate that parents have more positive beliefs, while on the negative subscale higher scores indicate more negative beliefs. Internal reliability for the negative scale was .71 and for the positive .88 (Trute & Hiebert-Murphy, 2002).

Results

Multivariate ANOVA, controlling for age and gender,

Table 1

Means and Standard Deviations for Family Impact of Childhood Disabilities (FICD) Subscales for Autism Spectrum Disorder (ASD) and Downs syndrome (DS) groups

FICD	ASD (N = 41)		DS (N = 33)		F
	M	SD	M	SD	
Positive Subscale	30.12	6.24	30.44	5.02	.09
Negative Subscale	30.64	5.48	24.24	6.31	18.05***

*** $p < .001$

- a. higher scores = more positive beliefs
b. higher scores = more negative beliefs

Table 2

Means and Standard Deviations for Family Impact of Childhood Disabilities (FICD) Negative Subscale Items for Autism Spectrum Disorder (ASD) and Downs syndrome (DS) groups

FICD	ASD (N = 41)		DS (N = 33)		t
	M	SD	M	SD	
Additional financial stress	3.82	.47	3.27	.67	3.99*
More chronic stress	3.27	.91	2.41	.99	3.82*
Reduced time for friends	3.18	.95	2.66	1.04	2.24
Hesitate to call friends	2.64	1.14	1.68	.99	3.86*
More tension between spouses	2.69	1.12	2.08	1.02	2.42
Postponed holidays	2.58	1.25	1.80	1.12	2.79*
Postponed purchases	3.15	1.06	1.93	1.06	4.94*

* $p < .0071$

was conducted to compare coping mechanisms and belief systems in parents of children with DS and ASD's. Paired sample *t*-tests were conducted to elucidate significant findings. Please note the two groups did not differ significantly in age.

Coping Strategies

No significant difference was found between mothers of children with DS and mothers of children with ASDs coping strategies, $F(6, 67) = .44, p = .847$.

Belief Systems

While there were no significant differences between mothers' positive beliefs about their children, mothers of children with ASD held more negative beliefs than mothers of children with DS, $F(1, 72) = 7.57, p < .001$. See Table 1.

T-tests using a Bonferroni adjusted alpha of .0071 revealed that parents of children with ASD had additional financial stress ($t(72) = 3.99, p < .001$), more chronic stress ($t(72) = 3.82, p < .001$), hesitated to call friends ($t(72) = 3.86, p < .001$), and postponed holidays ($t(72) = 2.79, p = .007$) and purchases ($t(72) = 4.94, p < .001$) more frequently than parents of children with DS. See Table 2.

Discussion

Given the increased level of stress experienced by mothers of children with ASD (e.g., Sanders & Morgan, 1997), it was hypothesized that these mothers might hold more negative beliefs about the implications of their child's disability on family life. While mothers of children with ASD held more negative beliefs than those of children with DS, their positive beliefs about having a child with a developmental delay did not differ. All mothers held high positive beliefs about their children (i.e., more tolerance, extraordinary time spent, belief that children are unique and special). Additionally, we found that mothers of children with ASD and DS did not differ in their coping strategies.

Parenting a child with ASD appears to be related to different challenges than parenting a child with DS. Hodapp (2002) suggests that behavioural styles may explain the different challenges these parents experience. Children with DS tend to be more sociable and have less maladaptive behaviour problems. Hodapp also posits that parental understanding of the nature and etiology of DS may also contribute to their overall well-being. Parents of children with ASD have reported that their child's impairments in social communication (Davis & Carver, 2008) and restricted or repetitive behaviours (Gabriels et al., 2005) are particularly stressful. Coping mechanisms that are effective in restricting negative beliefs in families with children with DS may not be sufficient for parents of children with ASD.

Results from this study are expected to inform practitioners and service providers about the different coping strategies used by parents of children with various developmental disabilities. Interventions aimed at targeting the general needs of families and children with special needs may not be sufficient. Parents of children with varying emotional, behavioural, and/or developmental difficulties or diagnoses present with unique needs that cannot be generalized. Service providers must be aware to tailor their interventions accordingly.

Limitations and Future Directions

This study's limitations should be noted. The study has a small sample size, which may have affected the robustness of the findings. Moreover, a clearer understanding of families' socioeconomic status and cultural background may have shed light on the underlying mechanisms of family coping mechanisms and belief systems. Given the financial impact that a child with disabilities can have on a family, families of lower socioeconomic status may have experienced a disproportionate amount of stress related to their fi-

nances. Families' cultural backgrounds can play an integral role in how families understand and cope with a child with a disability (Blacher & McIntyre, 2006; Hanson, 1998). Finally, a child's gender can also have an impact on families' beliefs about their child and their coping mechanisms.

A more comprehensive exploration of families coping mechanisms and belief systems would help contribute to the future development and implementation of effective evidence-based interventions for these families and their children.



References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*, 109(3), 237–54. doi:10.1352/0895-8017
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders*, (4th Ed. – Text Revision). Washington, DC: Author.
- Baker, Bruce L, Blacher, J., Crnic, K., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal of Mental Retardation*, 107(6), 433–44. doi: 10.1352/0895-8017(2002)107<0433:BPAPSI>2.0.CO;2
- Baker, B. L. Blacher, J. & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 47(8), 217-230. doi:10.1111/j.1365-2788.2005.00691.x
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, 50(3), 184-198. doi:10.1111/j.1365-2788.2005.00768.x
- Davis, N. O., & Carver, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278-91. doi:10.1007/s10803-007-0512-z
- Gabriels, R. L., Cuccaro, M. L., Hill, D. E., Ivers, B J., & Goldson, E. (2005). Repetitive behaviours in autism: Relationships with associated clinical features. *Research in Developmental Disabilities*, 26(2), 169-181. doi:10.1016/j.ridd.2004.05.003
- Griffith, G.M., Hastings, R.P., Nash, S., & Hill, C. (2010). Using matched groups to explore child behaviour problems and maternal well-being in children with Down syndrome and Autism. *Journal of Autism and Developmental Disorders*, 40(5), 610-619. doi: 10.1007/s10803-009-0906-1
- Hanson, M. J., Wolfberg, P., Zercher, C., Morgan, M., Gutierrez, S., Barnwell, D., & Beckman, P. (1998). The culture of inclusion: Recognizing diversity at multiple levels. *Early Childhood Research Quarterly*, 13(1), 185-209. doi:10.1016/S0885-2006(99)80032-5
- Hodapp, R. M. (2002). Parenting children with mental retardation. In M. H. Bornstein (Ed.), *Handbook of Parenting*, 2nd edn. Vol. 1: *Children and Parenting* (pp. 355-81)., Mahwah, NJ: Lawrence Erlbaum Associates.
- Järbrink, K., Fombonne, E., & Knapp, M. R. J. (2005). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *LSE Research Online*, 33(4), 395–400. doi: 10.1023/A:1025058711465
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman, & J. M. Patterson (Eds.), *Social stress and the family: Advances and developments in family stress theory and research* (pp. 7-37). New York: Haworth Press.
- Pisula, E. (2007). A Comparative Study of Stress Profiles in Mothers of Children with Autism and those of Children with Down's Syndrome. *Journal of Applied Research in Intellectual Disabilities*, 20(3), 274–278. doi:10.1111/j.1468-3148.2006.00342.x
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy*, 19(4), 15–32. doi:10.1300/J019v19n04_02
- Siklos, S., & Kerns, K. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*, 36(7), 921–933. doi:10.1007/s10803-006-0129-7
- Trute, B., & Hiebert-Murphy, D. (2002). Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts. *Journal of Pediatric Psychology*, 27(3), 271–80. doi: 10.1093/jpepsy/27.3.271
- Tunali, B., & Power, T. G. (2002). Coping by redefinition: cognitive appraisals in mothers of children with autism and children without autism. *Journal of Autism and Developmental Disorders*, 32(1), 25–34. doi: 10.1023/A:1017999906420
- Van Riper, M. (2007). Families of children with Down syndrome: Responding to a change in plans with resilience. *Journal of Pediatric Nursing*, 22(2), 116–28. doi:10.1016/j.pedn.2006.07.004