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Relations of Parental Perceptions to the Behavioural Characteristics of Adolescents with Down Syndrome

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Abstract

This study examined how the behaviours of individuals with Down syndrome relate to parent functioning during the adolescent years. Measures of personality, intelligence, adaptive, and maladaptive behaviour were collected for 42 adolescents with Down syndrome and related to parental depression, ways of coping, worries about the future, and positive perceptions. Across the adolescent years, most parents continued to feel rewarded by their adolescents with Down syndrome; adolescents who displayed more positive personality characteristics had parents who felt more rewarded by their children. Conversely, those who displayed higher levels of internalizing (but not externalizing) problem behaviours had parents who were significantly more worried about their adolescents' futures. Implications are discussed.

Many studies of families of individuals with Down syndrome (DS) have identified a "Down syndrome advantage" (Hodapp, Ly, Fidler, & Ricci, 2001; Seltzer & Ryff, 1994). This perspective holds that, compared to families of children with other intellectual and developmental disabilities, families of individuals with DS cope better. Compared to these other families, then, families of individuals with DS tend to be warmer (Mink, Nihira, & Meyers, 1983), mothers experience less stress (Hodapp, Ricci, Ly, & Fidler, 2003), fathers report close relationships (Hornby, 1995), and siblings report increased amounts of positive benefits (Hodapp & Urbano, 2007).

While the "Down syndrome advantage" does seem to exist, the reasons for its existence continue to be debated. Some argue that closer family dynamics may relate to the personality phenotype of the child. Specifically, children with DS often have fairly low levels of behaviour problems, more positive personalities (Dykens & Kasari, 1997; Kasari, Mundy, Yirmiya, & Sigman, 1990), and, compared to individuals with other types of intellectual disabilities, often have less difficult temperaments (Kasari & Sigman, 1997). Conversely, advantages for families may be due primarily to demographic characteristics. On average, parents of children with DS tend to be older (Urbano & Hodapp, 2007), to hold more senior job positions (Corrice & Glidden, 2009), and to be more affluent (Grosse, 2010). In some studies, controlling for such demographic variables reduced the parental rewards of raising children with DS (Corrice & Glidden, 2009).

To date, most studies have been conducted with families of younger children with DS (Hodapp, 2007), with little focus on adolescents. But just as for individuals without disabilities, adolescence is a difficult time for many individuals with intellectual and developmental disabilities. Moreover, across the adolescent years, age may be related to subtle increases in internalizing behaviours for many individuals with DS (Dykens & Kasari, 1997; Dykens, Shah, Sagun, Beck, & King, 2002).

Even if, when compared to those without DS, adolescents with DS increase in internalizing behaviours across adolescence, we do not yet know how internalizing behaviours affect others. Do, for example, the increased maladaptive behaviours of adolescents with DS affect parental reactions and their concerns about their child's transition to adulthood? Alternatively, certain (mostly unchanging) demographic characteristics may continue to explain the "Down syndrome advantage" across adolescence for individuals with DS.

This study related parent perceptions to the adolescents' personality, behaviours, and IQ. Specifically, this study cross-sectionally examined: (1) the personality, demographic, and behavioural characteristics of adolescents with DS; (2) parental coping styles, feelings of rewards, positive perceptions, and worries for the future; and, (3) the connections among the adolescent's characteristics and parental responses, positive perceptions, and transition concerns.

Method

Participants

This study included 42 adolescents with DS (26 M; 16 F) and their parents (3 M; 39 F). Most participants were White (90.2%), and the remaining participants were African-American. Adolescents averaged 15.12 years of age (SD = 2.82) with a range from 11–21 years. All adolescents were in the mild to moderate range of intellectual disability, with a mean IQ of 45.93 (SD = 6.77; range from 40 to 61). The mean standard score for verbal knowledge was 48.93 (SD = 9.38) and for non-verbal knowledge was 50.05 (SD = 9.78). Of those who were still in school, most adolescents (74.2%) were educated in a general education setting, while the remainder attended self-contained special education classes. Over half (62.1%) had repeated a grade in school and parents reported that their adolescents had an average of 1.81 friends (SD = 1.13).

The mean age of the mothers was 48.18 (SD = 5.94) and of fathers was 50.36 (SD = 6.67). Mothers worked an average of 21.49 hours (SD = 19.6) outside of the home and fathers 42.31 hours (SD = 15.32). Family size averaged 2.83 (SD = 1.0) children and, in 73.1% of families, the mother was married to the father of the adolescent.

Measures

Adolescents were administered the Kaufman Brief Intelligence Test (K-BIT) (Kaufman & Kaufman, 1990). A psychometric measure for individuals aged 4–90 years. The K-BIT includes a composite IQ as well as standard scores for verbal and for non-verbal knowledge. The K-BIT has been used with persons with intellectual disabilities (Dykens, Rosner, & Ly, 2001).

Parents also completed two packets of questionnaires, one of adolescent-related measures and another of parent-related measures.

Adolescent-Related Measures

The Wishart Scale (Wishart & Johnston, 1990) consists of 23 commonly-mentioned personality characteristics of individuals with DS. Parents rated each personality trait on a 5-point Likert scale, with possible scores ranging from 23 to 115 (higher scores denote individuals who are more outgoing and sociable). For this sample, Cronbach's alpha equaled .832.

Child Behavior Checklist (CBCL) (Achenbach, 1991) includes 112 items concerning maladaptive behaviours, each rated from 0 to 2 (0 = not present; 1 = somewhat or sometimes true; 2 = very true or often). The CBCL consists of two broad-band factors (Internalizing, Externalizing), which are composed of eight narrow-band factors. Higher scores indicate more maladaptive behaviours. A reliable and valid measure of maladaptive behaviour in children and adolescents, the CBCL has been used with individuals with intellectual disabilities (Dykens & Kasari, 1997).

The Reiss Profiles of Fundamental Goals and Motivational Sensitivities for Persons with Mental Retardation (Reiss Profiles) (Reiss & Havercamp, 1998) assesses motivational strengths and styles of individuals with intellectual disabilities. Respondents rated the adolescent on 100 statements along a 5-point scale (1 – strongly disagree, not at all characteristic of person to 5 – strongly agree, definitely characteristic). Although the Reiss Profiles have 15 factors, our interests were primarily in factors relating to five positive and social constructs (*independence* – desire to make own decisions; *curiosity* – desire to learn; *help others* – desire to help friends; *morality* – desire to behave in accordance with a code of conduct; and *social contact* – the desire to be in the company of others).

Parent-Related Measures

The Beck Depression Inventory (BDI) (Beck, Steer, & Brown, 1996) measures symptoms associated with depression (e.g., sadness, guilt, self-dislike, crying, insomnia). Respondents rated the severity in which they experience each symptom (0 to 3). Ranging from 0 to 63, scores above 10 fall within the clinical range.

Positive Perceptions in Families Questionnaire (PPFQ) assesses how rewarded the parent feels about having a child with a disability. Six statements are rated on a 4-point scale (1 = strongly disagree to 4 = strongly agree). Statements include: "I enjoy and feel satisfaction in my role as a parent of a child with a disability"; "Being a special parent has strengthened my marriage and our family"; and "I feel like I have my priorities straight because I am a special parent." Ranging from 6 to 24, higher scores indicate that parents feel more rewarded (alpha = .887).

Kansas Inventory of Parental Perceptions-Positive Contributions Section (KIPP-PC) (Behr, Murphy, & Summers, 1992) assesses how much the parent feels the adolescent with a disability positively contributes to the family. Respondents rated 41 statements on a 4-point scale (1 = strongly disagree; 4 = strongly agree). In this study, we used seven (of nine) KIPP-PC subscales: (1) Learning through experience with special problems (e.g., "My child is responsible for my increased awareness of people with special needs"; alpha = .679); (2) Happiness and fulfillment (e.g., "Because of my child, I have many unexpected pleasures"; alpha = .673); (3) Personal strength and family closeness (e.g., "Because of my child, our family has become closer"; alpha = .856); (4) Personal growth and maturity (e.g., "My child is the reason why I am a more responsible person"; alpha = .833); (5) Awareness of future issues (e.g., "I consider my child to be what makes me realize the importance of planning for my family's future"; alpha = .616); (6) Expanded social network (e.g., "My child is why I met some of my best friends"; alpha = .815); and (7) Career or job growth (e.g., "The presence of my child is an inspiration to improve my job skills"; alpha = .613).

COPE Questionnaire (Carver, Scheier, & Weintraub, 1989) is a 53-item index used to assess different coping styles. Respondents indicate how much they use a particular behaviour when they experience stressful events in their lives (1 = I usually don't do this at all to 4 = I usually do this a lot). Lyne and Roger (2000) identified three coping factors: (1) Rational-Active Coping (accept that a stressful situation occurred; "I try to come up with a strategy about what to do"); (2) Emotional Coping (express feelings and seek emotional support; "I try to get emotional support from friends and relatives"); and, (3) Avoidance-Helplessness Coping (behavioural disengagement and denial; "I act as though it hasn't even happened"). Scores range from 18 to 72 for Rational-Active Coping (alpha = .838), from 8 to 32 for Emotional Coping (.869), and from 11 to 44 for Avoidance-Helplessness Coping (.757).

Transition Daily Rewards and Worries Questionnaire (TDRWQ) (Glidden & Jobe, 2007) is a 28-item questionnaire measuring parental rewards and worries as their adolescents transition to adulthood. Respondents indicated their level of agreement on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree), with higher scores indicating more rewards and fewer worries. Questionnaire factors include: Positive Future Orientation (general feelings about the child's future; "I am optimistic about my child's future"; alpha = .682); Community Resources (feelings toward the child's job preparation and independent living; "I believe that there are a lot of resources available in my child's community"; .672); and Financial Independence (perception of the child's likelihood of becoming financially self-supporting; "I worry that my child will never be self-supporting"; .704). An additional domain, Family

Relationship with Siblings, was not used in this study, and a final domain, Family Relations, was not used because its component items did not form a single scale (alpha = -.353).

Procedure

Participants were recruited through DS support groups in Tennessee and Illinois. Interested parents either brought their adolescent with DS to the research lab or the researchers traveled to a location where the assessments could be completed (e.g., home; hotel conference room). Prior to the visit, parents were mailed a packet of adolescent-related measures to complete; during the visit, a research assistant conducted the K-BIT with the adolescent, while parents completed the parent-related measures.

Results

Characteristics of Adolescents with Down Syndrome

On average, parents rated these adolescents as having fairly social, outgoing personalities and relatively low levels of behaviour problems. Wishart Scale scores averaged 91.20 (SD = 9.98), significantly above the scale's mid-point (i.e., 69), $t(40) = 8.47$, $p < .001$. Similarly, most adolescents did not present many behavioural problems. On CBCL internalizing behaviours, 87.2% of adolescents scored in the normal range and 12.8% in the clinical range. Among specific narrow-band factors, thought problems showed the highest percentage of adolescents (23%) in the clinical range. Similarly for externalizing behaviours, 92.3% of adolescents scored in the normal range and 7.7% scored in the clinical range. For total behaviour problems as well, 84.6% scored in the normal range and 15.4% in the clinical range. No significant relations emerged between the participant's age or IQ and personality or maladaptive behaviours.

Characteristics of Parents

While adolescents with DS generally showed few problems, the reactions and perceptions of their parents were more mixed. On the positive side, parents held generally positive perceptions about raising an adolescent with Down syndrome. Compared to parents of children with various disabilities who answered about the positive contributions in the original KIPP-PC study (Behr et al., 1992), parents of these adolescents with DS scored higher on all but two of the 7 KIPP-PC sub-scales. Thus, whereas the original norming group scored slightly higher on the KIPP-PC's Happiness and Fulfillment domain, $t(1302) = -3.59$, $p < .01$, and no group differences emerged on Personal Growth and Maturity, $t(1302) = 0.94$, *ns*, parents of these adolescents with Down syndrome scored higher than did the norming group on Learning Through Experience with Special Problems, $t(1302) = 3.33$, $p < .01$; Personal Strength and Family Closeness, $t(1302) = 1.98$, $p < .05$; Awareness of Future Issues, $t(1302) = 2.19$, $p < .05$; Expanded Social Network, $t(1302) = 4.91$, $p < .001$; and Career or Job Growth, $t(1302) = 6.68$, $p < .001$.

Second, most parents showed high levels of Rational Coping (considered the best type of coping) and relatively low levels of Avoidant Coping. Compared to a mean on the COPE's Rational-Coping Domain of 33.29 (SD = 8.74) for Lyne and Roger's (2000) community-based sample, parents of these adolescents with DS scored 55.75 (SD = 6.57), $t(519) = 16.02$, $p < .001$. Conversely, compared to a community-sample average of 33.70 (SD = 4.74) on the COPE's Avoidance-Helplessness Coping domain, parents of these adolescents scored much lower, at 15.78 (SD = 3.78), $t(550) = 30.53$, $p < .001$. No differences emerged between the two groups on the COPE's Emotional Coping factor, nor were there significant correlations in the DS group among the three coping styles. Parents displaying higher levels of Rational-Active Coping felt more rewarded (PPFQ) and perceived their child as contributing more positively to their family within areas such as Learning Through Experience with Special Problems, Personal Strength and Family Closeness, and Awareness of Future Issues (see Table 1).

Third, parents' depression scores averaged significantly below the cutoff for mild depression, $t(38) = -6.87$, $p < .001$; several parents, however, experienced higher levels of depressive symptoms. Overall, the sample's BDI averaged 6.17 (SD = 7.12), with a range of 0 to 35. While most parents (71.1%) were not depressed, nine (23.7%) were mild/moderately depressed (scores

Table 1. Means of Parental Perceptions of Rewards and Contributions and Transitions, and correlations with Depression and Coping Styles

	M (SD)		*BDI*	*Rational Active Coping Style*
PPFQ (Rewards)	19.90	(3.62)	-.45**	.34*
KIPP-PC (Positive Family Contribution)				
Learning Through Experience with Special Problems	3.53	(0.46)	-.01	.54**
Happiness and Fulfillment	3.10	(0.57)	-.12	.31
Personal Strength and Family Closeness	3.23	(0.58)	-.34*	.49**
Awareness of Future Issues	3.11	(0.64)	-.04	.43**
Personal Growth and Maturity	2.74	(0.68)	-.28	.29
Expanded Social Network	3.00	(0.65)	-.26	.24
Career or Job Growth	2.96	(0.51)	-.18	.40*
TDRWQ (Transition Worries/Rewards)				
Positive Future Orientation	3.08	(0.72)	-.10	-.37*
Financial Independence	2.27	(0.93)	-.22	.04
Community Resources	2.40	(0.71)	.10	-.07

between 10.2 and 15.1) and two (5.2%) showed moderate-to-severe depressive symptoms (scores = 20.4 and 35.3). While no significant relations occurred between parental depression and parental perceptions of the child's positive contributions (*r's* of BDI to KIPP-PC factors = -.34 to -.01, *ns*), parental depression scores were negatively related to parental feelings of adolescent rewardingness (BDI to PPFQ). See Table 1.

Finally, parents of adolescents with DS characterized certain transitions as rewards or worries. Parents felt most concerned about their adolescent's future financial independence (2.27; SD = .93) and community resources (2.40; SD = .71).

Relations Between Parent and Adolescent Variables

Demographic and functional skills. No significant correlations emerged between the adolescent's age, gender, or IQ score and parental depression (BDI), coping styles (3 COPE factors), rewardingness (PPFQ), perceptions of adolescent's positive contributions (KIPP-PC), or transition rewards or worries (TDRWQ).

Adolescent Behaviour Problems. Parents' depression scores were positively related to the adolescent's Internalizing behaviours and, to a lesser extent, to total behaviour problems (see Table 2). Parental BDI scores were also related to the CBCL narrow-band domains of Thought Problems, $r = .59$, $p < .01$, Withdrawn/ Depressed, $r = .50$, $p < .01$, Social Problems, $r = .43$, $p < .01$, and Somatic Complaints, $r = .37$, $p < .05$.

Consistent relations also emerged between the adolescent's higher amounts of internalizing problems and parental worries about the adolescent's future. Specifically, those parents who judged their adolescents to have more Internalizing problems rated themselves lower on TDRWQ Positive Future Orientation. Such parental concerns about the child's future were significantly related to all Internalizing narrow-band domains (*rs* from -.56, with Somatic Complaints, to -.42, with Thought Problems; *ps* < .02). Negative correla-

Table 2. Correlations Between the Adolescent's Level of Behaviour Problems and Parent Depression, Feelings of Reward, Feelings of Adolescent Contribution, and Transition Worries or Rewards

	Internalizing Problems	*Externalizing Problems*	*Total Problems*
BDI	.425**	.130	.437**
PPFQ	.038	-.129	-.116
KIPP-PC			
Learning through experience	.175	.042	.088
Happiness and fulfillment	.018	-.063	-.055
Strength and family closeness	.029	-.015	-.035
Awareness about future issues	.070	.067	.042
Personal growth and maturity	.034	-.005	-.029
Expanded social network	-.117	.017	-.124
Career/job growth	.065	.103	.065
TDRWQ			
Positive Orientation	-.618**	-.160	-.395*
Community Resources	-.088	.145	-.021
Financial Independence	-.373*	-.297	-.397*

tions were also found between the adolescent Internalizing domain (and overall problems) and Financial Independence (see Table 2). No relations emerged between parental scores on the TDRWQ and the adolescent's level of Externalizing problems.

Personality. Parental perceptions were related to higher levels of positive—but not of negative—personality characteristics of the adolescent with DS. Specifically, the degree to which parents perceived their child as a source of reward (PPFQ) increased for parents who rated their adolescent higher on independence, curiosity, morality, and social contact. Parents reported less depression when their adolescents were more moral and independent. Similarly, as Table 3 shows, parents who rated their child higher on many of the more positive personality characteristics also viewed their adolescent as contributing more to their family's happiness/fulfillment, strength, learning, closeness, growth, expanded social network, and even career/job growth (KIPP-PC). Few correlations emerged between parental perceptions and any of the negative Reiss factors; nor were there consistent correlations of either positive or negative adolescent personality characteristics and worries or rewards related to transition. There were also no relations between parent depression, reward, or family contributions and parents' ratings of their child on the Wishart Scales (*r*'s = -.26 to .30, *ns*).

Discussion

Although for many decades individuals with Down syndrome and their families have been the subject of study, we continue to know little about how adolescent characteristics relate to parental reactions. As such, this study provides additional information about adolescents with DS, their parents, and the interplay between characteristics of adolescents with DS and their parents in relation to coping styles, transition, and positive effects.

This study produced four main findings. First, as a group, adolescents with DS remained friendly and cheerful during their teenage

Table 3. Correlations Between Positive Reiss Personality Factors and Parent Depression, Feelings of Reward, and Perceptions of the Adolescent's Positive Contribution to the Family

	Independence	*Curiosity*	*Help Others*	*Morality*	*Social Contact*
BDI	-.381*	-.333*	-.089	-.349*	-.261
PPFQ	.432**	.422**	.256	.406**	.391*
KIPP-PC					
Learning Through Experience	.483**	.366*	.352*	.220	.369*
Happiness/Fulfillment	.346*	.440**	.294	.385*	.383*
Strength/Family Closeness	.551**	.540**	.292	.363*	.397*
Awareness about Future Issues	.570**	.485**	.397*	.413**	.354*
Growth/Maturity	.408**	.485**	.351*	.417**	.345*
Expanded Social Network	.315*	.265	.082	.104	.376*
Career/Job Growth	.514**	.406**	.391*	.440**	.410**

years. While adolescence is often a difficult time for parents and their children, most parents of adolescents with DS continue to view these children as happy, affectionate, and with few internalizing or externalizing maladaptive behaviours. While internalizing problems may become more common as individuals with DS get older (Dykens, et al., 2002; Stores, Stores, Fellows, & Buckley, 1998; Tonge & Einfeld, 2003), these problems were not yet pervasive or of clinical significance in this sample.

Second, we noted the importance of active, rational coping for these parents. Even compared to Lyne and Roger's (2000) community group, parents of adolescents with DS more often endorsed a style of coping that was active and rational, less often one that relied on avoidance. Levels of rational coping, in turn, related to feelings of reward, both in relation to parenting the adolescent and from the benefits that parents perceived that child as bringing to the family. Prior studies have also noted that an active coping style relates to parents' feelings of reward and positive contributions (Mak & Ho, 2007), and that avoidant coping styles were not related to positive perceptions. Hastings and Taunt (2002) suggested that a focus on positive perceptions as coping resources could be used as an intervention to help families adapt to raising a child with disabilities. Those parents with more positive perceptions could also help parents who are struggling, in that contact with parents who have a positive attitude may make other parents' attitudes more positive, thus helping them cope more effectively.

Third, we noticed an intriguing pattern of relations between child negative and positive behaviours and parental perceptions-reactions. Thus, even though adolescent levels of internalizing problems were low, did not relate to age, and few participants showed clinical levels of CBCL Internalizing problems, such problems were worrisome to parents. Indeed, adolescent levels of Internalizing problems were related to increased parental depression, and greater worries (versus rewards) concerning their adolescents' positive future outcomes and financial independence. Conversely, parents feel that they and their families benefit when their children are more independent, social, moral and curious. Such connections varied slightly with different measures, but—just as parents are worried about internalizing or "inwardness" of their children—

they seem rewarded when the child shows more positive personality characteristics.

Fourth, several expected relations did not occur. In contrast to the large (over 200) cross-sectional sample noted in Dykens et al. (2002), we did not not find increases in CBCL Internalizing problems with increased adolescent age. Thus, even though parents worried about the inwardness of their children, levels did not seem to increase over age. Most likely such changes were more subtle and hard to detect with our smaller sample. In addition, few connections emerged between CBCL Externalizing problems and parental reactions of any type. From these data, then, Internalizing problems most affect parents; indeed, even the hint of a slightly less sociable, more inward-directed personality in their children seemed to influence parents.

While it offers many insights, this study nevertheless has certain limitations. Specifically, our sample was mostly comprised of highly educated, White parents; as such, these results may not be generalizable to families from different cultural and racial backgrounds. As a cross-sectional examination, we also provided only a snapshot of families of adolescents with DS; we thus cannot determine how parental perceptions and coping styles may have changed over time. Finally, with the exception of the K-BIT IQ test, parents served as the reporters of the child's personality-maladaptive behaviours and of their own reactions.

Still, this study constitutes a first step in describing families of adolescents with DS. Although research is needed using multiple time points, reporters, and contrast groups, this study sheds light on both adolescents with DS and their parents. Ultimately, if our goal is to support parents to help their adolescents, we need to understand more fully the characteristics of individuals with DS; of parental coping, depression, and rewards; and the connections between offspring and parental characteristics over the adolescent years.

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