Family Environments and Family Harmony: An exploration across Severity, Age, and Type of DD

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Abstract

The concept of family environment was explored in parents of children with developmental disabilities (DD) using the Moos & Moos (1981) Family Environment Scale (FES). The sample included 205 mothers and fathers of children with one of five types of DD: Down syndrome, Fragile X syndrome, Rett syndrome, Autism, and DD of unknown etiology. There were three age groups (0-5, 6-10, and 11-18) and three levels of severity of DD (mild, moderate, and severe). Parents' reports of their family environment did not differ from those of typical families and there were few group differences. There was, however, an intriguing finding associating increased diagnostic ambiguity with lower levels of family harmony.

There is little question that raising a child with a developmental disability (DD) constitutes a significant stressor for families, one which is often presumed to have negative consequences for the family. Indeed, some research has shown that parents of children with DD report a disproportionately greater level of stress than parents of children without DD (e.g., Baker, Blacher, Crnic, & Edelbrock, 2002; Baxter, Cummins, & Polack, 1995; Margalit & Ankonina, 1991). Mothers are typically reported to be more adversely affected and to bear the greater burden of caretaking for the child with DD (Bristol, Gallagher, & Schopler, 1988; Freeman, Perry, & Factor, 1991; Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986). However, fathers have been much less studied and may experience similar levels of distress (e.g., Perry, Sarlo-McGarvey, & Factor, 1992; Rimmerman, Turkel, & Crossman, 2003) or, perhaps, somewhat different

effects (Rodrigue, Morgan, & Geffken, 1992; Walker, 2002).

Conversely, other studies have found parents of children with DD to be no different from other parents on measures of stress (Dyson, 1997; Koegel, Schreibman, O'Neill, & Burke, 1983) and some studies even report positive impacts on families (e.g., Wilgosh & Scorgie, 2000). In all likelihood, there are many variables regarding the family and the child that need to be considered in order to appreciate this complex situation. A number of moderating variables within individual parents (e.g., coping strategies) and within families (e.g., marital relationship, family style) have been suggested to account for some of this variability (Perry, 2004). The present study focuses on the family climate and, in particular, the notion of family harmony.

In addition to parent and family variables that are relevant to positive and/or negative outcomes, it seems likely that certain aspects of the child's disability are also important contributing factors, such as age, level of functioning or severity, and particular diagnosis or type of disability. Generally, the literature supports the notion that the greater the severity of the disability, the more distress reported by parents (Minnes, et al., 1989). For example, in a study conducted by Martin (2001), parents of children with lower levels of adaptive functioning showed higher levels of parent and family problems, parental pessimism, and overall parental distress compared to parents of children with higher levels of adaptive functioning. Similarly, parents of children with more maladaptive behaviours report higher levels of distress (Baker et al., 2002; Hastings & Johnson, 2001).

Another factor that may be related to parental distress is the age of the child with a developmental disability. However, the research findings in this area are mixed and more difficult to interpret. Although some studies have suggested that parents of older children with general DD report higher levels of distress compared to parents of very young children (e.g., Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Warfield et al., 1999), other studies have demonstrated that mothers of younger children reported higher levels of psychopathology such as depressive symptomatology (Galvin, 2000).

Group differences in parental distress have also been demonstrated across various types of childhood disability, with parents of children with autism consistently showing higher levels of stress relative to parents of children with Down syndrome, parents of children seen on a psychiatric outpatient unit, and parents of children with DD (Donovan, 1988; Holroyd & McArthur, 1976; Konstantareas, 1991). According to the cognitive theory of coping (Folkman, 1991), the likelihood of a distress outcome as a result of

a stressor depends to a large extent on the individual's appraisal of the situation (what is at stake and what can I do about it?). Likewise, in family stress models (e.g., McCubbin & McCubbin, 1989), an important dimension is the family's perception of the problem or stressor. When the nature of the stressor and its implications are clear, it is easier to cope than when the situation is ambiguous. Several researchers have examined this notion in families of children with certain types of DD. For example, Goldberg et al. (1986) reported greater family stress in families of children whose DD was of unknown etiology compared with Down syndrome, for which the etiology is well established.

This notion of ambiguity may also partially explain the findings of greater stress in parents of children with autism relative to other disorders. Autism is of unclear etiology and children with autism often do not "look" disabled. Parents frequently report getting the "runaround" from friends, family and professionals who say their children will grow out of it or imply that poor parenting is an issue. This is particularly true of children with mild autism where parents have been found to be poor at estimating their child's developmental level and may thus more easily harbour unrealistic expectations when it comes to their child's prognosis (Bristol, 1984). Ambiguity may also lead to disagreements within the family as to the nature and cause of the child's problem, which may reinforce parental feelings of uncertainty and increases stress (Bristol, 1985; Norton & Drew, 1994). Finally, ambiguity complicates community acceptance and support of the child and the family (Gallagher, Beckman, & Cross, 1983).

Raising a child with a developmental disability not only increases the risk of distress in parents but places stress on the family as a whole. Social and community supports also emerge as a significant mediator of family stress (Hodapp, Fidler, & Smith, 1998; Martin, 2001). However, very little research has focused on resources within the family that might serve to mediate or moderate stress in families of children with DD.

The Family Environment Scale (FES) is one of the social climate scales developed by Moos and Moos (1981) designed to tap a range of dimensions of family style. In one study examining the family climate, parents of children with developmental disabilities described less supportive family relationships and fewer opportunities for personal growth compared to typical families (Margalit & Ankonina, 1991). Family harmony, based on this scale, has been shown to be a good predictor of family stress. In a study by Warfield, Krauss, Hauser-Cram, Upshur, and Shonkoff (1999), the family environments of children with DD were measured at entry to early

intervention, on their third birthday, and on their fifth birthday. Higher parental distress, at both the child's third birthday and fifth birthday, was predicted by lower income, less family support, and lower family harmony. Therefore, family functioning (and family harmony, in particular) seems to be a promising avenue of investigation for elucidating factors, over and above child characteristics, individual coping style, and social and community supports, that may serve to buffer families against the risk that is associated with raising a child with DD.

At this point in time, a paucity of research related to family environment means that there are many more questions than answers. Thus, the aims of the current exploratory study were three-fold. First, we set out to examine mothers' and fathers' perceptions of their family environment in our sample of families of children with various developmental disabilities, relative to families in the normative samples (both typical and distressed). Second, we examined the family environment profiles (using the 10 subscales of the FES) of mothers and fathers within our sample, in relation to the child's age, severity of DD, and specific type of DD (across five groups). Third, we explored the concept of "family harmony" and the degree to which the parent's gender, age of the child, severity of DD, and specific type of DD would impact on parental perception of family harmony. We anticipated that families in our sample would resemble healthy families more than distressed families and that mothers and fathers would not differ substantially. In addition, we expected that greater family harmony would be reported by parents of younger children and children with milder disorders. Given that ambiguity is stressful and that family harmony is negatively correlated with parental distress, we hypothesized that lower levels of family harmony would be reported by parents whose children have developmental disabilities with a more ambiguous etiology.

Method

Participants

The 205 participants included 143 mothers (70%) and 62 fathers (and, in some cases, both parents of the same child) of children with developmental disabilities. Families were recruited via several centres providing comprehensive services to families of children with developmental disabilities in moderate to large urban communities in Ontario (except for the Rett group who came from across Canada). The data used for the present study were archival, and some data has been included in previous publications (Minnes, 1988; Perry, Sarlo-McGarvey, & Factor, 1992). Table

1 outlines the specific characteristics for the participants including a breakdown of the sample in terms of age of the children as well as type and severity of developmental disability. Note that not all characteristics are similarly distributed in each group and that information on children's diagnoses and symptom severity was based on parent report.

Table 1. Characteristics of the sample used in the present study (n)

	Autism	*Rett*	*Fragile X*	*Down*	*DD unknown etiology*	*Total*
Gender:						
mothers	55	27	10	21	30	143 (70%)
fathers	24	21	7	7	3	62 (30%)
Age of Child:						
0-5	34	17	2	16	17	86 (42%)
6-12	31	14	2	9	14	70 (35%)
13-18	12	13	5	3	2	35 (17%)
n/a	2	4	8	-	-	14 (6%)
Severity of DD:						
mild	25	0	-	13	12	50 (24%)
moderate	33	0	-	11	12	54 (26%)
severe	21	48	-	4	11	84 (41%)
n/a	-	-	17	-	-	17 (8%)
Total	79 (39%)	48 (23%)	17 (8%)	28 (14%)	33 (16%)	205

Dependent Measure

The Family Environment Scale (FES; Moos & Moos, 1981) was used to investigate the research questions presented in this study. The FES is comprised of 10 rationally-derived subscales falling into three dimensions: Relationships (Cohesion, Expressiveness, and Conflict), Personal Growth (Independence, Achievement Orientation, Intellectual-Cultural Orientation, and Moral-Religious Affiliation) and System Maintenance (Organization and Control). The questionnaire requires parents to rate as true or false 90 statements tapping a range of family resources from expressiveness to recreational activities to religion. The FES was normed on 1,125 typical families and 500 distressed families. The validity of the scale was established by demonstrating that the two norm groups differed significantly on all of the ten subscales. In addition, intervention programs have resulted in improved FES scores. The psychometric properties of the FES are all within an

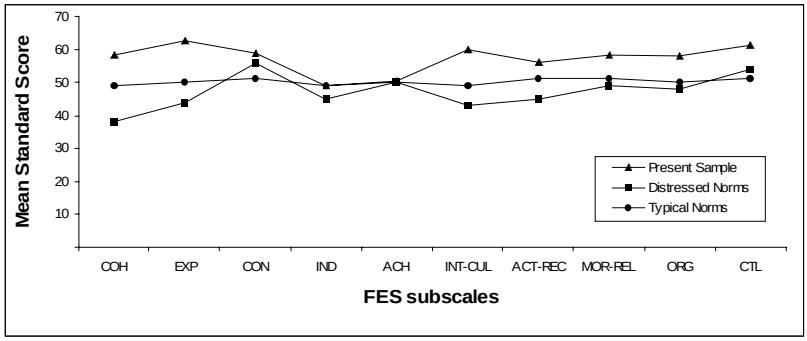
acceptable range. Internal consistencies of the 10 subscales range from .61 to .87 and test-retest reliability over 2 months ranges from .68 to .86.

Of particular relevance to the present study is a derived score based on the relationship dimension, called the Family Relations Index (FRI). This index examines the level of Cohesion and Expressiveness in a family with the level of Conflict subtracted out and may be thought of as a general measure of "family harmony".

Results

For the first set of analyses, we were interested in evaluating group differences on the FES. Therefore, all of the component subscales of the FES were calculated and graphed in order to compare group profiles. The first comparison was between our sample and the two samples on which the FES was normed. We compared the mean standard score of families raising a child with a developmental disability to the mean standard score of healthy families and distressed families, on each of the 10 subscales of the FES. The results are presented in Figure 1. Visual analysis of the graphed data reveals that, as predicted, the families in our sample reported doing as well or better in every area compared to typical families who formed the population on which the FES was normed. The FES profiles of the families in the present study did not resemble those of distressed families.

Figure 1. FES profile of the present sample compared to the norms (standardized T scores) for typical and distressed families (Moos & Moos, 1981).

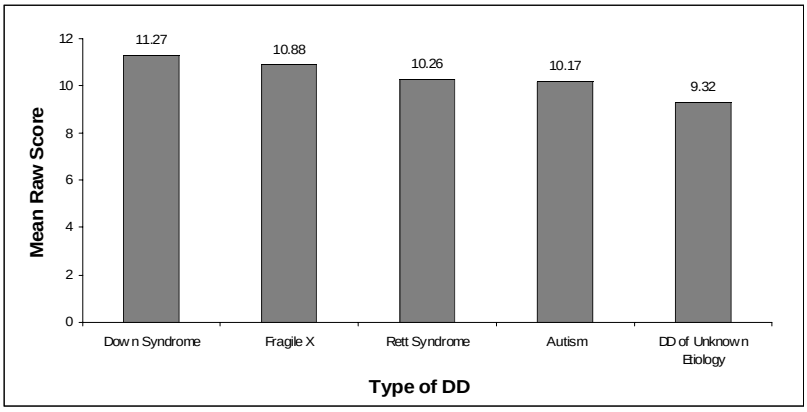


In the second set of analyses, we examined the family environment profiles (again using the 10 subscales of the FES) reported by mothers and fathers as a function of the child's age, severity of DD, and specific type of DD. There

were no significant group differences. The other comparison of interest involved evaluating sex differences on the FES. There were no significant sex differences between the group of 142 mothers and the group of 62 fathers in their perceptions of their family environment.

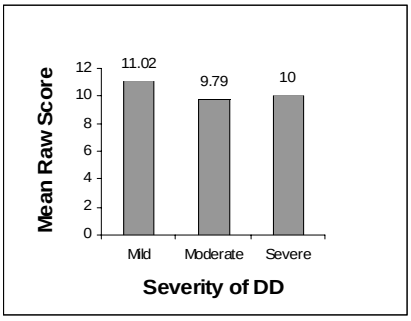
For the third set of analyses, we were interested in how the type of DD, the severity of DD, and the age of the child impact on the family harmony variable (as measured by the FRI score on the FES). The relationship between the type of DD and parent perceptions of family harmony was evaluated using an analysis of variance (ANOVA) to compare the mean score of each type of developmental disability in our sample on the FRI. No significant differences were found using a traditional ANOVA [$F(4, 189)=1.973$, $p=.100$]. However, given the inequities in the size and variance of each group, we also performed a non-parametric group comparison using the Kruskal-Wallis Test. This analysis did yield a significant finding [$c2(3) = 8.155$, $p=.043$]. These mixed results, combined with research and clinical experience suggesting that ambiguity may impact on parental stress, prompted us to perform post hoc analyses to further evaluate specific group differences. Using the Mann-Whitney Test, significant differences between some of the groups emerged in the directions expected. Figure 2 illustrates that as the etiology of the disorder becomes more ambiguous, there appears to be a declining trend in parent perception of family harmony. Parents of children with a DD of unknown cause reported significantly lower levels of family harmony compared to parents of children with Down syndrome, a disorder for which the etiology is well known ($Z= -2.661$, $p=.008$). There was no significant difference found between parents of children with Fragile X syndrome and parents of children with a DD of unknown cause ($Z= -1.864$, $p=.065$).

Figure 2. Family Harmony (FRI) as a function of Type of DD



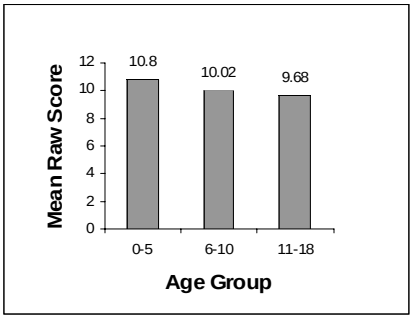
A one-way ANOVA was performed to evaluate the relationship between severity of DD in the child and parent perceptions of family harmony. As shown in Figure 3, results suggest a possible trend toward parents of children with a mild developmental disability reporting higher levels of family harmony relative to parents of children with greater severity of developmental disability [$F(2, 176)=2.853$, $p=0.06$]. However, in this case a non-parametric group comparison using the Kruskal-Wallace test was not significant.

Figure 3. Family Harmony (FRI) as a function of Severity of DD



Finally, we examined the relationship between parent perceptions of family harmony and the age of their child with a developmental disability. Neither the Kruskal-Wallace nor a traditional ANOVA yielded significant differences. As indicated in Figure 4, there may possibly be a trend towards higher family harmony within the youngest group of children (0 to 5 years) relative to families with older children.

Figure 4. Family Harmony (FRI) as a function of Age of child with DD



Discussion

In summary, our first two hypotheses were supported in that we anticipated that families in our sample would resemble healthy families more than distressed families and that mothers and fathers would not differ substantially in their FES profiles. Despite the widely accepted view that families of children with DD are at risk for and report higher levels of stress than typical families, it does not necessarily follow that these families also demonstrate negative outcomes as a result of their increased levels of stress. The present study showed that, at least on a measure of family environment which reflects the coping resources available within the family (e.g., expressiveness, organization, moral-religious emphasis), families raising children with DD are generally doing as well as or better than the norm and did not resemble distressed families at all. There were no significant differences in FES profiles as a function of type of DD, severity of DD, or age of the child with DD. These results contribute to the literature by supporting the notion that positive outcomes are prevalent in families who are living with the presumed stressor of raising a child with DD. Although it could be argued that this sample may not be representative of all families of children with DD and that more distressed families may not be as likely to participate in such research, the fact that similar patterns were seen in five different groups lends strength to this conclusion. These are, of course, generalizations from group data, and may not be true of every family individually.

There has been relatively little research to date regarding the impact of raising a child with DD on fathers. Although some studies suggest that fathers may show similar level of stress albeit perhaps manifested somewhat differently, one might expect similar sex differences in coping as well. Our study results showed no differences or negligible differences between mothers and fathers on all ten of the FES subscales. Therefore, fathers' perceptions of their family environment were similar to the perceptions of the mothers in our study. However, it is possible that this group of fathers may not be representative of other fathers who do not participate in research studies. It is also possible that the non-independence of the mothers and fathers for some cases may have minimized any difference.

For the remaining research questions we investigated the impact of type of DD, severity of DD, and the age of the child on family harmony. The concept of family harmony was of particular interest to us because poor family harmony has been found to be a good predictor of family stress. These analyses were hampered by limited statistical power as a result of

some small cells and unequal distribution across cells. However, there appears to be an intriguing trend (supporting our clinical hunch) between family harmony and the degree to which the cause of the child's DD is clearly understood versus ambiguous or unknown. As the etiology of the disorder is more well established (e.g., Down Syndrome and Fragile X), higher levels of family harmony are reported by parents. Families of children with DD of unknown etiology and autism reported the lowest levels of family harmony. This ambiguity notion would be an interesting variable for future researchers to measure more systematically in families at different stages following diagnosis and in different groups.

In this study, there was no significant relationship between family harmony and either severity of DD or child's age. However, data were suggestive of potential trends that may be worthy of further examination. A negative correlation between severity of DD and family harmony would be consistent with the literature on stress, which has repeatedly demonstrated that increased levels of problem behaviour and lower levels of adaptive functioning serve to increase stress. Given the weak relation between age and family harmony found in the present study and the equivocal results demonstrated in the literature on age and stress more generally, it is likely that variables related to age, rather than age itself, serve to increase stress in families. For example, older children are physically larger and their externalizing behaviour may be more difficult to manage, thereby increasing stress levels. On the other hand, sometimes children display lower activity levels as they get older which may serve to lessen the stress reported by parents.

Although the sampling in the present study was certainly not ideal and the statistical analyses did not provide overwhelming support for some hypotheses, the results clearly suggest that this line of research is promising and requires further attention. Identifying factors that moderate stress and which may, in turn, serve as protective factors for families at high risk for stress is of value for informing both our theoretical understanding of coping as well as improving our clinical practice with families.

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Author's Notes

This paper was presented in poster format at the Ontario Association on Developmental Disabilities Research Day in March 1999.

We would like to thank Carol Haddad, Natalie Sarlo-McGarvey, and Susana Correia, for their assistance with data collection and analysis, as well as all the families for generously agreeing to participate.

We appreciate the support of the TRE-ADD Program at Thistletown Regional Centre. However, the views expressed here are those of the authors and do not necessarily reflect those of the Ontario Ministry of Children and Youth Services.

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