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Consistent Stress Profiles in Mothers of Children with Autism[1]

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The present study extends the area of research on stress in parents of autistic children. In this study we used the Questionnaire on Resources and Stress (Holroyd, 1987) to compare the stress profiles across mothers (a) who lived in different cultural and geographic environments; (b) who had children of different ages; and (c) who had children with different functioning levels. Results showed a characteristic profile that was highly consistent across each of these subgroups. Major differences from the normative data oc-

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curred on scales measuring stress associated with dependency and management, cognitive impairment, limits on family opportunity, and life-span care. Results suggest the importance of developing treatment programs aimed at reducing stress in specific areas in families with autistic children.

Literature on families of children with autism has shifted from the historical emphasis on the psychological effect of the parent on the child (Bettelheim, 1967; Eisenberg, 1956; Rank, 1949; Ruttenberg, 1971) to a more recent emphasis on the psychological effect of the child on the parents. Rabkin and Struening (1976) pointed out that the literature on life stress suggests that among many threatening life events, those characterized by their magnitude, intensity, duration, and unpredictability tend to constitute the most stressful situations. Reflecting this emphasis, recent literature in the area of autism has focused on assessing and analyzing parental stress in families with handicapped children (e.g., Bristol, 1979; Bristol & Schopler, 1983, 1984; DeMyer, 1979; DeMyer & Goldberg, 1983; Holroyd & McArthur, 1976; Marcus, 1977; Plienis, Robbins, & Dunlap, 1988; Robbins, Dunlap, & Plienis, 1991; Schopler & Mesibov, 1984; Wolf, Noh, Fisman, & Speechley, 1989). There is increasing evidence that the presence of a child with autism has a particularly pervasive stressful effect, directly and indirectly affecting many aspects of family life (Bebko, Konstantareas, & Springer, 1987; Beckman & Pokorni, 1988; McAdoo & DeMyer, 1978; McKinney & Peterson, 1987). Although the literature is inconsistent in finding a general overall stress level (e.g., Cantwell, Baker, & Rutter, 1977; Donovan, 1988; Wolf et al., 1989; Koegel, Schreibman, O'Neill, & Burke, 1983; Ryde-Brandt, 1990), it does report that the presence of an autistic child may lead to *specific* areas of stress that affect family life (e.g., Bouma & Schweitzer, 1990; Bristol, 1979; DeMyer, 1979; DeMyer & Goldberg, 1983; Holroyd, 1974; Holroyd, Brown, Wikler, & Simmons, 1975; Holroyd & McArthur, 1976; Koegel et al., 1983; Marcus, 1977; O'Moore, 1978). For example, O'Moore (1978) found that mothers of children with autism showed a higher level of stress in activities that involved social contact such as going shopping or taking trips with the family. Bristol and Schopler (1983) noted that when they looked at the overall pattern of high stress, the pattern of Bristol's (1979) sample of parents in North Carolina was strikingly similar to the pattern obtained by Holroyd and McArthur (1976) with a population in California. This led Bristol and Schopler (1983) to speculate that there may be a characteristic profile of stress associated with parenting an autistic child.

Focusing on a specific pattern of subareas of stress in parents of children with autism has some important advantages. First, a clearer under-

standing of the situations leading to stress should allow for treatment providers to assist families in changing the environment within which the family operates. Second, given an understanding of specific child characteristics and/or behaviors associated with elevated stress in the parents, it should be possible to focus intervention more efficiently and in a manner that will reduce these specific stress areas.

The purpose of the present investigation was to replicate and extend the line of stress research by identifying a particular pattern of areas influencing specific or situational stress in families of children with autism using a well-researched and empirically standardized methodology. We used a short form of the Holroyd Questionnaire on Resources and Stress (QRS; Holroyd, 1987) which is an empirically based composite of the original long form of this measure (Holroyd, 1974). We wished to determine the robustness of a characteristic profile of stress by comparing the responses from mothers of autistic children across multiple cultural and geographic locations, across families with children of different ages, and across families with children of different functioning levels.

METHOD

Subjects

Fifty families of children with autism participated in this investigation. To assess the consistency of stress profiles identified in this investigation, the families were selected to represent a broad range in geographic/cultural location, age of child, and functioning level of the child. Thus, they represented the families in our research programs at the University of California campuses in Santa Barbara (12 families) and San Diego (14 families), at Marshall University in Huntington, West Virginia (12 families), and at the Max Planck Institute for Psychiatry in Munich, Germany (12 families). The demographic characteristics of the 50 families who participated in this investigation are listed in Table I. Overall, their characteristics were similar to those of parents of children with autism described in the literature in general. The fathers were involved in a broad range of careers, such as sales, management, small businesses, and the sciences. Some of the mothers worked outside of the home, but the majority were full-time homemakers. The families were similar across the geographic sites and represented a broad range in socioeconomic status (SES), with the mode in the middle to upper middle SES brackets. The individuals with autism all were diagnosed according to conventional criteria (e.g., DSM II-R, American Psychiatric Association, 1987). They ranged in age from 3.1 years to 23.1 years,

Table I. Demographic Characteristics of Families (in Percentage)

	Mother's Age			Mother's educational level		Age of child			Child's functioning level	
	20–30	31–40	Over 40	Below 9th grade	High school/ college	Preschool age	School age	Adult	IQ < 50	IQ > 50
California	12	50	38	4	96	19	76	4	46	54
Appalachia	17	83	0	0	100	50	50	0	67	33
Germany	17	58	25	17	83	17	83	0	67	33
Normative sample	N/A	N/A	N/A	8	92	0	100	0	0	100

and functioned within a range of severely retarded and untestable to near normal on standardized tests.

The normative data consisted of means and standard deviations obtained from Holroyd's 1987 manual. The families in our sample were selected to have similar characteristics to the children in Holroyd's normative sample (see Table I), and for both our autism group and the normative sample, the mother's QRS responses were used rather than the father's.

Description of Questionnaire on Resources and Stress

Holroyd's 11-scale 66-item QRS was administered to assess a possible pattern of stress level in parents of children with autism. This questionnaire is a statistically based approximation of the 15-scale 285-item QRS (Holroyd, 1974) that has been used widely and investigated empirically in the past decade (e.g., Dunset, Trivette, & Cross, 1986; Freidrich & Freidrich, 1981; Holroyd & McArthur, 1976; Konstantareas & Homatidis, 1985; Wikler, 1986). True and false items address numerous areas of potential parental stress. Sample questions from each of the 11 subscales are listed in Table II. Each child's mother was asked to complete this questionnaire anonymously. A question answered in the direction indicated in parentheses was tabulated as a stress item. Scores were obtained in the standard manner for all 11 subscales for each parent, with each scale receiving a number of stress items between 0 (indicating little or no stress) and 6 (indicating very high stress).

DATA ANALYSIS AND RESULTS

Consistency in Stress Profiles Across Subgroups

The major question in this investigation was whether there was a characteristic profile of stress for mothers of children with autism. We wanted to determine whether the profile evidenced for the autistic population was consistent across subgroups, yet different from normative data. Figure 1 shows the breakdown of the autism families by geographic/cultural location, by age of child, and by functioning level of child. The top portion of Fig. 1 shows the profiles for the California (San Diego and Santa Barbara) group versus the Appalachian (West Virginia, Kentucky, and Ohio) group versus the Germany group. The middle portion of Fig. 1 shows the breakdown in the profiles of age of child (below 7 years of age vs. above 7 years of age). The bottom portion of Fig. 1 shows the breakdown in the profiles

Table II. Sample QRS Items for Each of the Eleven Scales[a]

Scale 1: Dependency and management	
(T)	——— demands that others do things for him/her more than is necessary.
(T)	If ——— were more pleasant to be with it would be easier to care for him/her.
Scale 2: Cognitive impairment	
(T)	——— would be in danger if he/she could get out of the house or yard.
(F)	——— is aware of who he/she is (e.g., male 14 years old).
Scale 3: Limits on family opportunity	
(T)	One of us had to pass up a chance for a job because ——— could not be left without someone to watch him/her.
(T)	Outside activities would be easier without ———.
Scale 4: Life-span care	
(T)	I worry about what will happen to ———when I can no longer take care of him/her.
(T)	I worry about what will be done with ——— when he/she gets older.
Scale 5: Family disharmony	
(F)	Our family agrees on important matters.
(F)	——— is accepted by other members of the family.
Scale 6: Lack of personal reward	
(F)	Having to care for ——— has enriched our family life.
(F)	Caring for ——— gives one a feeling of worth.
Scale 7: Terminal illness stress	
(T)	As the time passes I think it will take more and more to care for ———.
(T)	——— cannot get any better.
Scale 8: Physical limitations	
(F)	——— can feed himself/herself.
(F)	——— can walk without help.
Scale 9: Financial stress	
(F)	We can afford to pay for the care ——— needs.
(T)	We can hardly make ends meet.
Scale 10: Preference for institutionalization	
(T)	There is no way we can possibly keep ——— in our house.
(F)	——— is better off in our home than somewhere else.
Scale 11: Personal burden	
(F)	——— is cared for equally by all members of our family.
(T)	Most of ———'s care falls on me.

[a](T) or (F) indicates the response scored as positive for stress.

by functioning level of child (i.e., severely impaired, with an IQ < 50, vs. mildly impaired, with an IQ > 50). Visually and statistically, these data show that the autism subpopulations all were very similar, and all were consistently different from the norms.

The correlation coefficients between all of the autism subgroups were extremely high. The correlations for mothers of autistic children in each of the three *geographic locations* were very high and were highly statistically significant ($p < .001$). The correlation coefficient for the California (Santa Barbara and San Diego) group versus the Germany group was .931; for the California group versus the Appalachian (Kentucky, West Virginia, and Ohio) group was .957; and for the Germany group versus the Appalachian group was .886.

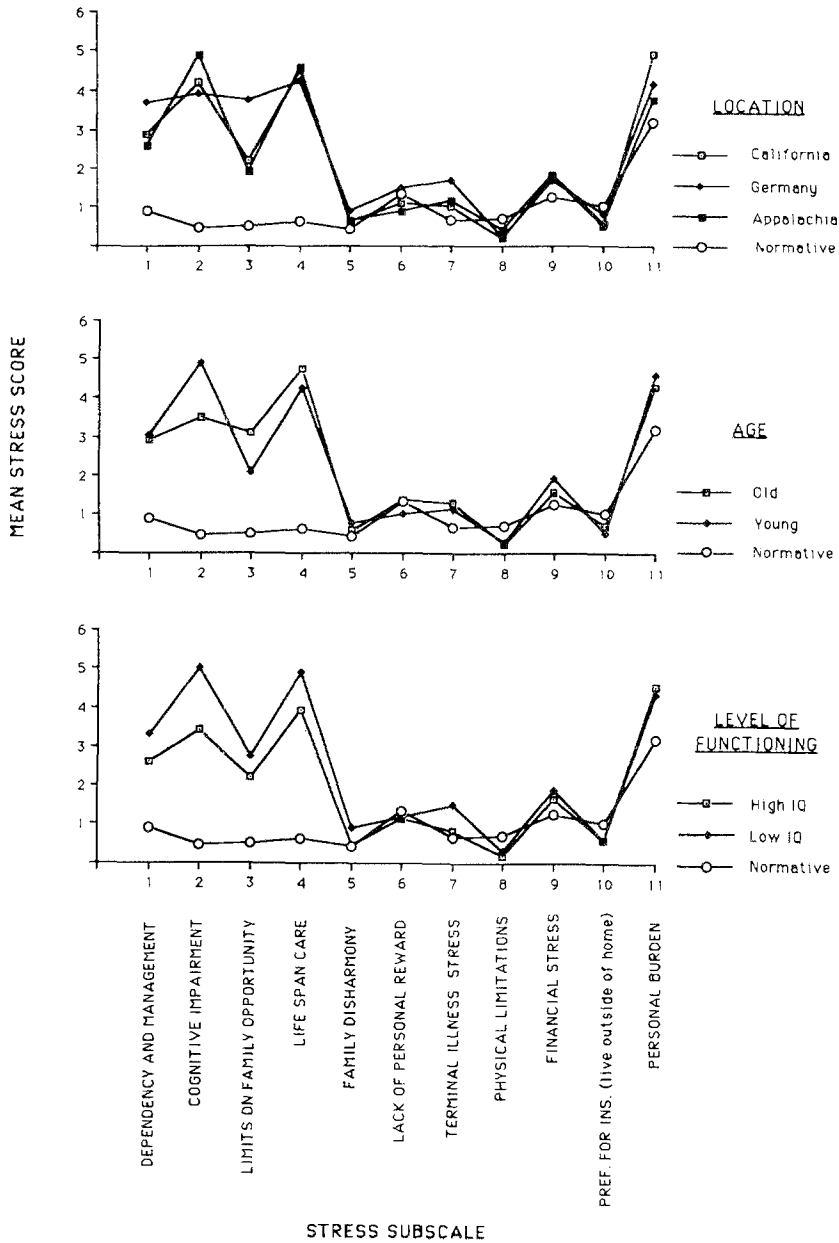

Fig. 1. Stress profiles for mothers of autistic children across geographic location, age, and functioning level of child. The stress profile for the normative comparison families also is plotted.

A correlation coefficient also was calculated with respect to the *ages* of the children. The stress profiles for mothers with younger (less than 7 years) versus older (7 years or older) autistic children revealed a very high correlation coefficient of .932 ($p < .001$).

A correlation coefficient also was calculated with respect to the *functioning levels* of the children. The stress profiles for mothers of low (IQ < 50) versus high (IQ > 50) functioning autistic children revealed a very high coefficient of .964 ($p < .001$).

In contrast to the above very high correlations, the correlation coefficients for the normative group versus the autism groups were all very low. The correlation coefficient for the normative group versus the California autism group was .392; for the normative group versus the Germany autism group was .228; and for the normative group versus the Appalachia autism group was only .172. Similarly, the correlation coefficient for mothers of younger autistic children versus the norms was .314; the correlation coefficient for mothers of older autistic children versus the norms was .302; the correlation coefficient for mothers of higher functioning autistic children versus the norms was .453; and the correlation coefficient for mothers of lower functioning autistic children versus the norms was .221. None of these correlations were statistically significant.

DISCUSSION

Overall, the results of this investigation suggest there may be a characteristic profile of stress in parents of autistic children that is relatively constant across many variables. The major differences between the autism families and the normative families were on Scales 1 through 4, and appeared to relate to a general high level of concern regarding the well-being of their child after the parents are no longer able to provide care for them. That is, the autism parents were very concerned about the future of their child (Scale 4), about the level of cognitive impairment and the child's ability to function independently (Scales 1 and 2), and the child's ability to be accepted in the community (Scale 3). This finding is consistent with the findings of other investigators (Bouma & Schweitzer, 1990; Bristol & Schopler, 1983; Holroyd & McArthur, 1976) suggesting that living with and caring for an autistic child presents very specific and stressful challenges that impact upon the lives of the families in rather specific ways. To further attest to the robustness of this finding, the present study found that these subareas of elevated stress are consistent across populations of mothers of children with autism discrepant in age, functioning level, geographical location, and culture.

The specific profile of stress indicated in our data relates to issues in the literature on stress in parents of handicapped children. Our findings are consistent with the literature indicating the concern parents have regarding issues of the child's dependence. Scales 1 through 4 all deal with concerns about the child's dependency, lack of current or potential independence, and the mother's concern with the long-term burden of parenting the autistic child. Holroyd and McArthur (1976) reported that mothers of children with autism and mothers of children with Down syndrome identified problems with their child's excessive dependence. The mothers of autistic children also reported that their youngsters were more physically dependent than did the mothers of those with Down syndrome, and also felt that their children had a poorer prognosis for independent living. Other investigators have likewise reported that parents of autistic children express serious concerns about their child's current dependence (Bristol, 1979; Wolf et al., 1989) and future prospects for independent living (DeMyer, 1979; Marcus, 1977; Wing, 1985; Wolf & Goldberg, 1986). Our finding of elevated stress on Scale 3 (Limits on Family Opportunity) is also consistent with the literature in this area (DeMyer & Goldberg, 1983; Dirlich-Wilhelm, 1989; Holroyd & McArthur, 1976; O'Moore, 1978). Other literature in this field also supports this notion. For example, research shows that parents of children with autism are more restricted in terms of their ability to engage in recreational and leisure activities outside the home (Koegel, Schreibman, Johnson, O'Neill, & Dunlap, 1984). The results indicated that the parents of autistic children spent relatively little time in these activities and more time in direct child-care activities.

Our finding of high stress related to cognitive impairment of the child is also consistent with existing literature in the area suggesting that one of the main stress areas for parents related to their concern over their child's linguistic and cognitive handicaps (Bristol, 1979; DeMyer, 1979; Marcus, 1977). This stress relates logically to parental concerns over life-span care, dependency, and potential for independent living in that cognitive limitations restrict the child's functioning in a wide variety of areas and will do so for the life of the child.

There are certain limitations one must impose upon these data. First, although we have attempted to gather data from a discrepant range of families, we have not exhausted the possibilities. For example, it will be interesting to obtain similar measures of families from even more diverse cultures to obtain some idea of the extent of the characteristic pattern of stress in families of children with autism. Second, although we have obtained data relating to parental report of stress, it remains to look more specifically at individual family and child characteristics associated with elevated stress. It is hoped that this investigation will stimulate research along these lines.

Treatment Implications

The findings of specific subareas of stress in mothers of autistic children has implications for further treatment research. One would hope that identification of stress areas would lead to the development of treatment and support systems aimed at assisting the family with the stressful burden of caring for and living with a child with autism. For example, our data suggest that one important way in which treatment providers might alleviate the stress for these parents is to develop treatments that reduce the child's dependency. It is apparent from the findings of this investigation, and from related research such as that reported by Bristol and Schopler (1983), that the child's pervasive management problems and prolonged dependency on the parent for care is an important source of stress on the parent, affecting many aspects of the family life. If this is the case, it suggests that reducing the child's behavior problems and teaching more independent living skills to the child, either directly or indirectly via parent training and/or training in self-management (Koegel & Koegel, 1990; Koegel, Koegel, & Parks, 1990; Stahmer & Schreibman, in press), holds the potential for reducing this serious stress area. Some existing data support this possibility. Koegel, Schreibman, Britten, Burke, and O'Neill (1982) reported data collected from 24-hour time activity diaries kept by parents of children with autism. These diaries allowed for the determination of the nature, and amount of time spent in, various activities such as outside recreation with family, leisure time at home, caring for the autistic child and, so forth. While parents were initially quite low on time spent in recreational/leisure activities, those parents who were trained to work with their children (i.e., reduce problem behaviors and dependency) subsequently reported significantly more time in recreational/leisure activities than did the parents who had not been trained to work with their children. Thus, these data are suggestive that changing the child's behavior can lead to positive changes in the parents' lives and may lead to specific treatment programs aimed at reductions in the stress related to their child's behavior.

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