

RUNNING TITLE: STRESS IN PARENTS OF ADULTS WITH INTELLECTUAL
DISABILITY

Brief Report: Stress in parents of adults with intellectual disabilities attending Special Olympics
competitions

Structured summary

Background. It is important to determine how programs serving the individual with intellectual disability may also help reduce stress in parents of adult children with intellectual disabilities. The aim of this study was to test whether parents who watch their children at Special Olympics competitions report less stress than parents who watch with less frequency.

Methods. Fifty-seven mothers and 39 fathers completed the Parenting Stress Index in reference to their children with intellectual disability, whose ages ranged from 17 to 42.3 years. Frequency of parental attendance at competition and volunteering for Special Olympics was also assessed.

Results. Parents who attended their children's competitions reported less stress than parents who attended with less frequency. Mothers who volunteer reported more child-related stress than mothers who did not volunteer. A number of other gender specific relations were found.

Conclusions. These results support the hypothesis that parents who see their children compete in Special Olympics have a more positive parent-child experience than parents who do not attend with the same frequency. Experimental research, with controlled pre-post designs, is needed to directly assess any causal effect.

Abstract

Parents of individuals with intellectual disabilities often experience higher levels of child-related stress than parents of individuals without an intellectual disability. The present study examines differences in the degree of maternal and paternal stress found in parents who watch their adult children at Special Olympics competition events compared to parents who watch less frequently. Fifty-seven mothers and 39 fathers completed the Parenting Stress Index (3rd Ed; Abidin, 1995) in reference to their children with intellectual disability, whose ages ranged from 17 to 42.3 years. Also measured were the frequency of parental attendance at competition and whether or not parents volunteered for Special Olympics. Results indicated that mothers and fathers who almost always watched their adult child compete experienced more reinforcement and more acceptability than parents who did not watch with the same frequency. This did not depend on their volunteer membership with Special Olympics, although mothers who had volunteered for the organization reported more child-related stress than mothers who had not volunteered.

Stress in parents of adults with intellectual disabilities attending Special Olympics competitions

Introduction

Having a child with an intellectual disability can place enormous amounts of stress on both the family as a system, and on individual family members. Prior research examining stress related to raising a child with an intellectual disability has found that both mothers (Chetwynd, 1985; Crnic *et al.*, 1983) and fathers (Bristol *et al.*, 1988; Cummings, 1976) experience higher levels of stress than do parents of typically developing children. An important area of research involves delineating the factors related to this increased stress as well as the factors that may help to mediate or moderate stressful outcome. The present study reports on how stress is linked to parents' involvement in their children's physical activity program: Special Olympics.

Abidin (1995) makes a distinction between two sources of parenting stress. The first, *child-related stress*, involves child behaviours and characteristics that make parenting difficult, and contributions to parenting stress. The second, *parent-related stress*, is attributed to characteristics and experiences of the parent that do not directly involve the child but that contribute to parenting stress, such as parental competence or the relationship with a spouse.

The importance of Special Olympics for participants

Special Olympics is a sports organization for individuals with intellectual disabilities that boasts over 1.2 million athletes worldwide (Special Olympics, 2003). A number of studies have positively correlated athlete involvement in Special Olympics to self-concept (Dykens & Cohen, 1996; Wright & Cowden, 1986), feelings of social acceptance and actual competence (Dykens & Cohen, 1996), and less maladaptive behaviour (Gencoez, 1997). More recently, the number of competitions experienced by athletes has been linked to general self-worth and actual social and personal competency (Weiss *et al.*, 2003). Some authors have asserted that Special Olympics can

have negative effects on the psychological well-being of participants, due to its segregated sports structure (e.g., Storey, 2004); however empirical research does not support this hypothesis, at least with respect to self-concept. Studies have either found that both integrated and segregated programs have similar beneficial effects (Castagno, 2001; Riggen & Ulrich, 1993), or that different types of programs have positive effects on different aspects of the self-concept (Duvdevany, 2002).

The importance of Special Olympics for parents

Few studies have examined the link between Special Olympics and the larger family unit general, and no studies have examined its relation to parenting stress in particular. Klein and colleagues (1993) surveyed the attitudes held toward Special Olympics by parents of Special Olympians, and found that a large majority of parents believed that Special Olympics was beneficial for participants' social adjustment and life satisfaction, and enhanced family support, involvement, cohesiveness, and understanding.

The present research examines the possibility that parental involvement in Special Olympics is associated with their feelings of stress and how they view their children. Given the dearth of literature pertaining to Special Olympics, this study is exploratory in nature and is meant to be the first step in addressing the need for research into the active ingredients in programs that support families of individuals with intellectual disabilities (Hauser-Cram *et al.* 2001). Much of the previous research in the area has been limited to parents with young children, and relatively little work has been done examining the factors that contribute to stress in parents of adults with intellectual disabilities (for exceptions, see the work by Essex, *et al.* 1999; Lustig, 1999; McIntyre *et al.* 2002; Sandler & Mistretta, 1998). The present sample

addresses this deficiency by examining the stress experienced in parents of adult-age children, and examines mothers and fathers separately.

Parental involvement is gauged by the degree to which parents attend their child's competitions, and by whether or not they volunteer for Special Olympics. Parents who see their child compete in sport and behave competently may gain a more positive perspective of them. Previous research has found that the more positive a parent's perspective of their child, the lower the child-related stress (Hodapp, *et al.* 2003; Ricci & Hodapp, 2003). Within everyday experience, parents of individuals with intellectual disabilities may see their children experience repeated failure and decreased motivation (Zigler & Hodapp, 1986). In contrast, Special Olympics competitions are socially accepting environments, maximize opportunity for success, and have been positively correlated to athlete's personal and social competence (Weiss, *et al.* 2003). Thus, parents may benefit from viewing their adult child's positive attempts at task mastery and social interaction, and their success at competition. It is also possible that volunteering for Special Olympics may provide parents with an opportunity to meet other parents and establish a social support network, and thus may be related to parenting stress. Volunteerism can take on many forms (i.e., coaching, fundraising, driving, etc.), and has been linked to many factors that improve well-being (Crist-Houran, 1996). Volunteering can improve one's self-esteem and sense of community (Omoto & Snyder, 2002), and may help a person adjust to stressful situations (Schwartz & Sendor, 2000).

Method

Participants

Sixty-three families with parent stress data were included in the present study, out of a sample of 94 families who participated in a larger project on Special Olympics.¹ Results from a missing value analysis found that the group with parent stress data did not differ in age, IQ, economic income, athlete diagnosis, or mean number of children, from the group with missing data (all p 's > .05). A total of 57 mothers and 39 fathers completed the parent stress measure. Parents' ages ranged between 39 and 73 years ($M = 54.5$, $SD = 9.1$). Seventy-three percent of parents reported to be married, while 27% were widowed, divorced, or never married. Families had between 1 and 8 children ($M = 3$ children, $SD = 1.3$). In terms of ethnicity, 50 families noted Caucasian, 3 noted First Nations / Aboriginal, 2 noted Other, 1 noted Asian, while 7 did not answer.

In terms of attendance during competition, 3 parents noted that they "never attended", 11 noted "occasionally", 6 noted "often", and 43 noted "almost always". As such, the sample was dichotomized into parents who "almost always" attend competitions ($n = 43$) and those who "did not always attend" ($n = 20$). Forty-three parents had volunteered for Special Olympics, while 20 had never volunteered. T-tests and Chi-square tests verified that parents did not differ in terms of their attendance at competition or their volunteer status on child age, IQ, parent age, gender, number of siblings, or income level² (all p 's > .05).

Athletes included 63 individuals from Special Olympics (38 males, 25 females; M age of 26.5 years, $SD = 7.2$), who varied in ability level, age (from 17.0 to 42.3 years), and type of sport. Athlete IQ scores ranged from 40 to 90 ($M = 53.6$, $SD = 11.5$). The vast majority of

¹ The 94 families were sampled from regional Special Olympics chapters across Ontario, and were families who agreed to participate out of a randomly selected group of 150 families.

² 1:less than \$20,000; 2:\$20,000-\$40,000; 3: \$40,000-\$60,000; 4: \$60,000-\$80,000; 5:Above \$80,000

participants lived with at least one parent ($n = 51$), whereas 6 lived in residential care and 6 lived independently.

Parents were asked to report any diagnosis given to participants (2 parents chose not to respond). Diagnoses occurring only once in the entire sample were collapsed into “Organic Specified Other”, and included such genetic causes of intellectual impairment such as SOTOS and Williams Syndrome. Of the sample, 39% had Down syndrome, 34% was of Unknown cause, 17% fell under Organic Specified Other, 5% had Autism, and 5% had Fragile X Syndrome. Findings are therefore representative of a heterogeneous group of individuals.

Measures

Demographic information and involvement in Special Olympics. Participant involvement in Special Olympics was assessed by parental completion of a demographic questionnaire that elicited information regarding individual characteristics (e.g., age, sex, type of disability), child and parent Special Olympics involvement (e.g., number of years in SO, sports, medals, competitions attended), and family characteristics (SES, family educational background, ethnicity). Parents were asked to rate how often they watch their children participate during competition, on a four-point scale ranging from 1-Never to 4-Almost always. Parents were also asked if they were volunteers for Special Olympics.

IQ. Participants’ cognitive abilities were assessed using the Kaufman Brief Intelligence Test (K-BIT; Kaufman & Kaufman, 1990). The K-BIT is a motor-free individually administered screener of verbal and nonverbal intelligence, and has good reliability.

Parent Stress. Parent stress levels were assessed using the Parenting Stress Index, Third Edition (PSI; Abidin, 1995). The PSI is a 120-item questionnaire commonly used to measure stress within families of children with intellectual disabilities. Questions are answered by the

parent on a Likert-type scale ranging from “strongly agree” to “strongly disagree” with reference to current life stress. The PSI has good reliability and validity, and is one of the most widely used measures of parenting stress in the literature.

The PSI is divided into a Child-Related and a Parent-Related domain. The Child domain of the PSI contains six subscales: Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. Higher scores indicate an increased degree of negative parental appraisal of the child’s qualities. For example, a high score on the Reinforces Parents subscale indicates agreement with statements such as: “When I do things for my child, I get the feeling that my efforts are not appreciated very much”. The Parent-Related domain also contains six subscales: Parental Competence, Isolation, Attachment to Child, Health, Role Restriction, Depression, and Relationship with Spouse. Higher scores in the Parent domain reflect an acknowledgement of problems outside those attributed to the child’s qualities that may cause parenting stress. For example, high scores on Role Restriction would reflect agreement with statements such as: “I find myself giving up more of my life to meet my children’s needs than I ever expected”.

While the PSI is psychometrically sound and widely used in researching families with individuals with intellectual disabilities, this study assessed parents of individuals who go beyond the usual age range of the PSI (birth – 12 years of age). We adapted and pilot tested the PSI to be age-appropriate, making minor modifications to the item language. For mothers and fathers, Cronbach’s alphas for the PSI child-related and parent-related domains were .90 each (subscale range = 54-.83), similar to the normative data (Abidin, 1995) and to a recent study using the PSI with fathers of children and young adults with intellectual disabilities (Ricci &

Hodapp, 2003). Previously published research has used the PSI with older children and young adults (Hodapp, *et al.*, 2003; Orr, Cameron, Dobson, & Day, 1993; Ricci & Hodapp, 2003).

Procedure

After obtaining informed consent from parents and athletes, mothers and fathers were each mailed a copy of the PSI and were asked to complete it separately, along with the demographic questionnaire. This research was part of a larger study of psychological well-being in families, and athletes were interviewed in their homes for a measure of IQ.

Results

Initial analyses examined potential mother and father differences in stress levels. Paired samples t-tests were conducted, demonstrating a significant difference only on the Role Restriction subscale, $t(45) = 2.10, p = .04$, with mothers feeling more restricted than fathers (all other p 's $> .05$). Pearson correlations indicated significant correlations between mothers' and fathers' overall child-related scores, $r(33) = .85, p < .001$, and parent-related scores, $r(33) = .47, p = .004$, with considerably more variability among subscales (range = .20-.83). Thirty percent of our sample of mothers and fathers fell within Abidin's (1995) clinical range for child-related stress, and 17% of mothers and 13% of fathers fell within the clinical range for parent-related stress (at or above the 85th percentile). Pearson correlations and independent samples t-tests were calculated to investigate any relations among mother and father child-related stress and the demographic variables of child age, IQ, parent age, number of siblings, income level, and child's gender. The relations among demographic variables and parent stress were small and nonsignificant (all p 's $> .05$).

A series of standard multiple regressions were then performed on maternal and paternal overall child-related and parent-related stress and on each subscale, testing the hypothesis that

Frequency of Attendance at competitions and Volunteer status would be significant predictors, after controlling for children's age, IQ, residential status (Coded as a dummy value: In home vs. out of home residence), and family income. Recent research has reported differences in child-related stress for parents of children with Down syndrome compared to children with other causes of intellectual disability (Ricci & Hodapp, 2003). As such, the child's diagnosis was also entered into the regression equation as a dummy value (coded as Down's Syndrome vs. Non-Down's Syndrome) All control variables were entered into the regression as a first block, followed by Frequency of Attendance and Volunteer status.

Mother child-related stress

Table 1 lists the significant predictor variables, demonstrating the consistency of Diagnosis, Frequency of Attendance, and Volunteer Status in predicting maternal child-related stress. Mothers who almost always attended competitions had significantly lower scores than mothers who attended with less frequency; accounting for 14% unique variance in Overall child-related stress, and 6%-17% unique variance in Adaptability, Reinforces parent, Demandingness, and Acceptability. Mothers of children with Down's Syndrome were significantly less stressed than mothers of children with other causes of intellectual disability; accounting for 8% unique variance in Overall child-related stress and 8-10% unique variance in the domains of Demandingness, Adaptability, Mood, and Acceptability. Mothers who volunteered had significantly higher scores than mothers who did not volunteer; accounting for 7% unique variance in Overall child-related stress and 6%-8% unique variance in the Reinforces parent and Acceptability domains.

Mother parent-related stress

As shown in Table 1, Frequency of Attendance was the most consistent predictor, with mothers who almost always attended having lower scores on Overall parent-related stress ($sr^2 = .08$), Attachment ($sr^2 = .08$), Social support ($sr^2 = .07$), and Depression ($sr^2 = .11$), compared to mothers who attended less. Child age was a significant predictor of Overall stress ($sr^2 = .09$) and Attachment ($sr^2 = .10$). In contrast to the child-related domains, the role of Volunteer status was only important for one subscale (Attachment).

Father child-related stress

A similar set of multiple regressions was performed on father's child-related scores, reported in Table 2. Frequency of Attendance was a predictor of Overall child-related stress ($sr^2 = .16$) and all the subscales except Hyperactivity (sr^2 range = .08 - .19), in the same direction as for mothers. Diagnosis was also an important predictor, accounting for 11% unique variance in Overall child-stress, and 8%-12% variance of the Mood, Acceptability, and Hyperactivity domains. Child age was negatively related to Reinforces parent ($sr^2 = .16$) and Hyperactivity ($sr^2 = .34$) scores. In contrast to the maternal data, Volunteer status was not found to be a significant predictor of stress for fathers.

Father parent-related stress

Fathers who almost always attend competition had significantly lower scores on Overall parent-related stress ($sr^2 = .10$), Isolation, Role restriction, and Spouse support (sr^2 range = .12 - .14), compared to fathers who did not attend with the same frequency. As well, children who continued to live at home had fathers with significantly higher scores on Overall parent-related stress ($sr^2 = .14$), Spouse support ($sr^2 = .19$), and Depression ($sr^2 = .10$). In contrast to mothers, paternal Attachment scores were not related to any variables. Paternal Competence scores were significantly related to the family's income ($sr^2 = .15$).

Discussion

The current findings add to our understanding of the characteristics of parents involved in their adult children's physical activity programs, in that a number of predictor variables have been highlighted for future research. Our findings may be of use to organizations that provide service to adults with intellectual disabilities and involve their parents. However, given the relatively small effect sizes for many of the relations (especially for mothers); it is evident that many other factors not measured are necessary for understanding parenting stress.

The primary hypothesis of this study was supported, in that parenting stress could be predicted by the frequency of attendance at their children's Special Olympics competitions. These results were evident after controlling for age, IQ, finances, diagnosis, and residential status. Frequency of parental attendance was significantly related to nearly every maternal and paternal child-related subscale (except for Hyperactivity). The PSI Child-related scale measures parents' evaluations of their children's qualities, with the idea that negative appraisals lead to more parenting stress. Results suggest that parents who attend competition with greater frequency view their children as having more positive characteristics.

Frequency of attendance was also predictive of overall parent-related stress, albeit to a lesser degree than of child-related stress. Mothers who almost always attend report higher levels of attachment to their child, more spousal support, and less depression, than mothers who attend less. Fathers with lower levels of isolation, more spousal support, and less role restriction tend to attend more frequently.

Another consistent predictor was diagnosis: Parents of individuals with Down syndrome report less child-related stress compared to a group of parents of individuals with other types of

etiology. These results suggest that the ‘indirect effects’ of etiology on child-related stress reported by others (Hodapp, *et al.* 2003; Ricci & Hodapp, 2003) may extend into adulthood.

A number of other relations were different for mothers and fathers. An unexpected and potentially useful finding of the present study was that mothers who volunteer have more child-related stress, and more negative attachments, than mothers who do not volunteer -a difference not evident for fathers. It is important that organizations be aware that mothers who volunteer may be at risk for increased child-related stress. This is an unexplored area of a research, and studies are needed to delineate parents’ motivations for volunteering. It is interesting to note that fathers with an adult child living at home rated their child as more demanding and had higher parent-related stress, compared to fathers of children living outside of the home. As well, fathers’ sense of parental competence was linked to family income. Fitting with these results, several other studies that have found that mothers and fathers report similar levels of parenting stress, but that the predictors of stress for mothers are often more social and external to the family, while for fathers are more centered around family cohesiveness, greater economic resources, and problem solving (Hauser-Cram *et al.* 2001; Krauss, 1993; Roach, Orsmond, & Barratt, 1999).

This study is correlational and did not assign parents to different levels of involvement. As such, the directions of the effects are unknown, and may be unidirectional or bi-directional (Emerson, Robertson & Wood, 2003). It may be that parents who feel less stress and perceive their children in a more favourable light have more desire to attend competitions. Conversely, seeing their child’s competence at competitions may help increase parental warmth and gratification in the parent-child relationship. Future research is needed to assess these possibilities directly, by employing pre-post experiments and longitudinal designs.

Table 1

Significant predictors of standard multiple regression analyses of maternal stress

Dependent	Predictor(s)	β	t	p	sr²	R	R²	F	p of F
Child stress	Diagnosis	.33	2.26	.03	.08	.56	.31	2.87	.02
	Frequency of Attendance	-.44	-2.05	.005	.14				
	Volunteer Status	-.31	-2.95	.05	.07				
Adaptability	Diagnosis	.36	2.56	.01	.10	.46	.21	1.98	.08
	Frequency of Attendance	-.29	-2.04	.05	.06				
Reinforces Parent	Frequency of Attendance	-.34	-2.46	.02	.09	.47	.22	2.17	.05
	Volunteer Status	-.32	-2.30	.03	.08				
Demandingness	Diagnosis	.32	2.39	.02	.08	.54	.29	3.01	.01
	Frequency of Attendance	-.49	-3.56	.001	.17				
Mood	Diagnosis	.30	2.11	.04	.07	.46	.21	1.95	.08
Acceptability	IQ	-.34	-2.58	.01	.08	.54	.29	3.23	.006
	Diagnosis	.36	2.78	.007	.09				
	Frequency of Attendance	-.28	-2.21	.03	.07				
	Volunteer Status	-.31	-2.36	.02	.06				
Hyperactivity	-	-	-	-	.41	.18	1.60	.16	
Parent stress	Child age	.35	2.13	.04	.09	.50	.25	1.83	.11
	Frequency of Attendance	-.35	-2.01	.05	.08				
Competence	-	-	-	-	.46	.21	1.83	.11	
Isolation	-	-	-	-	.31	.09	.81	.58	
Attachment	Child age	.35	2.87	.006	.10	.59	.35	3.98	.001
	Frequency of Attendance	-.32	-2.53	.02	.08				
	Volunteer Status	-.32	-2.45	.02	.07				
Role restriction	-	-	-	-	.31	.10	.88	.53	
Spouse support	Frequency of Attendance	-.30	-2.07	.04	.07	.48	.23	1.92	.09
Depression	Frequency of Attendance	-.39	-2.61	.01	.11	.46	.21	1.95	.08

Table 2

Significant predictors of standard multiple regression analyses of paternal stress

Dependent	Predictor(s)	β	t	p	sr²	R	R²	F	p of F
Child stress	Diagnosis	.40	2.42	.02	.11	.70	.49	3.81	.005
	Frequency of Attendance	-.45	-2.99	.006	.16				
Adaptability	Frequency of Attendance	-.45	-2.97	.006	.16	.66	.43	3.73	.009
Reinforces Parent	Child age	-.42	-2.78	.009	.14	.66	.44	3.43	.008
	Frequency of Attendance	-.48	-3.11	.004	.18				
Demandingness	Residence	.37	2.14	.04	.09	.61	.38	2.57	.03
	Frequency of Attendance	-.32	-2.04	.05	.08				
Mood	Diagnosis	.41	2.31	.03	.12	.59	.35	2.33	.05
	Frequency of Attendance	-.39	-2.29	.03	.12				
Acceptability	Diagnosis	.40	2.40	.02	.10	.64	.41	3.14	.01
	Frequency of Attendance	-.36	-2.28	.03	.09				
Hyperactivity	Child Age	-.58	-3.72	.001	.34	.63	.40	2.93	.02
	Diagnosis	.35	2.06	.05	.08				
Parent stress	Residence	.34	2.00	.05	.08	.61	.37	2.50	.04
	Frequency of Attendance	-.39	-2.28	.03	.10				
Competence	Family income	-.43	-2.60	.01	.15	.61	.38	2.65	.03
Isolation	Frequency of Attendance	-.41	-2.27	.03	.13	.45	.21	1.19	.34
Attachment	-	-	-	-	-	.45	.20	1.17	.35
Role restriction	Frequency of Attendance	-.45	-2.45	.02	.12	.48	.23	1.34	.27
Spouse support	Residence	.51	3.38	.002	.19	.69	.48	4.10	.003
	Frequency of Attendance	-.43	-2.89	.007	.14				
Depression	Residence	.37	2.28	.03	.10	.65	.42	3.09	.01

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Acknowledgements

This research was supported by Ontario Special Olympics, Inc., and by a scholarship from the *Fonds de la Recherche en Santé du Québec* (Fonds FCAR) to the first author and an *Ontario Graduate Scholarship* to the second author. The authors wish to thank April Sullivan and the anonymous reviewer for their helpful comments and the many families in Special Olympics for their participation.

Key words: Intellectual disability, Parents, Stress, Competition, Volunteerism