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Stress and Family Functioning in Parents of Girls with Rett Syndrome[1]

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Mothers and fathers of 29 girls with Rett syndrome provided data about their levels of parenting stress, marital adjustment, and family functioning. Their scores were compared to normative and clinical samples. The parents of girls with Rett syndrome reported more stress, lower marital satisfaction, and certain adaptations in family functioning compared to norms. However, most parents scored in the normal range on most measures and their scores were not related to SES. There was little relationship between specific characteristics of the daughter with Rett syndrome, such as her age and level of functioning, and her parents' scores on these measures. There were few significant differences between mothers' and fathers' scores. Results are discussed in terms of patterns of family adaptation and coping. Clinical implications are also discussed.

Rett syndrome is a severe developmental disability (DD) involving both physical and mental handicaps. It affects only girls, and appears after an

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apparently unremarkable prenatal, perinatal, and early infancy period. Symptoms, typically first noticed between 6 and 24 months, include the loss of purposeful hand use (replaced by characteristic hand wringing or other mannerisms); the loss of previously acquired speech (if any); severe psychomotor retardation; and an ataxic and apraxic gait. There may also be respiratory dysfunctions, EEG abnormalities, seizures, scoliosis of the spine, and other physical symptoms (Hagberg, Aicardi, Dias, & Ramos, 1983; Perry, (1991) Rett Syndrome Diagnostic Criteria Work Group, 1988).

There has, to our knowledge, been no empirical research on families who have a daughter with Rett syndrome. One might expect these parents to be particularly highly stressed because the children are so severely incapacitated and require considerable caretaking throughout their life; because the disorder is progressive and there is little hope for significant treatment gains; and because the child seems healthy initially, allowing parents to form expectations about her future, which are then dashed.

There does exist, however, a great deal of clinical and empirical literature on families of children with other disorders, including autism and mental retardation. Parents of DD children can be said to experience greater stress, depression, and health problems than parents of normal controls (Donovan, 1988; Friedrich & Friedrich, 1981; Holroyd, 1974; Wilton & Renaut, 1986; Wolf, Noh, Fisman, & Speechley, 1989).

A DD child is often thought to have a negative effect on his or her parents' marriage, but some parents report positive effects as well (Blackard & Barsh, 1982; Carr, 1988; DeMyer, 1979; Friedrich & Friedrich, 1981; Gath & Gumley, 1984). For example, some report that having the DD child has brought them closer together. The literature indicates that a strong marital relationship is one of the most important factors which can mediate parental distress (Bristol, 1984; Bristol & Schopler, 1984; Friedrich, Wilturner, & Cohen, 1985; Perry, 1990).

It is widely believed that mothers are more adversely affected by having a DD child than are fathers, and it is generally acknowledged that the burden of caretaking falls disproportionately on mothers (Bristol, Gallagher, & Schopler, 1988; DeMyer, 1979; Gallagher, Scharfman, & Bristol, 1984; Konstantareas & Homatidis, 1987; Milgram & Atzil, 1988). Some literature has begun to focus on fathers' experience of having a DD child, suggesting that it is qualitatively different from that of mothers, but not more or less difficult (Bristol & Gallagher, 1986; Gallagher, Cross, & Scharfman, 1981; McConachie, 1982; Meyer, 1986; Vadasy, Fewell, Meyer, & Greenberg, 1985).

Undoubtedly, the whole family is affected by the DD child, with different issues emerging at different stages in the family life cycle which can have positive or negative consequences for the family (Turnbull, Sum-

mers, & Brotherson, 1986; Wikler, Wasow, & Hatfield, 1983). One aspect of family life which is frequently reported to be particularly adversely affected is the family's recreational and recuperative function (Bristol, 1984; Bristol & Schopler, 1983; Cutler & Kozloff, 1987; DeMyer & Goldberg, 1983).

Individuals, couples, and families cope with the situation of having a DD child in many different ways and, ultimately, the majority cope well (Bristol, 1984; DeLuca & Salerno, 1984; Kornblatt & Heinrich, 1985). This is accomplished by employing a variety of coping resources, including factors in their larger social context (e.g., social support from friends) as well as factors within themselves (e.g., personality and beliefs). Religious faith, in particular, has been reported to be an important coping resource in families of DD children (Bristol, 1984; Fewell, 1986; Friedrich, Cohen, & Wilturner, 1988).

It is often assumed that specific child characteristics are directly correlated with the parents' level of stress. These include age, sex, diagnosis, IQ, level of self-help skills, and so forth. Clearly, these characteristics do make an important contribution to parents' stress level (Bristol, 1987; DeMyer, 1979; Factor, Perry, & Freeman, 1990; Friedrich et al., 1985; Marcus, 1984; Morgan, 1988; Perry, 1990), but it is not a simple linear function and many other factors must be taken into account (Perry, 1990).

The purpose of the current study is to present the first empirical investigation of parental stress, marital satisfaction, and family functioning in parents of girls with Rett syndrome. We set out to answer three questions. First, what is the level of stress experienced by these parents compared to norms? Second, what is the relationship between specific child characteristics (such as chronological age, severity of disorder, and age at onset) and the family variables? Third, what are the similarities and/or differences between mothers' and fathers' experiences of stress and family functioning?

METHOD

Subjects and Procedure

Subjects for the study were recruited in two ways. First, letters describing the study were sent by the Canadian Rett Syndrome Association to 53 Ontario families who had a daughter with Rett syndrome. To preserve the confidentiality of the Association's mailing list, parents who wished to participate were asked to contact the investigators. Thirteen of the 53 fami-

lies (25%) responded. Because of this method of subject recruitment, it was not possible for the investigators to contact families directly to follow up and/or determine reasons for nonparticipation. Second, 16 families were approached directly at a Rett syndrome conference in Western Canada, and 14 of these (88%) agreed to participate. A further two families contacted one of the investigators who was giving a presentation at another Rett syndrome conference.

There were three components to the study. First, parents were interviewed in order to gather demographic and diagnostic information and to obtain an estimate of the girl's current level of adaptive functioning using the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). Second, parents were asked to complete a package of questionnaires (see Measures) and return them. There was a 93% return rate and, in the case of two-parent families, questionnaires were completed separately for mothers and fathers in all cases. Third, whenever access to the daughter with Rett syndrome was possible, she was assessed using the Cattell Infant Intelligence Scale (Cattell, 1940).

The final sample consisted of 29 families (including 6 single-mother families), though not every family completed each component of the study. Twenty-six families completed both interview and questionnaires; two families were interviewed but did not return the questionnaires despite repeated follow-up; and one family completed the questionnaires but could not be interviewed because of distance. All were biological parents with the exception of three stepparents and one grandmother who was the primary caregiver for the child. In addition, 15 of the girls with Rett syndrome were assessed (all families seen in their homes as well as two whose daughters attended the conference).

Families were predominantly white Canadians, two were European immigrants, and one was from the United States. The sample was close to normally distributed in terms of socioeconomic status (SES), calculated according to the Blishen system (Blishen & Carroll, 1978; Blishen & McRoberts, 1976) (see Table I).

The girls with Rett syndrome ranged in age from 2 years 11 months to 19 years 6 months with a mean of 9 years 5 months (see Table II). The actual diagnosis of Rett syndrome (Hagberg et al., 1983; Rett Syndrome Diagnostic Criteria Work Group, 1988) was made independently of the present study, primarily by pediatric neurologists (79% of the children), including 4 cases (14%) diagnosed by Dr. Rett himself. The remaining 21% were diagnosed by geneticists and other medical specialists. The cognitive and adaptive behavior level of the girls was assessed for the present study and, as shown in Table III, all girls were found to be profoundly develop-

Table I. Socioeconomic Status of Families according to Blishen and McRoberts (1976)[a]

SES class[b]	*n*	%
1	3	10.4
2	5	17.2
3	9	31.0
4	7	24.1
5	3	10.4
6	2	6.9

[a]Family SES defined as either the higher of the two parents' individual SES categories in the case of two-parent families, or mother's SES in single-mother families.
[b]Class 1 is the highest SES, Class 6 the lowest.

mentally disabled. These results are described more fully in a separate report (Perry, Sarlo-McGarvey, & Haddad, 1991).

Measures

Parenting Stress Index (PSI). The PSI (Abidin, 1986) is a 101-item scale intended to identify parent–child subsystems under stress. The total Child Domain score and seven Parent Domain subscales (Depression, Attachment, Restriction of Role, Sense of Competence, Social Isolation, Relationship with Spouse, and Health) were used. The PSI has good psychometric properties and norms for various samples.

Dyadic Adjustment Scale (DAS). The DAS (Spanier, 1976) is composed primarily of Likert type items designed to assess the quality of relationship in married (or cohabiting) couples. It has four factors: Dyadic Consensus, Dyadic Satisfaction, Affectional Expression, Dyadic Cohesion, and a total score called Dyadic Adjustment. The DAS is very well known, has excellent reliability, and clearly differentiates married from divorcing couples.

Family Environment Scale (FES). The FES (Moos & Moos, 1981) is a 90-item true–false instrument designed to tap various aspects of family functioning. It has 10 rationally derived subscales: Cohesion, Expressiveness, Conflict, Independence, Achievement Orientation, Intellectual/Cultural Orientation, Active/Recreational Orientation, Moral/Religious Emphasis, Organization, and Control. Internal consistency and test–retest reliability are good to high. Norms are available for "normal" and "distressed" families, and the scale has been used with various clinical populations.

Table II. Age Distribution of Subjects (N = 28)

Age range (years-months)	*n*	%
0-00 to 4-11	5	17.9
5-00 to 9-11	12	42.9
10-00 to 14-11	8	28.5
15-00 to 19-11	3	10.7

RESULTS

Table III. Characteristics of Rett Syndrome Sample

	M (months)	*SD*	*n*
Chronological age	113.3	56.2	28
Age of onset	12.1	7.4	28
Cattell mental age	3.0	2.0	15
Vineland Adaptive Behavior Scales			
Communication	17.4	5.5	28
Daily Living Skills	16.9	7.3	28
Socialization	25.0	4.9	28
Motor Skills	13.6	10.2	28

Means and standard deviations for the stress and family functioning variables are shown in Table IV along with values for the normative samples. These results indicate that parents of girls with Rett syndrome differ from norm groups in a number of ways. However, many of these differences are modest and, on all measures, the majority of individual parents scored in the normal range.

On the PSI, scores for the Child Domain were, not surprisingly, substantially higher than norms, indicating that the girls with Rett syndrome were perceived as much more stressful than children in the normative sample. The Parent Domain scores were also significantly higher, indicating greater parenting stress in the present sample. There were four significant differences on the seven individual subscales. Parents of girls with Rett syndrome experienced greater stress in their feelings of Attachment to their daughters, greater Social Isolation, more stress in their Relationship with Spouse, and more parental Health problems than did parents in the normative sample. Between 23 and 31% of parents scored in the "clinical range" on these subscales.

The analyses of the DAS scores (excluding the six single mothers) are also shown in Table IV. According to the overall Dyadic Adjustment score and three of the subscales, the parents in this sample were less satisfied with their marital relationships than were the "happily married" nor-

Table IV. Comparison of Means and Standard Deviations for Stress and Family Functioning Measures for Current Sample and Norm Sample

Measure and subscale	Current sample		Norm sample		
	M	*SD*	*M*	*SD*	*t*
PSI (n = 48)					
Child domain	131.6	16.6	98.4	19.2	11.85[c]
Parent domain	132.8	21.5	122.7	24.6	2.79[b]
Depression	20.0	5.2	20.4	5.6	
Attachment	13.6	3.2	12.6	3.1	2.20[a]
Restriction of Role	20.1	5.4	19.0	5.2	
Competence	30.6	5.8	29.2	6.3	
Isolation	15.1	3.8	12.8	3.8	4.16[c]
Relationship with spouse	19.7	4.7	16.8	5.1	3.93[c]
Health	13.2	3.2	11.9	3.3	2.79[b]
DAS (n = 42)					
Consensus	46.4	7.3	57.9	8.5	-8.86[c]
Satisfaction	37.5	6.1	40.5	7.2	-2.74[b]
Affectional expression	8.2	2.1	9.0	2.3	-2.15[a]
Cohesion	14.7	3.8	13.4	4.2	1.99[a]
Dyadic adjustment	106.9	15.7	114.8	17.8	-2.89[b]
FES (n = 47)					
Cohesion	52.8	14.4	50.0	10.0	
Expressiveness	48.1	15.0	50.0	10.0	
Conflict	46.9	12.5	50.0	10.0	-2.16[a]
Independence	45.7	13.4	50.0	10.0	-2.95[b]
Achievement orientation	49.4	8.7	50.0	10.0	
Intellectual/cultural orientation	48.1	11.9	50.0	10.0	
Active/recreational orientation	45.1	13.2	50.0	10.0	-3.38[b]
Moral/religious emphasis	55.2	11.2	50.0	10.0	3.59[c]
Organization	54.2	11.3	50.0	10.0	2.88[b]
Control	51.8	12.1	50.0	10.0	

[a] $p < .05$.
[b] $p < .01$.
[c] $p < .001$.

mative group. Of the four DAS subscales, the biggest difference was found on the Consensus score, indicating that the couples in the current sample experience more disagreement about a variety of issues (family, friends, money, religion, sex, etc.). On the Satisfaction and Affectional Expression subscales there were small but significant differences, indicating less happiness in the current sample compared to norms. Interestingly, on the Cohesion subscale, the sign of the t statistic is opposite, indicating that the present sample reports their marriages to be closer, more supportive, and more cohesive. It should be noted that these couples were, on the whole, much more similar to the norms for the happily married group than to those for couples who were divorcing.

As shown in Table IV, 5 of the 10 FES subscales showed significant differences compared to the norms. Parents in the current study reported significantly less open Conflict than norms for "happy families" and considerably less than norms for "distressed families." There was also less Independence for family members to do things on their own and a much lower Active/Recreational Orientation. On these two scales, the present sample scored very similarly to the distressed norm group. However, the parents of girls with Rett syndrome had a higher Moral/Religious Emphasis. They also reported greater family system Organization compared to norms, and scored much higher in this respect than the distressed families. In addition, families in the present sample reported somewhat more Cohesion ($p = .06$) than norms, again scoring considerably higher than distressed families.

All stress, family functioning, and marital satisfaction variables were analyzed according to SES. None of the 24 correlations between individual parents' SES and their test scores was significant, indicating that there was no linear relationship between SES and family variables. One-way ANOVAs for the six SES categories were also calculated for each variable. There were 3 of 24 significant F values, but in 2 of these 3 cases, Scheffé posttests indicated no significant group differences. The remaining significant ANOVA was for the FES Conflict subscale, but the Scheffé posttest indicated a significant difference between Groups 2 and 3 only. This result can probably be attributed to chance. It was clear from careful examination of the six SES mean scores for each variable that there was no consistent ordering of family variables by SES.

To address the study's second question, correlations[3] were computed between the principal child characteristics as shown in Table III and the stress and family variables. Looking first at the child's chronological age, 7 of the 24 correlations with family variables were significant, though only moderate in size (-.31 to -.48). These were 3 of 10 FES subscales (Cohesion, Expressiveness, and Intellectual/Cultural Orientation) and 3 of 4 DAS subscales (Consensus, Satisfaction, and Cohesion) as well as total Dyadic Adjustment. (None of the PSI subscales was correlated with child's age.) All seven significant correlations were negative, indicating that parents of older girls reported greater marital or family problems.

Age of onset of Rett syndrome was also correlated with the family variables. Eight of 24 correlations were significant though, again, only of moderate size (-.29 to -.39). These were the PSI Child Domain, 3 of 10 FES subscales (Expressiveness, Conflict, and Independence), 3 of 4 DAS subscales (Satisfaction, Affectional Expression, and Cohesion) as well as

[3]Correlations are available by writing to the first author.

total Dyadic Adjustment. All correlations were in the direction of greater marital and family problems as age of onset increased. Generally speaking, there were few significant correlations between the child's cognitive and adaptive behavior scores and the family variables.

The third question for investigation concerned mother–father differences. For the 21 couples, paired *t* tests were calculated for all stress and family variables. These values, shown in Table V, indicate that husbands and wives perceived their family situation quite similarly, for the most part. Of 24 *t* tests computed, only 3 detected significant differences, although several others approached significance. The three were all from the FES and suggest that mothers perceived their families more positively than fathers. Mothers reported significantly greater Cohesion, greater Expressiveness, and greater Independence than did their husbands.

DISCUSSION

Looking at the profile of subscale similarities and differences compared to norms, it seems as though these families, as a group, have developed a pattern of adaptation to their situation that is sensible and essentially healthy. The family is close and cohesive, there is little open conflict, there is a high degree of organization, and religious beliefs are an important coping mechanism. However, there are costs associated with this pattern of adaptation, both to family members as individuals and to the marital relationship. For individuals, there is limited independence for meeting one's own needs (especially as felt by fathers), a lack of opportunity to engage in recreational activities, a degree of social isolation, and consequences in terms of parents' health. In the marriage, although there is a sense of closeness, there is some disagreement about important issues. However, there is little openly expressed conflict (especially as perceived by fathers), suggesting that discussion of issues is not a prevalent coping strategy in these families. It is likely that a great deal of the couple's energy is channeled into parenting rather than into their relationship.

It must be stressed that this "pattern of adaptation" is based on group means and does not necessarily apply to all families or all individuals. It is also speculative on our part to suggest that it has developed in response to the presence of the daughter with Rett syndrome, since we do not know how these families functioned prior to having the child with Rett syndrome. However, the finding that questionnaire scores were independent of SES is consistent with the notion that there is a characteristic pattern of adaptation in families with a severely DD child. Furthermore, a virtually iden-

Table V. Mother-Father Comparisons Within Couples

Measure and subscale	Mothers		Fathers		
	M	*SD*	*M*	*SD*	Paired *t*
PSI (n = 21)					
Child domain	134.4	18.5	129.3	15.7	
Parent domain	134.1	26.7	128.2	15.1	
Depression	20.9	5.6	18.8	4.9	
Attachment	13.0	3.4	14.3	3.4	
Restriction of Role	21.1	5.4	18.6	4.9	
Competence	30.8	7.6	29.4	3.7	
Isolation	14.9	4.5	15.1	3.0	
Relationship with spouse	20.1	5.2	18.5	3.9	
Health	13.4	3.6	13.1	3.2	
DAS (n = 19)					
Consensus	47.8	6.8	45.6	7.1	
Satisfaction	38.0	5.0	37.5	5.4	
Affectional expression	8.4	2.3	8.2	2.0	
Cohesion	14.6	3.6	14.5	4.0	
Dyadic adjustment	108.7	13.1	105.9	16.0	
FES (n = 20)					
Cohesion	58.1	11.9	51.2	14.3	-3.21^b
Expressiveness	55.5	12.8	42.7	14.9	-5.15^c
Conflict	46.0	11.6	48.5	14.2	
Independence	48.2	11.5	42.3	14.3	-2.19^a
Achievement orientation	49.3	8.8	49.6	7.9	
Intellectual/cultural orientation	49.6	13.0	45.8	10.8	
Active/recreational orientation	48.6	11.7	43.3	12.3	
Moral/religious emphasis	56.5	11.0	54.9	11.8	
Organization	55.2	11.2	50.3	10.7	
Control	48.6	13.0	53.7	11.0	

$^a p < .05$
$^b p < .01$.
$^c p < .001$.

tical pattern of subscale differences and similarities was found in a previous study of parents of children with autism (Perry, 1990).

In general, there was very little relationship in the present study between specific child-functioning indices and family variables. From a statistical point of view this is not surprising, since there was very little variability in the intellectual level and adaptive behavior of the girls with Rett syndrome.

The finding that some of the marital and family variables tended to be related to the daughter's age is likely to be a reflection of several factors. The constant caretaking demands (changing, feeding, etc.) over a long period take an increasing toll on the resources and energy of parents. Also, the parents are themselves growing older, and there may be a decline in marital satisfaction as part of normal family life-cycle changes.

The correlations of family stress variables with age of onset are somewhat difficult to interpret. One hypothesis is that, after the child is born and appears to be developing normally, parents build up a set of expectations about the child's future. The longer parents have to do this (i.e., the later the age of onset), the more difficult it is to relinquish these dreams and aspirations when it becomes clear that the child will never attain them.

There were very few significant mother–father differences in this study. Although mothers' scores were slightly higher on a number of stress-related variables, the only three statistically significant sex differences in the study did not support the popular clinical assumption of greater maternal distress.

Most parents in this sample scored in the normal range and, as a group, the sample was more similar to normal than distressed norms except for a few specific family functions. Clearly, it cannot be assumed that all parents of girls with Rett syndrome are devastated. However, since this was a volunteer sample of parents who, it may be claimed, are particularly well adjusted, the results may not be generalizable to all parents of girls with Rett syndrome. However, the unrepresentativeness issue is a common and inevitable concern in research of this type.

These findings need to be considered within the complex reality of the social situation of the families. Parents of DD children are, without doubt, exposed to additional stressors compared to other parents. However, the potential negative consequences resulting from these additional stressors are mediated by the quality of the marital relationship prior to the child's diagnosis, the level of support from their social network, and the individual parents' personality, beliefs, and coping abilities. Future research should attempt to deal with this complexity as far as possible, both in terms of concepts and variables measured and in selection of suitable data analysis procedures.

There are a number of clinical implications that emerge from this study. Clearly, one major avenue of intervention involves strengthening the marriage. This could include teaching communication skills, which would enable the couple to more effectively express their feelings and deal with disagreements. A second major area is to help parents achieve a balance between meeting the needs of the family and their own individual needs. Each parent should have the opportunity to have some outside interest or activity as a source of self-esteem, social support, and general mental health. Provision of respite care is one of the most effective ways that professionals can help individuals and couples meet these other needs. Given the importance of religious beliefs as a coping strategy for many of these people, it is possible that religious communities and organizations could be a significant source of social support and validation. Most importantly,

professionals should respect the fact that many parents are coping quite well with little or no outside intervention.

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