Psychological Well-being in Fathers of Adolescents and Young Adults with Down Syndrome, Fragile X Syndrome, and Autism

Sigan L. Hartley¹, Marsha Mailick Seltzer¹, Lara Head², and Leonard Abbeduto¹
¹University of Wisconsin-Madison
²Gundersen Lutheran Medical Hospital

Abstract

The psychological well-being of fathers of children with developmental disabilities remains poorly understood. The present study examined depressive symptoms, pessimism, and coping in fathers of adolescents and young adults with Down syndrome (DS; n = 59), autism spectrum disorders (ASDs; n = 135), and fragile X syndrome (FXS; n = 46). Fathers of sons/daughters with ASDs reported a higher level of depressive symptoms than the other groups of fathers. Fathers of sons/daughters with DS reported a lower level of pessimism than the other groups of fathers. There were no group differences in paternal coping style. Group differences in paternal depressive symptoms and pessimism were, in part, related to differences in paternal age, the child’s behavior problems, risk of having additional children with a disability, and maternal depressive symptoms. Findings from this study can be used to educate providers and design services for fathers during the later parenting years.

Approximately 1% to 2% of children in the United States have a developmental disability, defined as a severe condition due to a mental or physical impairment that manifests prior age 22 years that is likely to continue indefinitely and markedly impairs everyday functioning (National Center on Birth Defects and Developmental Disabilities, 2006). Parenting a child with a developmental disability presents extraordinary challenges; parents often must assist their son or daughter with everyday living skills and manage their symptoms and comorbid behavior problems, and navigate the complex disability service system (Hodapp & Ly, 2005). These challenges are not limited to the early parenting years, but extend into the son or daughter’s adolescence and adulthood. Adolescents and adults with developmental disabilities often continue to reside with parents (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001) and thus, parents continue to have high levels of day to day parenting responsibilities and stress (Seltzer et al., 2001; Smith et al., 2009).

These parenting challenges can have a negative effect on parents’ well-being; mothers of both young and grown children with developmental disabilities present with more psychopathology than do mothers of similarly-aged children without disabilities (e.g., Baker, Blacher, Crnic & Edelbrock, 2002; Seltzer et al., 2009). The extent of this negative effect, however, varies according to the nature of the child’s disability; some child disabilities are related to high rates of parenting stress and poor psychological well-being in mothers, whereas other child disorders have much less impact (Abbeduto et al., 2004; Sellinger & Hodapp, 2005). In contrast to the large body of research on mothers, little is known about the psychological well-being of fathers of children with developmental disabilities. Although mothers tend to bear more responsibility for childcare than fathers.
within families of children with developmental disabilities (Ricci & Hodapp, 2003; Simmerman, Blacher, & Baker, 2001), fathers are not immune to child-related challenges. Indeed, the few studies that have included fathers of younger children with developmental disabilities indicate that fathers often report higher parenting stress and poorer psychological well-being than fathers of children without disabilities (Dyson, 1997; Roach, Orsmont, & Barrati, 1999) and similar levels of parenting stress as mothers (Dyson, 1997; Hastings, 2003; Keller & Honig, 2004). These studies also indicate that there is a great deal of variability in paternal psychological well-being. As with mothers, some of this variation may be due to the nature of their child’s disability; however, research on fathers is sparse.

Down syndrome (DS), autism spectrum disorders (ASDs) and fragile X syndrome (FXS) constitute three of the most common developmental disabilities. DS, which occurs in 1 in 800 births (Shin et al., 2009), typically results from a non-inherited chromosomal error (trisomy 21) and generally leads to mild to moderate levels of intellectual disability (Dykens, Hodapp, & Finucane, 2005). ASDs are a spectrum of conditions marked by impairments in communication, social reciprocity, and restricted/ repetitive behaviors (American Psychological Association, 2000). Half to about three-fourths of individuals with an ASD also have intellectual disability (Fombonne, 2003) and the majority evidence comorbid behavior problems, such as inattention and disruptive behavior (e.g. Brereton, Tonge, & Einfeld, 2006). ASDs occur in 1 in 110 children (Autism and Developmental Disabilities Monitoring Network, 2009) and are believed to result, in large part, from inherited and non-inherited genetic mechanisms (Freitag, 2007). FXS is an inherited genetic condition involving changes to the FMR1 gene located on the X chromosome, which may occur as often as 1 in 2,500 persons (Hagerman, 2008). FXS results in cognitive impairment ranging from mild learning disabilities to intellectual disability, behavior problems, including inattention and hyperactivity, and an increased risk for ASDs (Bailey, Raspa, Olmsted, & Holiday, 2008).

Differences in the nature (i.e., etiology and behavioral presentation) of DS, ASDs, and FXS may lead to divergent parenting contexts and stressors and thereby differentially affect psychological well-being. The present study was designed to compare the psychological well-being of fathers of adolescent and young adult children with DS, ASDs, and FXS and to identify the factors contributing to potential group differences. Current family services within the field of developmental disabilities are predominately focused on the early parenting years and directed toward mothers, with little consideration of fathers (Parette, Meadan, Hedda, & Doubet, 2010; Turbiville & Marquis, 2001). Information from the present study may provide information useful in advocating for and designing interventions to involve and address the needs of fathers and the challenges they face in later parenting years. In the general population, paternal psychological well-being has important interconnections with child well-being (e.g., Lovejoy, Graczyk, O’Hare, & Newman, 2010) and maternal well-being (e.g., Walker, Luszcz, Gerstort, & Hoppmann, 2010). Evidence suggests that there are similar interconnections between father, mother, and child well-being in families of children with developmental disabilities (e.g., Stoneman & Payne-Gavida, 2006; Hastings, 2003). Thus, efforts to understand and then develop interventions to promote optimal psychological well-being in fathers of children with developmental disabilities has implications for fostering positive well-being in multiple family members.

**Father Psychological Well-Being and Child Diagnosis**

Given the paucity of studies comparing the psychological well-being of fathers of young or grown children with different types of developmental disabilities, we turn to research on mothers to inform hypotheses in the present study. The child diagnoses most taxing on mothers may also be the ones that are most taxing on fathers, as they may alter parenting
contexts and stressors in ways that affect both parents. Indeed, our own previous research has found significant positive inter-spouse correlations in parenting burden within families of adolescents and young adults with ASDs (e.g., Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011).

Mothers of young and grown children with DS, ASDs, and FXS have been shown to experience varying levels of psychological well-being (e.g., Abbeduto et al., 2004; Hodapp, Ricci, Ly, & Fidler, 2003). Research has consistently shown a pattern of ‘DS advantage,’ in which mothers of children with DS report lower levels of stress (Hodapp et al., 2003), view caregiving more positively (Sellinger & Hodapp, 2005), and report more support-seeking coping (Poehlmann, Clements, Abbeduto, & Farsad, 2005) than mothers of children with other types of disabilities. In contrast, a pattern of ‘ASD disadvantage’ has emerged in which mothers of children with ASDs report higher levels of stress (Sanders & Morgan, 1997) and increased depressive symptoms (Olson & Hwang, 2001) as compared to mothers of children with other disabilities, including DS. Our own research suggests that this diagnostic-related pattern of psychological well-being continues in mothers of adolescents and young adults with DS and ASDs (Abbeduto et al., 2004). Our previous research also suggests that mothers of adolescents and young adults with FXS appear to fare somewhat better than mothers of adolescents and young adults with ASDs, but worse than mothers of adolescents and young adults with DS (e.g, Abbeduto et al., 2004; Lewis et al., 2006; Poehlmann et al., 2005).

Although the data on fathers are limited, fathers of young children with DS have also been found to report lower levels of stress than fathers of children with other types of disabilities (Fidler, Hodapp, & Dykens, 2000; Ricci & Hodapp, 2003). Similarly, fathers of young children with ASDs have been shown to report higher levels of stress than fathers of children with other disabilities (Sanders & Morgan, 1997). However, there have been no studies examining whether these diagnostic-related differences in paternal psychological well-being continue into the son or daughter’s adolescence and adulthood, as is true for mothers. Moreover, the relative psychological well-being of fathers of adolescents and young adults with FXS remains unstudied.

Factors Contributing to Differences by Child Diagnosis

The pattern of differences in the psychological well-being of mothers of young and grown children with DS, ASDs, and FXS is often attributed to the divergent nature of these disabilities. Specifically, the varying etiology and behavioral presentation of these disabilities leads to different parenting contexts and stressors in terms of parent age, the child’s behavior problems, and likelihood of having additional children with a disability. The chromosomal error that causes DS occurs in a higher proportion of the pregnancies of older women (aged ≥35 years), and thus the ‘DS advantage’ is often attributed to increased parent resources due in part to older maternal age and hence greater maturity at the time of the child’s birth (Abbeduto et al., 2004; Urbano & Hodapp, 2007), although recent studies have shown that advanced maternal age is not as consistent an explanation of positive maternal well-being outcomes as previously thought (Esbensen & Seltzer, 2011). Moreover, advanced paternal age has recently been linked to an increased risk of having a child with an ASD (Durkin et al., 2008), underscoring the important of paternal age in studies of parental well-being in families to children with different types of developmental disabilities.

The ‘DS advantage’ has also been attributed to the profile of less negative (e.g., fewer behavior and sleep problems) and more positive behaviors (e.g., more independent living skills and behavioral flexibility) exhibited by individuals with DS as compared to individuals with ASDs and other disabilities (Cotton & Richdale, 2006; Didden et al., 2008;
Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2011). In contrast, individuals with ASDs and FXS evidence a stressful profile of comorbid behavior problems, including hyperactivity, inattention, and disruptive behaviors (Smith et al., 2009; Bailey et al., 2008), which can intensify during adolescence and young adulthood (Hatton et al., 2006; Taylor & Seltzer, 2010a). Child behavior problems, as opposed to intellectual functioning, has consistently been shown to be a strong predictor of parenting stress (e.g., Baker, Blacher, Crnic, & Edelbrock, 2002), and thus, the more frequent and severe profile of comorbid behavior problems in individuals with ASDs and FXS may be an important contributor to poor parental psychological well-being.

Moreover, unlike parents of individuals with DS, who only have a slightly increased risk of having an additional child with a disability, parents of individuals with ASDs (Piven, 2001) and FXS (Bailey, Raspa, Bishop, & Holiday, 2009) have a substantial heightened risk of having an additional children with a disability due to the inherited genetic etiology of these disorders. Caring for multiple children with disabilities has been shown to take a toll on mothers’ well-being (Hartley et al., in press; Orsmond, Lin, & Seltzer, 2007), and may similarly have a negative effect on fathers’ well-being. Paternal age, child behavior problems, and presence of additional children with a disability may similarly account for diagnostic-related differences in the psychological well-being of fathers.

In addition, the psychological well-being of one spouse has been shown to be an important determinant of the psychological well-being of the other spouse in both families of typically developing children (e.g., Dufouil & Alperovitch, 2000; Goodman & Shippy, 2002) and families of younger children with disabilities (Baker, Blacher & Olsson, 2005). The depressed mood of one spouse has been shown to be transmitted through daily interactions to the other spouse (e.g., Larson & Almeida, 1999; Thompson & Bolger, 1999). Moreover, spousal mental health problems can lead to additional caretaking burden for the non-affected spouse and strained marital interactions (e.g., Barling, MacEwen, & Kelloway, 1994; Ruscher & Gotlib, 1988). For some outcome measures, there is evidence that fathers, more than mothers, are negatively impacted by marital distress (Belsky et al., 1991; Cummings & O’Reily, 1997) and poor spousal well-being (Walker et al., 2010). Thus, the poor psychological well-being seen in mothers of children with ASDs may contribute to poor psychological well-being of fathers in these same families. Moreover, in many families affected by FXS, mothers have the premutation of the FMR1 gene and related affect problems (Bailey et al., 2008). Thus, it is important to understand the extent to which differences in maternal psychological well-being can account for variation in the psychological well-being of fathers in these same families.

In the present study we compared the psychological well-being of fathers of adolescents and young adults with DS, ASDs, or FXS and examined factors that contribute to potential group differences. Three indicators of fathers’ psychological well-being were examined: depressive symptoms, pessimism about the child’s future, and coping style. These indicators were selected because they have been shown to vary by child diagnosis in mothers (Abbeduto et al., 2004; Poehlmann et al., 2005; Olson & Hwang, 2001). In order to further understand group differences in paternal psychological well-being, we also examined the extent to which paternal age, the child’s behavior problems, presence of additional children with a disability, and maternal depressive symptoms could account for these differences.

We hypothesized that, as seen for mothers, there would be a pattern indicative of a ‘Down syndrome advantage’ and ‘ASD disadvantage’ in paternal psychological well-being. Specifically, we predicted that fathers of adolescents and young adults with ASDs would report a higher level of depression and pessimism than fathers of adolescents and adults with DS. We also predicted that fathers of adolescents and adults with ASDs would report greater
use of emotion-focused coping and less use of problem-focused coping than fathers of adolescents and adults with DS. Emotion-focused coping is defined as efforts to manage emotions surrounding the problem (e.g., trying to wish away negative feelings or distract oneself) and is generally found to be less effective at buffering the negative impact of stress (e.g., Seltzer, Greenberg, & Krauss, 1995), whereas problem-focused coping is defined as efforts to alter the stressor itself (e.g., seeking information and problem-solving) and is generally found to be effective at buffering the negative impact of stress (e.g., Hastings & Brown, 2002). We expected fathers of adolescents and young adults with FXS to fall in the middle of these other groups on all measures. We also hypothesized that paternal age, the child’s behavior problems, presence of additional children with a disability, and maternal depressive symptoms would account for a significant portion of the diagnostic-related difference in paternal psychological well-being.

Method

The families reported on in the present study overlapped with the sample of families reported in the Abbeduto et al (2004) study analyzing maternal psychological well-being. This sample was drawn from two large research projects involving families of individuals with developmental disabilities. The first project involved families of individuals with DS or FXS (Abbeduto et al., 2004) conducted between 1997 and 2004. The second project is an ongoing longitudinal study of adolescents and adults with an ASD (Seltzer et al., 2003; Seltzer et al. in press). In both projects, families were recruited through local media advertisements, newsletters to national and regional disability organizations, and brochures and postings in clinics, disability listservs, and a university research registry. The present analyses include the subset of 59 fathers who had an adolescent or young adult child (aged 10 to 22 years) with DS, 135 fathers who had an adolescent or young adult child with ASDs, and 46 fathers who had an adolescent or young adult child with FXS.

Sample Members

Adolescents and Young Adults—Diagnosis of DS and FXS were confirmed through medical reports and genetic testing. One (1.7%) individual with DS and 7 (15.2%) individuals with FXS had received a current diagnosis of an ASD from an independent educational or health professional and scored above a cutoff of 44 (Volkmar et al., 1988) on the Autism Behavior Checklists (Krug, Arick, & Almond, 1980) by at least two of the three informants. This prevalence of co-occurring ASD is consistent with previous reports using larger samples of individuals with DS and FXS (Belmonte, 2006; DiGuiseppi et al., 2010). These individuals were included within the DS and FXS groups, respectively, as co-occurring ASD is an important aspect of these syndromes. Within the ASD project, all individuals had received an ASD diagnosis (Autistic Disorder, Asperger Disorder, or PDD-NOS) from an independent educational or health professional, and had a research-administered Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Coutuer, 1994) profile consistent with the diagnosis. Nearly all (94.6%) of the individuals in the ASD group met lifetime criteria for a diagnosis of Autistic Disorder, with the remainder meeting criteria for Asperger Disorder or PDD-NOS. None of the adolescents or adults with ASD had a diagnosis of FXS or DS.

Socio-demographic characteristics of the adolescents and young adults are presented in Table 1. The adolescents and young adults ranged in age from 10 to 22 years, and were predominately male. There was not a significant difference in the gender of the adolescents and young adults among the diagnostic groups. Adolescents and young adults with an ASD were significantly older than were the adolescents and young adults with DS. Intellectual disability (ID) status was determined using a variety of sources of information. In the ASD
sample, IQ was assessed with the Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000) and adaptive behavior was assessed with the Vineland Screener (Sparrow, Carter, & Cicchetti, 1993). Individuals who had standard scores of 70 or below on both measures (or on educational or psychological records) were classified as having ID. In the FXS and DS sample, IQ was assessed with the nonverbal subtests in the Stanford-Binet Intelligence Scale, Fourth Edition (Thorndike, Hagen, & Sattler, 1986). Individuals who obtained a partial composite IQ of 69 or below on these three subtests were classified as having ID. The adolescents and young adults with DS (100%) and FXS (92.3%) were significantly more likely to have ID than those with an ASD (62.8%). The prevalence of ID across the diagnostic groups is consistent with previous studies using larger samples (Reiss & Dant, 2003; Edelson, 2006).

Fathers—Table 1 also presents the socio-demographic characteristics of the 240 fathers in the present study. All fathers in the sample were identified as the biological father of the target adolescent or adult. The vast majority of fathers were Caucasian, married, and had at least a college education. A significantly higher percentage of fathers of adolescents and young adults with ASDs had a college education as compared to the fathers of adolescents and young adults with DS, with fathers of adolescents and young adults with FXS in the middle of these groups. There was not a significant difference in household income among the groups, with about half of the families reporting an income of greater than $75,000. Families of adolescents and young adults with FXS and DS had a significantly higher number of total children than families of adolescents and young adults with an ASD.

Measures

Factors Contributing to Group Differences in Paternal Well-Being—Four factors proposed to contribute to the differences in the well-being of parents of grown children with DS, ASDs, and FXS were assessed: paternal age, child’s behavior problems, presence of additional children with a disability, and maternal depressive symptoms. Fathers reported their age in years. Mothers were asked to indicate whether there were any additional children in the family with a disability (defined as having a physical, mental health, or developmental disability requiring special care). The behavior problems of the adolescent or adult son or daughter with the developmental disability were assessed by mothers using eight corresponding items from the Autism Behavior Checklist (ABC; Krug et al., 1980) in the DS and FXS samples and the Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) in the ASD sample. Both the ABC and SIB-R include questions regarding the presence (yes = 1, no = 0) of 8 behavior problems: hurt self, hurt others, destructive, disruptive behavior and tantrums, unusual habits/rituals, offensive behavior, withdrawn, and uncooperative behavior. We used the total number of behavior problems in the present analysis. Maternal depressive symptoms were assessed through maternal self-report using the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The CES-D consists of 20 items on which individuals endorse the frequency of depressive symptoms during the previous week using a 4-point Likert scale ranging from 0 (rarely) to 3 (most of the time). The CES-D has been shown to have excellent internal consistency, test-re-test reliability, and validity with other measures of depression (Radloff, 1977). Alpha reliability for this instrument for the mothers in this sample was .90. The mean CES-D score across all mothers was 9.98 (SD = 10.12).

Paternal Psychological Well-being—Three indicators of psychological well-being were assessed. To assess paternal pessimism, fathers completed the 10-item Pessimism subscale from the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983). The Pessimism subscale assesses the parent’s perceptions of pessimism regarding the child’s immediate and long-term ability to achieve self-sufficiency. Items were
endorsed based on whether the father agreed or disagreed with the presented statement. Higher scores reflect greater pessimism. The QRS-F has been shown to have high internal consistency and construct validity (Friedrich et al., 1983). Alpha reliability for fathers on the Pessimism scale in this study was .68, which was slightly lower than in previous studies of mothers (Essex, Seltzer, & Krauss, 1999; Abbeduto et al., 2004). Paternal depressive symptoms were assessed with the CES-D; Radloff, 1977). Alpha reliability for the CES-D for fathers in this sample was .91. Scores of 16 or above indicate the potential for the presence of clinical depression. The mean CES-D score across all fathers was 9.76 (SD = 9.93).

Fathers reported on their coping style on the Multidimensional Coping Inventory (Carver, Scheier, & Weintraub, 1989). This scale consists of 14 subscales comprised of four items each. Items are rated using a Likert scale based on the frequency with which various coping strategies are used during stressful experiences (1 = not at all to 4 = a lot). For this study, we only examined the problem-focused coping (created from the active coping, planning, suppression of competing activities, and positive reinterpretation and growth subscales) and emotion-focused coping (created from the denial, focusing on and venting of emotions, behavioral disengagement, and mental disengagement subscales) summary scores. These summary scores have been shown in previous studies to have strong internal consistency and convergence with other measure of coping (Seltzer, Greenberg, & Krauss, 1995). Alpha reliability for fathers in present study was .89 for problem-focused coping and .78 for emotion-focused coping.

Missing Data

At least 75% of all items within a scale or subscale had to be completed by the participant in order for his responses on a measure to be included in the study. The participant’s mean score was substituted in place of any item with a missing response. Less than 1% of all items across all participants and measures had missing values.

Data Analysis Plan

There were several significant differences in the socio-demographic characteristics of our three diagnostic groups, including child ID, paternal education, child age, and total number of children. These demographics were not the focus of the present study and were controlled for in remaining analyses. First, one-way analyses of covariance (ANCOVAs), controlling for relevant socio-demographic characteristics (e.g., child age, paternal education, total number of children, and child ID), were conducted to examine differences in our three indicators of paternal psychological well-being by diagnostic group. Second, we conducted group comparisons of the four factors (paternal age, child behavior problems, presence of additional children with a disability, and maternal depressive symptoms) hypothesized to contribute to the pattern of diagnostic-related difference. Next, we examined the extent to which these four factors accounted for variation in paternal psychological well-being in our sample using hierarchical linear regressions. We hypothesized that once these four factors were controlled for in regression models, the difference in paternal psychological well-being between our diagnostic groups would be reduced.

Results

Table 2 presents the means, standard deviations, and one-way ANCOVA results for our indicators of paternal psychological well-being by diagnostic group. There was a significant difference by diagnostic group in depressive symptoms and pessimism. There was not a significant difference in the use of emotion-focused or problem-focused coping by diagnostic group. The predicted pattern indicative of a ‘DS advantage’ was found for...
pessimism. Follow-up Fisher’s least significant difference (LSD) post-hoc tests indicated that fathers of adolescents and young adults with DS reported a significantly lower level of pessimism than fathers of adolescents and young adults with ASDs or FXS. There was not a significant difference in the level of pessimism between fathers of adolescents and young adults with ASDs versus FXS. In contrast, for depressive symptoms, a pattern of ‘ASD disadvantage’ was found. LSD post-hoc tests indicated that fathers of adolescents and young adults with ASDs reported a significantly higher level of depressive symptoms than fathers of adolescents and young adults with DS or FXS. There was not a significant difference in level of depressive symptoms between fathers of adolescents and young adults with DS versus FXS. In terms of clinically significant depressive problems, 30.4% (N = 41) of the fathers of adolescents and young adults with ASDs reported scores of 16 or above (cutoff for clinically significant problems) on the CES-D compared to 15.9% (N = 7) of fathers of adolescents and young adults with FXS and 6.8% (N = 4) of fathers of adolescents and young adults with DS.

Table 3 presents the descriptive statistics for paternal age, number of child behavior problems, number of additional children with a disability, and maternal depressive symptoms by diagnostic group. One-way ANCOVAs indicated a significant difference in paternal age, number of child behavior problems, number of additional children with a disability, and maternal depressive symptoms. Follow-up LSD post-hoc tests indicated that the pattern of differences were in the expected direction. Fathers of the adolescents with young adults with an ASD were older than fathers of adolescents and young adults with FXS. There was not a significant difference in paternal age between the DS and FXS groups or between the FXS and ASD groups. As expected, adolescents and young adults with an ASD exhibited the highest number of behavior problems, followed by those with FXS, with adolescents and young adults with DS exhibiting the fewest behavior problems. Also as expected, the families of adolescents and young adults with FXS had more additional children with a disability than the ASD and DS groups. Fathers of adolescents and young adults with ASDs had more additional children with a disability than fathers of adolescents and young adults with DS. The difference in maternal depressive symptoms by diagnostic group was also in the expected direction; mothers of adolescents and young adults with ASDs reported a higher level of depressive symptoms than mothers of adolescents and young adults with DS or FXS. There was not a significant difference in maternal depressive symptoms between the DS and FXS groups.

Next, hierarchical linear regressions were conducted to examine whether these four factors could, in part, explain the pattern of diagnostic-related differences in paternal psychological well-being. Regressions were conducted separately for depressive symptoms and pessimism. Coping indicators were not examined as these indicators did not significantly differ by diagnostic group. In Step 1, the impact of diagnostic group on the indicator of psychological well-being was entered. Dummy-variable coding was used to contrast the diagnostic groups (Cohen, Cohen, West, & Aiken, 2003; pg 303–310). For depressive symptoms, ASD was selected to be the reference group (i.e., assigned value of zero in dummy coded variables), to which each of the other diagnostic groups was compared (DS and FXS; assigned value of 1 in each respective dummy coded variable). This decision was based on the pattern of findings indicative of ASD disadvantage for depressive symptoms, but no difference between the DS and FXS groups. For pessimism, DS was selected to be the reference group, to which the other diagnostic groups (ASD and FXS) were compared. This decision was based on the pattern of findings indicative of a DS advantage for pessimism, but no difference between the ASD and FXS groups. Relevant socio-demographic variables (child age, paternal education, total number of children, and child ID) were also controlled in this step. In Step 2, paternal age, behavior problems, presence of additional children with a disability, and maternal depressive symptoms were entered. We reasoned that if significant
differences between the diagnostic groups at Step 1 were diminished at Step 2, then the factors (paternal age, behavior problems, presence of additional children with a disability, and maternal depressive symptoms) entered at Step 2 could be seen as explaining, at least in part, our pattern of diagnostic-related variation in paternal psychological well-being.

Table 4 presents the results of the regression analyses for paternal depressive symptoms. Fathers of adolescents and young adults with ASDs had a significantly higher level of depressive symptoms than fathers of adolescents or young adults with DS and FXS at Step 1. However, after the other variables were entered into the model at Step 2, these group differences became non-significant. Additional children with a disability and higher level of maternal depressive symptoms were significant positive predictors of paternal depression at Step 2. The final regression model predicted 15% of the variance in depressive symptoms across fathers. In terms of paternal pessimism (see Table 5), fathers of adolescents and young adults with DS reported a lower level of pessimism than fathers of adolescents and young adults with ASDs or FXS (Step 1). The significant advantage of fathers of adolescents and young adults with DS as compared to fathers of adolescents and young adults with ASDs was sustained even after other variables were entered into the model at Step 2. By contrast, the advantage of fathers of adolescents and young adults with DS compared to fathers of adolescents and young adults with FXS became non-significant in Step 2, when other variables were entered into the model. The final regression model predicted 20% of the variance in pessimism across fathers.

**Discussion**

Despite evidence that fathers are not immune to child-related stress, their psychological well-being has largely been ignored in developmental disability research. The goal of the present study was to examine psychological well-being of fathers of adolescent and young adult children with DS, ASDs, and FXS and the factors contributing to group differences. We found that fathers of adolescents and young adults with ASDs reported more depressive symptoms than fathers of adolescents and young adults with DS or FXS, with the two latter groups experiencing similar levels of depressive symptoms. Fathers of adolescents and young adults with DS experienced less pessimism about their son or daughter’s future than did fathers of adolescents and young adults with ASDs or FXS, with the two later groups experiencing similar levels of pessimism.

There were no significant differences among the groups in fathers’ use of problem-focused or emotion-focused coping, similar to our earlier study of coping in a sample of mothers of adolescents and adults with DS, FXS, and ASDs that overlapped with the current sample of families (Abbeduto et al., 2004). These findings suggest that mothers and fathers of adolescents and young adults with DS, FXS, and ASDs use similar types of coping strategies to deal with child-related stress, yet experience different levels of depressive symptoms and pessimism about their son or daughter’s future. It may be that group differences in depressive symptoms and pessimism are driven by differences in the type and severity of child-related stressors encountered. The challenges related to parenting adolescents or young adults with ASDs, and to a lesser extent adolescents or young adults with FXS, have been found to be more stressful for parents than the challenges related to parenting adolescents or young adults with DS (Abbeduto et al., 2004; Lewis et al., 2006; Poehlmann et al., 2005). Thus, despite not differing in their likelihood of using adaptive coping strategies, parents of adolescents and young adults with ASDs, and to lesser extent parents of an adolescents and young adults with FXS, may experience poorer psychological well-being as a result of encountering more severe and difficult types of child-related stressors.
A pattern of poorer psychological well-being associated with ASDs as compared to DS was also found in earlier studies of fathers of younger children (Fidler et al., 2000; Sanders & Morgan, 1997). Our study builds on these findings by showing that this difference persists in later in the life course. Moreover, this is the first study to present information on the relative psychological well-being of fathers of individuals with FXS. Our overall findings that fathers of adolescents and young adults with FXS fare better than fathers of adolescents and young adults with ASDs, but worse than fathers of adolescents and young adults with DS are consistent with our previous research on mothers (Abbeduto et al., 2004).

We also examined the extent to which factors related to the varying nature (etiology and behavioral presentation) of these disabilities contributed to group differences in paternal psychological well-being. Fathers of the adolescents and young adults with an ASD were older than fathers of adolescents and young adults with FXS. This finding is in consistent with recent findings that older fathers are at risk of having children with ASDs (e.g., Durkin et al., 2008). Fathers in the DS group did not significantly differ in age from fathers in the ASDs or FXS groups. In line with expected diagnostic differences, the adolescents and young adults with ASDs in our sample evidenced more behavior problems and their mothers had a higher level of depressive symptoms than was true of the DS or FXS groups. Also as expected, adolescents and young adults with FXS exhibited more behavior problems than the adolescents and young adults with DS. In line with the genetic pathways contributing to these disabilities, fathers of adolescents and young adults with FXS also had more additional children with disabilities than did fathers of adolescents and young adults with DS, with fathers of adolescents and young adults with ASDs in the middle of these groups.

Using hierarchical linear regressions, we found that once these factors (paternal age, child’s behavior problems, additional children with a disability, and maternal depressive symptoms) were controlled, most diagnostic differences in paternal depressive symptoms among the groups became non-significant. The ‘ASD disadvantage’ in terms of heightened depressive symptoms as compared to both the DS and FXS groups was, at least in part, related to advanced paternal age, child’s heightened number of behavior problems, increased risk of having additional children with a disability, and increased maternal depressive symptoms. However, presence of an additional child with a disability and maternal depressive symptoms were the only significant predictors of paternal depression in the overall model.

Similarly, the difference in pessimism between the DS and FXS groups became non-significant in the full model when other variables were added. Thus, the ‘DS advantage’ over FXS in terms of pessimism was, at least in part, related to fewer behavior problems by the child, absence of additional children with disabilities in the family, and lower level of maternal depressive symptoms; however, it is important to note that none of these factors were independently significantly related to pessimism in the overall model. In contrast, fathers of adolescents and young adults with DS continued to have significantly lower level of pessimism than fathers of adolescents and young adults with ASDs in the full model. Thus, the diagnostic difference in pessimism between the ASDs and DS groups may be driven by other factors. Symptoms or impairments of ASDs, apart from behavior problems, may contribute the increased paternal pessimism of fathers. For instance, as compared to chronological and mental-age matched youth with DS, individuals with ASDs evidence more deficits in and social skills (Esbensen et al., 2010; Loveland & Kelly, 1988). These deficits may lead to realistically more pessimistic views of future prospects by fathers. It is interesting to note that ID status was significantly positively related to paternal pessimism; yet, adolescents and young adults with ASDs had lower rates of ID than the other groups.

There are several limitations to this study. Fathers in the present study were recruited through research projects focused on mothers. As a result, fathers were almost exclusively
married, in all cases to the biological mother of the son or daughter with the developmental disability, and lived with their spouse. Findings from the present study may not generalize to fathers of grown children with developmental disabilities in alternative family structures (e.g., single, remarried, or stepfathers). In addition, only a subset of the factors proposed to account for differences in parent psychological well-being were examined in this study. Further research is needed to determine the extent to which factors such as the timing and certainty surrounding the child’s diagnosis and genetic vulnerabilities related to presence of mild autism-like symptoms in fathers of children with ASDs affect paternal outcomes. In addition, behavior problems were assessed using a summary score based on eight overlapping items from the ABC in the DS and FXS groups and the SIB-R in the ASD group. The extent to which differences in the remaining items on these varying measures influenced reporting of these 8 overlapping items is not known. Behavior problems were also reported on by mothers as opposed to fathers and thus fathers may have endorsed different behavior problems by their son or daughter than did mothers. Moreover, parents reported on only 8 types of behavior problems. A larger portion of diagnostic-related differences in paternal psychological well-being may have been accounted for by behavior problems if we had used a broader and more in-depth measure of behavior problems rated by fathers.

Our indicators of psychological well-being were limited to depressive symptoms, pessimism, and coping styles, as these have been shown to vary in mothers. Future research should examine diagnostic-related variation in other domains of paternal well-being, such as feelings of anger, work and financial stress, and marital satisfaction, as the toll of stress may be more strongly linked to these other domains in men as opposed to women (e.g., Matud, 2004). Finally, future studies should explore indices of positive paternal psychological well-being in fathers of grown children with developmental disabilities, as previous studies on parents of younger children highlight that parenting a son or daughter with a developmental disability can also offer rewards (Stainton & Besser, 1998).

**Implications for Practice and Future Research**

Despite widespread recognition of the benefits of family-centered services within the field of developmental disabilities, current services and supports are directed toward mothers, with little consideration of fathers (Parette et al., 2010; Turbiville & Marquis, 2001). Moreover, despite the lifelong nature of developmental disabilities, these services and supports are concentrated on families of young children; while there are a variety of early intervention services for parents of young children with developmental disabilities, there are few services for families of adolescents and adults (Howlin, 2005; Taylor & Seltzer, 2010b).

In part, this lack of attention to fathers and families of adolescents and young adults with developmental disabilities by intervention programs is due to the relative lack of research on the experiences and needs of fathers and families of grown children. The present study is one of the first studies to begin documenting the factors contributing to the psychological well-being of fathers in families of adolescents and young adults with developmental disabilities, and offers important information for designing services to address the needs of this group.

Our findings indicate that fathers of individuals with ASDs, and to a lesser extent FXS, have poorer psychological well-being of fathers of individuals with DS. Whereas 30.4% of fathers of adolescents and young adults with ASDs reported depressive symptoms warranting clinical attention, 15.9% of fathers of adolescents and young adults with FXS, and only 6.8% of fathers of adolescents and young adults with DS had a clinically significant level of depressive symptoms. Thus, services should include more intensive supports for fathers of adolescents and young adults with ASDs and FXS as compared to fathers of adolescents and young adults with DS. Research on service effectiveness in
mothers suggests that a combination of interventions aimed at improving functioning and reducing behavior problems in the child with the developmental disability (e.g., behavioral support), and helping parents cope with parenting challenges (e.g., respite care and stress management), and coordination of these services (e.g., case management) leads to the best outcomes (e.g., Hastings & Beck, 2004). The mode of service delivery for parent-focused interactions may need to differ for fathers. Turbiville and Marquis (2001) found that fathers of young children with developmental disabilities preferred services that involved multiple family members, and thus family-based services that teach strategies for managing child-related stress that are attended by multiple family members may be most appealing to fathers.

Our findings also indicate that services should focus on fathers who have more than one child with a disability, as these fathers are at greater risk for experiencing depressive symptoms. These interventions that teach fathers how to manage and cope with the multiple child-related stressors related to having more than one child with a disability are needed. These interventions will likely need to include both time management strategies (e.g., how to juggle childcare responsibilities, work, and leisure) as well as stress management strategies (e.g., interventions teaching coping strategies). Our finding of a significant relation between child ID status and paternal pessimism also suggests that intervention programs may need to help fathers redefine their definition of “success” for their adolescent and adult son or daughter with ID. Adolescence and adulthood for individuals with ID often does not include the transitions (e.g., going to college, getting a job, and getting married) that that typically define “success” for adolescents and adults with average IQs. Interventions aimed at helping fathers identify more flexible and obtainable criteria for their child’s “success” in adolescence and adulthood may help them be more optimistic about their son or daughter’s future. However, in order to be effective, fathers should also be assisted in locating and accessing services that help their adolescent or young adult obtain their highest level of independence (e.g., support for transition out of high school and job training/job coach).

Perhaps most importantly, findings from the present study suggest that a family systems approach should be used in interventions. Such an approach should recognize the that fathers are affected by the nature of their child’s disability, in addition to its impact on mothers, and that a father’s psychological well-being is connected to the psychological well-being of their wife. Interventions that recognize the importance of family interconnectedness have to potential to foster positive well-being within multiple family members and result in a stronger family system. Finally, it is important to note that only a modest portion of variance in paternal psychological well-being in our sample was due to diagnostic differences. Further research on the child and family contextual determinants of psychological well-being is needed to strengthen services for fathers.

**Acknowledgments**

This research was supported by the National Institutes of Health Grants R01 AG08768 (to M. Seltzer), P30 HD03352 (to M. Seltzer), R01 HD024356 (to L. Abbeduto), R03 HD048884 (to L. Abbeduto), and T32 HD07489 (to L. Abbeduto). We would like to express our deepest appreciation to the families who generously gave their time and shared their lives with us.

**References**


Sparrow, SS.; Carter, AS.; Cicchetti, DV. Vineland Screener: Overview, reliability, validity, administration, and scoring. New Haven, CT: Yale University Child Study Center; 1993.


Taylor, JL.; Seltzer, MM. The transition to adulthood for individuals with ASD and their families. In: Howlin, P., editor. What really matters: Measuring outcome and addressing the needs of adolescents and adults with ASD; Invited Educational Symposium conducted at the International Meetings for Autism Research; Philadelphia, P.A.. 2010b. (Chair)


Table 1

Socio-demographic Characteristics of Sample

<table>
<thead>
<tr>
<th></th>
<th>DS</th>
<th>FXS</th>
<th>ASD</th>
<th>Test statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 59</td>
<td>n = 46</td>
<td>n = 135</td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married (%)</td>
<td>96.6%</td>
<td>97.4%</td>
<td>96.2%</td>
<td>$\chi^2 = 6.70$</td>
</tr>
<tr>
<td>College Degree + (%)</td>
<td>54.2%</td>
<td>59.0%</td>
<td>81.0%</td>
<td>$\chi^2 = 25.52^{**a,b,c}$</td>
</tr>
<tr>
<td>Income &gt; $75K (%)</td>
<td>45.8%</td>
<td>59.0%</td>
<td>44.5%</td>
<td>$F = 0.21$</td>
</tr>
<tr>
<td>Total Children (M, SD)</td>
<td>3.34 (1.67)</td>
<td>3.02 (1.73)</td>
<td>2.04 (1.02)</td>
<td>$F = 23.23^{**b,c}$</td>
</tr>
<tr>
<td>Adolescent or Adult</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (M, SD)</td>
<td>15.22 (2.96)</td>
<td>15.63 (2.63)</td>
<td>16.03 (2.83)</td>
<td>$F = 2.98^{*c}$</td>
</tr>
<tr>
<td>Male (%)</td>
<td>69.6%</td>
<td>79.5%</td>
<td>72.3%</td>
<td>$\chi^2 = 2.10$</td>
</tr>
<tr>
<td>ID (%)</td>
<td>100%</td>
<td>92.3%</td>
<td>62.8%</td>
<td>$\chi^2 = 21.95^{**b,c}$</td>
</tr>
</tbody>
</table>

Note.

$^a$ = DS versus FXS;

$^b$ = FXS versus ASD,

$^c$ = DS versus ASD.

$^*$ $P \leq .05$

$^{**}$ $P \leq .01.$
Table 2
Means, Standard Deviations and One-way Analyses of Covariance Statistic, controlling for child age, paternal education, total number of children and child ID, for Paternal Well-being

<table>
<thead>
<tr>
<th></th>
<th>DS N = 59</th>
<th>FXS N = 44/46*</th>
<th>ASD N = 135</th>
<th>F statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pessimism</td>
<td>4.37 (2.03)</td>
<td>5.67 (2.21)</td>
<td>6.34 (2.25)</td>
<td>9.99**a,c</td>
</tr>
<tr>
<td>Depressive Symptoms</td>
<td>6.78 (6.32)</td>
<td>8.56 (8.94)</td>
<td>11.78 (9.96)</td>
<td>8.43**b,c</td>
</tr>
<tr>
<td>Problem-Focused coping</td>
<td>30.60 (8.23)</td>
<td>32.20 (7.27)</td>
<td>30.48 (8.28)</td>
<td>1.48</td>
</tr>
<tr>
<td>Emotion-Focused coping</td>
<td>11.17 (5.53)</td>
<td>11.49 (5.19)</td>
<td>12.30 (6.11)</td>
<td>2.12</td>
</tr>
</tbody>
</table>

Note.

* DS versus FXS;

* FXS versus ASD;

* DS versus ASD.

* N = 44 for depressive symptoms.

* P ≤.05

** P ≤.01.
Table 3

Means, Standard Deviations and One-way analyses of Covariance Statistic, controlling for child age, paternal education, total number of children, and child ID, for Factors Hypothesized to Account for Diagnostic Differences

<table>
<thead>
<tr>
<th></th>
<th>DS N = 59</th>
<th>FXS N = 46</th>
<th>ASD N = 135</th>
<th>Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paternal Age</td>
<td>48.41 (7.25)</td>
<td>45.56 (6.41)</td>
<td>49.77 (9.77)</td>
<td>F = 4.15&lt;sup&gt;ab&lt;/sup&gt;</td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>0.53 (0.84)</td>
<td>1.73 (1.71)</td>
<td>2.51 (2.01)</td>
<td>F = 29.72&lt;sup&gt;***abc&lt;/sup&gt;</td>
</tr>
<tr>
<td>Additional children With disability</td>
<td>0.19 (0.58)</td>
<td>0.84 (1.03)</td>
<td>0.33 (0.67)</td>
<td>F = 16.62&lt;sup&gt;***abc&lt;/sup&gt;</td>
</tr>
<tr>
<td>Maternal depressive symptoms</td>
<td>6.65 (6.04)</td>
<td>9.18 (6.84)</td>
<td>12.89 (9.01)</td>
<td>χ² = 9.42&lt;sup&gt;***bc&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Note.

<sup>a</sup> = DS versus FXS;  
<sup>b</sup> = FXS versus ASD;  
<sup>c</sup> = DS versus ASD.  
<sup>*</sup> P ≤ .05  
<sup>**</sup> P ≤ .01.
### Table 4
Regression Results for Paternal Depressive Symptoms

<table>
<thead>
<tr>
<th></th>
<th>Depressive Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
</tr>
<tr>
<td>ASD</td>
<td>----</td>
</tr>
<tr>
<td>DS</td>
<td>−.30**</td>
</tr>
<tr>
<td>FXS</td>
<td>−.21*</td>
</tr>
<tr>
<td>Paternal Education</td>
<td>−.01</td>
</tr>
<tr>
<td>Total # of Children</td>
<td>.14</td>
</tr>
<tr>
<td>Child age</td>
<td>.09</td>
</tr>
<tr>
<td>Child ID</td>
<td>.03</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
</tr>
<tr>
<td>DS vs. ASD</td>
<td>−.14</td>
</tr>
<tr>
<td>FXS vs. ASD</td>
<td>−.14</td>
</tr>
<tr>
<td>Paternal Education</td>
<td>.03</td>
</tr>
<tr>
<td>Total # of Children</td>
<td>.12</td>
</tr>
<tr>
<td>Child age</td>
<td>.13</td>
</tr>
<tr>
<td>Child ID</td>
<td>.01</td>
</tr>
<tr>
<td>Paternal age</td>
<td>.03</td>
</tr>
<tr>
<td>Behavior problems</td>
<td>.14</td>
</tr>
<tr>
<td>Additional Child with Disability</td>
<td>.16*</td>
</tr>
<tr>
<td>Maternal depressive symptoms</td>
<td>.23**</td>
</tr>
<tr>
<td>Adjusted $R^2$; F value (Step 1)</td>
<td>.07; $F = 3.13^{**}$</td>
</tr>
<tr>
<td>Adjusted $R^2$; F value (Step 2)</td>
<td>.15; $F = 3.99^{**}$</td>
</tr>
</tbody>
</table>

Note.

* $P \leq .05$.

** $P \leq .01$.

Change in $R^2$ significant at $P < .05$. 

_Fam Relat._ Author manuscript; available in PMC 2013 April 01.
Table 5

Regression Results for Paternal Pessimism

<table>
<thead>
<tr>
<th></th>
<th>Pessimism</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
</tr>
<tr>
<td>DS</td>
<td>----</td>
</tr>
<tr>
<td>ASD</td>
<td>.52**</td>
</tr>
<tr>
<td>FXS</td>
<td>.23*</td>
</tr>
<tr>
<td>Paternal Education</td>
<td>−.01</td>
</tr>
<tr>
<td>Total # of Children</td>
<td>−.12</td>
</tr>
<tr>
<td>Child Age</td>
<td>.07</td>
</tr>
<tr>
<td>Child ID</td>
<td>.30**</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
</tr>
<tr>
<td>ASD vs DS</td>
<td>.44**</td>
</tr>
<tr>
<td>FXS vs DS</td>
<td>.19</td>
</tr>
<tr>
<td>Paternal Education</td>
<td>−.01</td>
</tr>
<tr>
<td>Total # of Children</td>
<td>−.13</td>
</tr>
<tr>
<td>Child age</td>
<td>.0</td>
</tr>
<tr>
<td>Child ID</td>
<td>.29**</td>
</tr>
<tr>
<td>Paternal age</td>
<td>.06</td>
</tr>
<tr>
<td>Behavior problems</td>
<td>.04</td>
</tr>
<tr>
<td>Additional Child with Disability</td>
<td>.08</td>
</tr>
<tr>
<td>Maternal depressive symptoms</td>
<td>.12</td>
</tr>
<tr>
<td>Adjusted R²; F value (Step 1)</td>
<td>0.19; (F = 8.16^{**})</td>
</tr>
<tr>
<td>Adjusted R²; F value (Step 2)</td>
<td>0.20; (F = 5.50^{**})</td>
</tr>
</tbody>
</table>

Note.

* \(P ≤ .05\),

** \(P ≤ .01\).

Change in \(R^2\) not significant at \(P < .05\).