Stress Profile of Peruvian Parents Caring for Children with Autism

by
Yash Bhagwanji and Ximena Suárez-Sousa

Yash Bhagwanji, Ph.D. and Ximena Suárez-Sousa, M.Ed., belong to the Department of Teaching and Learning at the University of Louisville, Louisville, Kentucky, USA.

Research on stress involving parents of children with autism from developing countries is seriously lacking. A search using ERIC and PSYCHLIT databases yielded only one peer-reviewed stress study that included parents of children with autism from a developing nation. In that study, Liwag (1992) studied the association between family demographics and stress experienced by 25 Filipino parents of children with autism. The characteristics of the child with autism and the permanence of autism (i.e., the prospect for the child not achieving normalcy) were described as producing the most stress in the parents from the Philippines. After conducting in-depth interviews with the parents, implications were drawn for strategies that may assist Filipino parents in coping with stress associated with caring for children with autism.

There were 14 other peer-reviewed published studies about parenting children with autism and stress, all involving parents from developed western countries. The countries represented in these studies were Australia, Canada, Germany, and the United States. All but four of the studies drew implications for intervention, services, support, or resources for the parents.

Based on the current status of research on the topic, three conclusions can be drawn for research that is needed. One, more studies that include parents of children with autism from other countries, especially developing countries, are needed. Two, when enough studies have been conducted involving parents from a representative range of countries, analyses are needed to draw parallels and contrasts about (a) the experiences of parents in caring for children with autism, and (b) what has been found helpful in reducing the stress of the parents. Three, experimental studies are needed to validate the effectiveness of the helpful approaches.

This study responds to the first need identified above. The focus is on parents of children with autism in Peru: a non-western, developing country in South America, and home country of the second author. Specifically, this study examined the stress profile of parents of children with autism and compared it to the stress profile of parents of children without disabilities in Peru. Because no previous data are available, the null hypothesis is that there is no difference between the two groups.

METHOD

Participants

The participants constituted an experimental sample of 77 Peruvian parents of children with autism and a control group of 77 Peruvian parents of children without disabilities.

Experimental group. The experimental group was randomly selected and constituted a sample representing approximately one-half of all families of children with autism enrolled in a large center located in Lima, Peru. With a population of more than seven million people, almost a third of the entire country's population lives in Lima (Instituto Nacional de Estadistica e Informatica, 2001). The center is an internationally-known, nonprofit, private center primarily serving children diagnosed as having Pervasive Developmental Disorders (PDDs). The center also serves as "a research, demonstration, and training model" in serving persons with disabilities in Peru and other developing countries (Center's Director, personal communication, August 2000). Interviews with the parents indicated few other programs were available and willing to serve children with autism in Peru. Approximately 15% of the parents indicated either commuting daily (by private or public transportation) or moving to Lima from a distance of at least 100 miles in order to obtain services from the center. About 80% of the parents also paid fees for services received at the center.

Fifty-one of the participants were mothers, while 26 were fathers. More specifically, 41 mothers were married (23 had spouses participating in the study) and 10 mothers were single. In other words, 23 married fathers and three single fathers participated in the study. See Table 1 for characteristics of families and children.

Family economic status was determined by the center's social worker. A scoring system was used to determine high, middle, or low economic status. Points were tabulated based on a number of criteria, including current household income, number of dependents, ownership of properties, unmet needs (e.g., food, clothing, shelter), and opportunities for recreation. The majority of the parents (46%) were from low economic status.

The majority of parents (66%) in the study had higher education credentials (e.g., had university degree, or completed coursework towards a degree). Close to 8% of the parents had primary education or less. The youngest age of parents participating in the study was 26 years old. The largest group of parents (49%) was between 26 and 40 years. The smallest group (8%) was 56 years and older.

Children with features of autism constituted 43% of all participating children. Children with moderate level of severity was at 39%, while children with severe autism was at 19%. Sixty-seven percent of the children were 12 years old and younger; 33% were 13 years and older. Male children were the largest group by gender at 80%.

Control group. A sample of 110 Peruvian families volunteered to participate in the study. Demographic information was obtained for this group. Parents were then randomly selected until 23 married couples, 18 married mothers, and 13 single parents were found, the same configuration as the experimental group.

Measure

Measure of parental stress. Holroyd's (1987) *Questionnaire on Resources and Stress (QRS): For Families with Chronically Ill or Handicapped Members (Short Form Scales)* was used to obtain the Peruvian parents' stress profile. The director of the center, who has a doctoral degree in Human Development from a university in the United States, took the first step in translating the instrument into the Spanish language. The English and Spanish versions were then distributed to three bilingual psychologists and a certified translator. All were staff at the center, each with at least 10 years of professional experience in special education settings. Each staff member independently provided comments through writing and discussions with the director. The director then drafted a revised version of the instrument in Spanish, based on the comments and discussions. The revised version was again submitted to the staff members for further input. Following the input, the final Spanish version was produced and used in the study. See Table 2 for a list of the stress scales.

For each of the 11 scales, six statements were presented. See Table 3 for examples of statements for selected scales. All statements required a "true" or "false" response. Forty-six statements were scored one point each if marked "true." For the same 46 statements, zero is scored for each "false" response. Twenty statements were scored one point each when the response was "true," and zero when marked "false." A parent may score between 0 and 6 for each scale, and between 0 and 66 points for a total scales score. The higher the score for the scale or the total of all scales, the higher the stress level. Refer to Table 3 for an explanation of the scoring system.

Based on a longer version, the QRS Short Form Scales' overall reliability is at .79 (Salisbury, 1985) and .85 (Holroyd, 1974) using Kuder-Richardson internal consistency measures. The longer version of the QRS was developed with input from experts on the topic of family stress related to caring for persons with disabilities and chronic health problems. Criterion validity has been established for most of the scales based on results obtained from over 20 studies (Holroyd, 1987). Construct validation is ongoing; for example, Bristol (1987) and Konstantareas, Homaditis & Plowright (1992) used the instrument to assess aspects of the ABCX theory of family stress. The current study will discuss the results obtained from the QRS Short Form Scales within the contexts of transactional (Sameroff & Fiese, 1990) and ecological (Bronfenbrenner, 1977) theories.

Measure of level of autism. *The Childhood Autism Rating Scale (CARS)* was used to determine each child's level of autism. The same translation procedures described above were used to develop a Spanish version of the CARS. Consisting of 15 scales, scores ranged from 15 to 30 for "features of autism," 31 to 36.5 for "moderate," and 37 to 60 for "severe" level of autism. Internal reliability of the English version is .94; reliability with experts is .71; and test-retest reliability is .88 (Schopler, Reichler & Renner, 1986). Criterion validity is at .84 and construct validation is demonstrated by the use of CARS in the fields of medicine and educational psychology, with an average score of .82 (Schopler et al., 1986).

The measures in the Spanish language are available upon request from the authors.

Procedures

From a pool of over 150 parents of children with autism at the center, 100 were randomly selected. The purpose, procedures (including confidentiality of information provided by parents), and benefits of the study were described to all the parents in the experimental group. Seventy-seven parents verbally agreed to participate in the study. The parents were then administered the instruments at the center, either in a group setting or on an individual basis.

Parents of children without disabilities were recruited through various contacts in the community (e.g., church

leaders, service agency administrators, university professors). After explaining the purpose, procedures, and benefits of the study, verbal consent was obtained from 77 parents. The parents were administered the QRS Short Form Scales in their homes.

Analysis

Data were analyzed in two ways. First, t test for independent means was used to determine the differences in the mean score per scale between the experimental and control groups. A very conservative alpha level of .0045 was used to correct for inflation of Type I error. The Bonferroni correction procedure was used to determine the alpha level (.05/11=0.0045). Second, t test for independent means was used to determine whether there were subgroup differences within each independent variable per scale. To reduce the Type I error rate, the alpha level was also set at .0045.

RESULTS

Differences between parents of children with and without autism. Peruvian parents of children with autism reported significantly higher stress levels in (a) cognitive impairment, and (b) life-span care ($p<.0045$, two-tailed test; see Table 4 and Figure 1). The Peruvian parents of children with autism also showed significantly higher overall stress level compared to Peruvian parents of children without autism.

Subgroup differences within independent variables in the experimental group. Only one independent variable was found to have statistically significant subgroup mean differences. Subgroups within "family economic status" reported statistically significant mean differences for financial stress (see Table 5). The "low" economic status subgroup reported significantly higher financial stress compared to both the "middle" and "high" economic status subgroups ($p<.0045$, two-tailed). No difference was found between the "middle" and "high" economic status subgroups.

No other independent variable subgroup mean differences were found to be statistically significant for any of the other stress scales.

Follow-up Interviews. Follow-up interviews with 30 randomly-selected parents of children with autism helped in explaining the sources of stress. Related to cognitive impairments, more than one-half of the parents reported their children to be limited in their ability to make decisions, keep themselves safe and healthy, and be independent. For example, a mother of a 12-year-old male child expressed the following safety concern about her son: "me da mucho miedo dejarlo solo en la casa, hay tantas cosas ahí que pueden resultar peligrosas si nadie lo está supervisando" [I am so afraid about leaving him alone at home, because there are many things that could be dangerous to him if nobody is supervising him].

Another mother expressed concern related to her son's ability in daily self-care activities: "Yo no tengo esposo entonces para mí es un problema tener que bañar a mi hijo que ya es casi un hombrecito" [I do not have a husband so it become a problem having to bathe my son who is almost a grownup].

A father expressed a safety concern he had about his son this way: "Algunas veces cuando el está bien molesto puede llegar a lanzar cosas de la casa contra las paredes o contra nosotros mismos" [Sometimes when he is very angry, he would throw home items at the walls or us].

Another mother commented about her son's level of self-awareness: "Si, siempre que salimos con él no le despegamos nuestros ojos, porque si se pierde despues él no va a saber decir quien es o dar el número de teléfono de le casa" [Yes, every time we go out with him we have to keep an eye on him all the time because, if he gets lost, he won't be able to say what his name or home phone number is].

Stress related to life span care was demonstrated through comments such as: "Quién se hará cargo de mi hijo cuando yo ya no esté?" [Who will take care of my child when I'm gone?]; "Mis otros hijos tendrán que quedarse con su hermana cuando yo me muera" [My other children will have to take care of their sister when I die]; or, "Nosotros hemos abierto una cuenta de banco, ahí estamos ahorrando para que quien se haga cargo de él se pueda ahyudar con esa plata" [We have opened a bank account, so whoever takes care of him in the future can count on that money].

Related to financial stress, parents of children with autism from the low economic status group reported more difficulties in paying for respite care services, daily living skills training for their children, and specialized medical and therapeutic services than parents from both the middle and high economic status groups. For example, one parent said:

"Uy no, contratar a alguien para que venga a la casa por las tardes está muy caro y no es fácil encontrar a una persona que sepa así como saben los profesores de su colegio" [To hire someone to come home during the afternoons is too expensive and it is not easy to find a per-

son who is knowledgeable as much as the teachers in her school].

Additionally, with income reduced through limited maternal employment or unemployment because of the level of supervision and care required by children with autism, many families' financial capacity became even more exacerbated. One father commented:

"La plata a veces no alcanza" [Sometimes we don't have enough money].

For several of the families interviewed, fathers were holding down two or more jobs. One father explained why:

"Ahora estoy trabajando en dos sitios diferentes, así me alcanza para cubrir los gatos de cada mes" [Right now I am working in two different places, so I can pay all the monthly expenses].

DISCUSSION AND IMPLICATIONS

The transactional model of child development suggests that stress experienced by parents may lead to parental behaviors (e.g., availability, consistency in interaction that is nurturing) that could negatively impact the developmental outcomes for children (Sameroff & Fiese, 1992). Therefore, the more stress experienced by the Peruvian parents of children with autism (e.g., cognitive impairment, life span care, financial stress), the higher the potential for negative developmental outcomes beyond the risk already associated with diagnosis of autism. In order to identify resources and supports that may be useful for the parents in coping with or reducing stress, Bronfenbrenner's ecology of human development (1977) provides a conceptual framework.

In the area of cognitive impairment, for example, services may be provided at the child or family level (microsystem). At the child level, service providers can develop effective means to train children with autism to become as independent as possible. At the family level, families may be provided with resources that help them manage their children better (e.g., parent education, in-home assistance).

Relationships between direct service providers and family members (mesosystem) are another area of support for families. Given the limited amount of services currently available, for example, more frequent home visits and full-day classroom services could be made available. More home visits could provide parents with more opportunities to discuss and problem-solve issues related to the caretaking of the child with autism. The home visits could also provide opportunities to discuss and problem-solve family matters. Full-day classroom services, on the other hand, may enable parents to more fully engage in employment and other family activities that reduce stress and increase family capacities.

The exosystem represents agencies that could provide needed services for families. As indicated previously, the Peruvian parents are in need of respite care, daily living skills training for their children, specialized medical and therapeutic services, and other low-cost services. Additionally, programs located closer to homes or places of employment may assist parents by reducing commuting time and energy required to transport the child, especially when using public transportation.

At the macrosystem level, the Peruvian parents may benefit from entitlements that support their families in accessing needed services. As the economy of Peruvian society improves over time, the government could fund services currently unavailable or inaccessible in order to help reduce parental stress and increase family self-efficacy. Better family efficacy and functioning may, in turn, reduce the families' long-term dependence on social services required for caring for children with autism.

CONCLUSION

A direction for future research is to obtain concrete evidence of family needs for services and, in the absence of needed services, supports that may help families in developing coping strategies. This information could be obtained through in-depth interviews or case studies describing families' lived experiences. It would also be helpful to understand the experiences of parents from other South American countries, and how their experiences compare to the Peruvian families. A broader understanding may suggest a range of approaches or alternatives to reducing family stress associated in caring for children with autism.

See tables 1 through 5 on following pages...

Table 1
Characteristics of Families and Children in the Experimental Group

Independent Variables and Subgroups	N	%
Family economic status		
High	16	20.7
Middle	26	33.8
Low	35	45.5
Family structure		
Two-parent families	64	83.1
Single-parent families	13	16.9
Gender of parents		
Female	51	66.2
Male	26	33.8
Education of parents		
Primary education	6	7.8
Secondary education	20	26.0
Higher education	51	66.2
Severity of autism of children		
Features only	23	42.6
Moderate level	21	38.9
Severe level	10	18.5
Age of children		
12 years and younger	36	66.7
Over than 12 years	18	33.3
Gender of children		
Female	11	20.1
Male	43	79.9

Table 2

List of Stress Scales

Stress Scale	Definition*
Scale 1: Dependency and Management	Stress related to the level of care and supervision requested by or needed for the child
Scale 2: Cognitive Impairment	Stress related to child's level of self-awareness, ability to be independent, and stay out of danger
Scale 3: Limits on Family Opportunities	Stress related to missed opportunities for members of the family because of child
Scale 4: Life Span Care	Stress related to future of child
Scale 5: Family Disharmony	Stress related to family cohesion and adaptation
Scale 6: Lack of Personal Reward	Stress related to adequacy of enriching rewards and feelings of self-worth caring for child
Scale 7: Terminal Illness Stress	Stress related to child's health status and how that will affect family life (including child)
Scale 8: Physical Limitations	Stress related to child's current level of independence
Scale 9: Financial Stress	Stress related to adequacy of finances to make ends meet and care for child
Scale 10: Preference for Institutional Care	Stress related to setting that will provide better care and attention for child
Scale 11: Personal Burden for Respondent	Stress related to the level of time and energy provided personally by the respondent

* Developed by first author, based on questions for each scale in Questionnaire on Resources and Stress (QRS): For Families with Chronically Ill or Handicapped Members (Short Form Scales) (Holroyd, 1987)

Table 3

Examples of QRS Statements for Selected Scales

Scale	Examples of Statements
Dependency and Management	(Name of child) demands that others do things for him/her more than is necessary*
	(Name of child) is easy to live with**
	(Name of child) doesn't do as much as he/she should be able to do*
Lack of Personal Reward	We enjoy (name of child) more and more as a person**
	Caring for (name of child) gives one a feeling of worth**
Limits of Family Opportunities	The constant demands for care for (name of child) limit growth and development of someone else in our family*
	Outside activities would be easier without (name of child)*

*A response of "true" is scored one point (indicating stress); a "false" response is scored zero (indicating no stress)
** A response of "false" is scored one point (indicating stress); a "true" response is scored zero (indicating no stress)

Table 4

T-Test for Independent Mean Scores per Scale Between Parents of Children With and Without Autism

Scale	Experimental Group Mean	Experimental Group SD	Control Group Mean	Control Group SD	t
1	2.45	1.42	1.30	2.84	3.19
2	3.75	1.66	1.00	3.32	6.50*
3	2.40	1.73	1.00	3.46	3.18
4	3.90	1.29	1.05	2.58	8.64*
5	0.75	1.19	0.50	2.38	0.83
6	0.95	1.13	1.06	2.26	0.38
7	1.85	0.99	1.20	1.98	2.60
8	0.25	0.56	0.25	1.12	0
9	3.85	1.44	1.85	2.88	2.13
10	1.30	0.98	1.10	1.96	0.80
11	2.60	1.55	2.60	3.10	0
Total	24.32	6.59	12.93	13.18	6.87*

* $p < .0045$, two-tailed test, $df = 152$

Table 5

Means of Subgroups Per Independent Per Scale

	Family Economic Status			Family Structure		Gender of Parents		Education of Parents		
Scale	High	Middle	Low	Two-parent	Single parent	Female	Male	Primary	Secondary	Higher
1	2.40	2.60	2.45	2.66	2.80	2.69	2.31	2.50	2.60	2.55
2	4.05	3.95	3.40	3.66	3.30	3.69	3.77	2.33	3.50	3.96
3	2.15	1.95	2.75	2.66	3.20	2.76	2.00	3.50	2.20	2.51
4	3.95	3.65	4.15	3.93	4.00	3.94	3.88	4.67	3.95	3.82
5	0.40	0.55	1.05	0.61	1.18	0.84	0.65	0.67	1.35	0.57
6	1.40	0.90	0.70	1.07	1.10	1.08	0.77	1.50	1.00	0.90
7	1.95	1.75	1.85	1.93	1.90	1.92	1.77	2.33	2.00	0.96
8	0.10	0.25	0.40	0.32	0.48	0.33	0.23	0.17	0.45	0.25
9	2.70*	3.70*	4.85*	4.15	4.10	4.14	3.62	4.17	4.45	3.75
10	1.00	1.55	1.15	1.29	0.90	1.26	1.32	1.00	1.45	1.20
11	3.15	2.00	2.90	3.05	3.00	3.04	2.15	3.33	3.00	2.57
Total Score	25.5	22.9	25.4	25.0	26.2	25.04	22.46	26.17	25.3	23.69
Total SD	6.40	7.09	6.28	5.75	8.47	6.28	6.94	2.99	6.50	6.91

Table 5 (continues)

	Severity of Autism			Age of Child		Gender of Child	
Scale	Feature	Moderate	Severe	< 13 years	> 12 years	Female	Male
1	2.45	2.47	3.00	2.41	2.81	2.55	2.50
2	3.36	3.73	4.50	3.86	3.42	4.35	3.60
3	2.48	2.36	2.86	2.43	2.65	3.45	2.35
4	3.67	3.90	4.43	3.73	4.31	3.85	3.95
5	0.52	0.91	1.14	0.84	0.65	0.30	0.85
6	0.94	1.00	1.00	0.94	1.04	0.65	1.00
7	1.97	1.70	2.00	1.84	1.92	1.95	1.95
8	0.24	0.27	0.50	0.27	0.35	0.20	0.30
9	4.03	3.63	4.50	3.73	4.42	4.25	3.80
10	1.42	0.97	1.43	1.22	1.31	1.05	1.30
11	2.27	2.90	3.50	2.75	2.73	2.30	2.65
Total Score	23.1	23.6	28.7	23.8	25.2	23.3	23.98
Total SD	6.80	5.96	5.65	7.21	5.14	6.5	6.75

* $p < .0045$, two-tailed test, $df = 76$

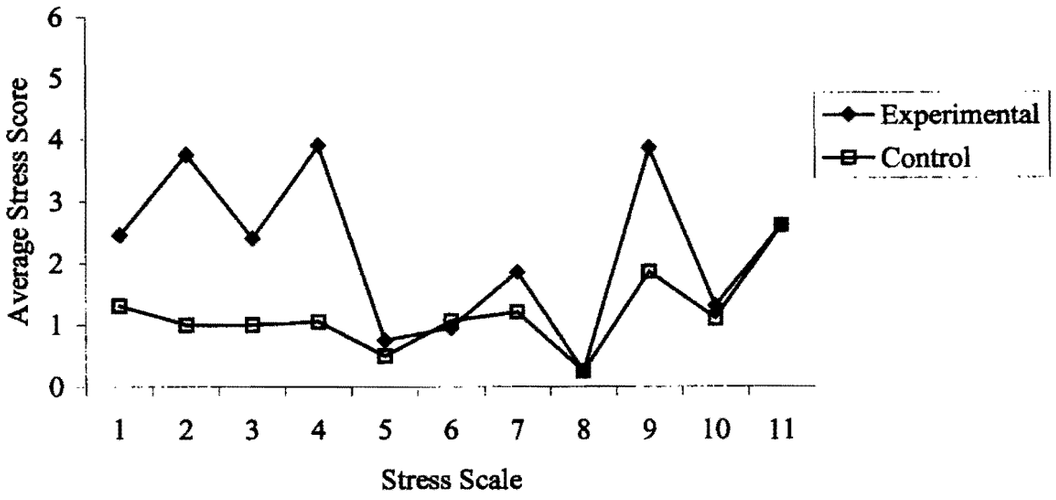

Figure 1. **Comparison of stress profiles between Peruvian parents of children with and without autism.**

References

Bristol, M.M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the double ABCX model. Journal of Autism and Developmental Disorders, 17(4), 469-486.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. American Psychologist, 32, 513-531.

Holroyd, J. (1974). The Questionnaire on Resources and Stress: An instrument to measure family response to a handicapped family member. Journal of Community Psychology, 2, 92-94.

Holroyd, J. (1987). Questionnaire on resources and stress: For families with chronically ill or handicapped members. Brandon, VT: Clinical Psychology Publishing Co., Inc.

Instituto Nacional de Estadistica e Informatica. (2001). "Peru: Ciudades Con Mayor Poblacion: 2000." World Wide Web: (http://www.inei.gob.pe).

Konstantareas, M.M., Homaditis, S., & Plowright, C.M.S. (1992). Assessing resources and stress in parents of severely dysfunctional children through the Clarke modification of Holroyd's Questionnaire on Resources and Stress. Journal of Autism and Developmental Disorders, 22(2), 217-234.

Liwag, M.E. (1992). Mothers and fathers of autistic children: An exploratory study of family stress and coping. Philippine Journal of Psychology, 22, 3-16.

Salisbury, C. (1985). Internal consistency of short form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 89, 610-616.

Sameroff, A.J. & Fiese, B.H. (1990). Transactional regulation and early intervention. In S.J. Meisels & J.P. Shonkoff (Eds.), Handbook of early childhood intervention (pp. 119-149). New York: Cambridge University Press.

Schopler, E., Reichler, R.J., & Renner, B.R. (1986). The Childhood Autism Rating Scale (CARS) for diagnostic screening and classification of autism. New York: Irving Publishers, Inc.