MOTHERS AND FATHERS OF AUTISTIC CHILDREN:
An Exploratory Study of Family Stress and Coping

Ma. Emma Concepcion D. Liwag
Ateneo de Manila University

Thirteen mothers and 12 fathers participated in two phases of a study that explored the stress and coping experiences of families of autistic children undergoing therapy. In the first phase, the parents responded to a three-part questionnaire that assessed family and parental demographic characteristics. In the second phase, a semi-projective test, the Sentence Completion Form (SCF), and in-depth interviews elicited parents' emotional reactions towards the autistic child and attitudes towards the handicap. Only the SCF data is reported in this paper. Content analysis of the parents' completions revealed that families were most stressed by the defects and disabilities associated with autism itself, including lack of speech, hyperactivity, and tantrum behavior. A second source of stress is the permanence of the child's condition and the anxiety that the child will never be normal. Two forms of family coping were identified—instrumental adjustments so that the autistic child becomes the focal point of family life; and emotional acceptance of the child and the handicap. The stress and coping data were hypothesized to resemble Farber's concept of a "tragic crisis" typical of high and middle SES parents' response to a child's abnormality.

It has been said that no parent is ever prepared to become the parent of a handicapped child. The identification of a mother and father in that role always comes as a painful surprise. In recent years, considerable research attention has been directed to the experiences of families with children who are congenitally disabled, mentally retarded, handicapped, or chronically ill. Most investigators have dealt with the immediate psychological effects of the child on the family—the emotional impact of and the reactions of parents to the diagnosis, and their perceptions and attitudes towards the child's abnormality. Wolfensberger (1967), Meadow and Meadow (1971), and Sarason and Doris (1979) provide excellent reviews of empirical studies that depict an almost infinite variety of parental reactions to a child's disability—ranging from alarm, ambivalence, anger, anxiety, bitterness, confusion, denial, embarassment, grief, guilt, helplessness, pain, self-pity, shock, and sorrow.

The present study is inspired by the researcher's clinical work with a special group of handicapped children and their families—all victims of one of childhood's most cruel diseases, early infantile autism. This bewildering clinical syndrome was first described by the child psychiatrist Leo Kanner in 1943. Based on the accumulated case studies of 11 unique young patients who displayed extreme detachment from all human relationships, Kanner recognized this autism (literally "self-ism") or total self-centeredness as the fundamental pathogenic condition in their illness. In addition, autistic children suffer from multiple sensory and perceptual handicaps, developmental delays, cognitive deficits, and severe language disabilities (NSAC, 1984). In his earlier writings, Kanner implicated certain parental characteristics (emotional frigidity, over-intellectuality, and mechanical child-rearing styles) as the probable causes of the autistic reaction in children (Kanner & Lesser, 1958). Since then, the family literature on autism has focused on parental "pathology" as psychoanalytically-oriented researchers (Bettelheim, 1967) argued for this parental causation hypothesis against their medical colleagues who preferred a neurological explanation for autistic behavior (Ornitz & Ritvo, 1976). Consequently, very little mention was made of parents in the context of their *feelings* and *reactions*, and the impact of the child's autism on them.

It was only in the mid-60's that a trickle of papers began to reflect the increasing concern for the difficulties, frustrations, and human needs of families with autistic children. It became evident then that the confusing and paradoxical clinical features of early infantile autism (normal appearance, intellectual retardation or giftedness, behavioral peculiarities, emotional disturbance, and presence or absence of neurological damage) add a different coloring to the distressing experiences of these families. Some researchers felt that earlier findings implying disturbed family functioning, deviant child-rearing styles and unusual parental traits in autistics' families may be reinterpreted as expressions of familial stresses that arise from living with an autistic child (Creak & Ini, 1960; Wolff & Morris, 1971; Holroyd & McArthur, 1976).

It is the objective of this present exploratory study to look into early infantile autism, not with the end goal of seeking support for any *a priori* hypothesis of causation. Instead, the researcher believes that a more balanced and clinically meaningful strategy of studying families of autistic children is to understand the depth and complexity of the stresses they undergo; and examine their coping patterns and styles of adaptation. This viewpoint will focus on healthy as well as pathological aspects of family response to the autistic child, the resourcefulness as well as the inadequacies. It will also be a humanizing process, since regardless of whether they are primary or secondary causes, troubled families share certain qualities and suffer in personal, tangible ways. Attending to these factors creates a research (and therapeutic) atmosphere of empathy and support, rather than one of judgment and blame.

Relative to this, the literature on coping and adaptation covers a broad spectrum of human experiences (Hill, 1971). Considering families of autistic children in this light allows for significant parallels as the capacity of individuals and families to endure and struggle with chronically stressful situations is examined.

Thus, this research sought to study in-depth the families of Filipino autistic children to explore the following questions:

1. What stresses associated with the autistic child are experienced by these families?
2. What coping patterns are utilized by these families in living with their autistic child?
3. How are these stresses and coping patterns differentially experienced by the mothers and fathers of autistic children?

The decision to study the family as a unit is congruent with a family systems view that emphasizes the interactive character of family stress. Whatever stress is felt by one member of the family resonates through the system and is felt by all members in some way (Andolfi, 1979).

Method

The present research was mainly exploratory, and clinical-descriptive, in nature. Since it intended to investigate the range and detail of the experience of families related to stress and coping with an autistic child, it confined itself to the intensive study of a small number of families. Hence, the research design employed a multiple case study approach wherein 13 families of autistic children were studied with a variety of clinical methods. A projective questionnaire procedure and semi-structured interviews elicited rich quantitative and qualitative data on family demographic characteristics, parental attributes, and familial stress and coping. However, no attempt was made to quantify either the intensity of the stresses or the effectivity of coping of the family members studied. Instead, every effort was made to stay close to the true, lived experiences of these families.

The Sample of Families

Purposive sampling was utilized to select the families for inclusion in this research. The families of the 13 autistic children were drawn from two sources—from a private clinic in

Metro Manila where autistic children are referred for assessment and psychotherapy; and from eight special schools in the metropolis that offer remedial, special, or mainstreamed programs for autistic children.

Families were recruited for the study that had at least one child who had been independently diagnosed as autistic or autistic-like according to current DSM-III criteria (DSM-III, 1980). To further ensure a homogeneous sample of autistic children, a minimum clinical criteria was applied to judge the inclusion of a particular family. Their index child must have exhibited at least the following three symptomatic behavior (representative of the cardinal symptoms of early infantile autism) in the course of his or her autistic disorder:

1. Lack of eye contact
2. Delayed speech, mutism, or echolalia
3. Ritualistic, compulsive, and peculiar play with objects.

Procedure

In the first phase of the study, 13 mothers and 12 fathers of autistic children responded to a three-part questionnaire that assessed family demographic characteristics and parental attributes including such variables as educational background, occupation, and marital adjustment (measured by Farber's Index of Marital Integration). The resulting detailed description of the 13 autistics' families in relation to two comparison groups (10 families of normal, non-autistic children and six families of congenitally brain-damaged children) has been reported elsewhere (Liwag, 1987) and will not be elaborated on in this paper.

The second phase of the study combined the findings from a semi-projective test, the Sentence Completion Form, and in-depth interviews with family members to present an intimate picture of how these families have experienced life with an autistic child. Only the SCF data will be reported in this paper.

The Sentence Completion Form

This instrument was a sentence completion test modified from Thurston (1960) and administered separately to mothers and fathers of the 13 autistic children. The original Thurston Sentence Completion Form (TSCF) was developed to assess parental reactions to institutionalized cerebralpalsied children. It consisted of 45 sentence stems divided into seven reactional and attitudinal areas.

In adapting the TSCF for the present study, all the items dealing with attitudes and reactions specifically related to the problem of cerebral palsy were omitted. Fourteen such items were dropped from the original form. Instead, nine new sentence stems were written in their place to reflect the present research concern—family stress and coping with an *autistic child*. Furthermore, the term "handicapped child" in the original test was replaced by the less anxiety-arousing term "special child" or simply "child." When the items referred to autistic children, in general, the term "autistic child" was used.

The final sentence completion form administered consisted of 40 sentence stems. The responses of the parents to the SCF were analyzed by means of a content analysis of their completions. Following Thurston's procedure, the completions were carefully tabulated by three judges and classified into significant attitudinal areas.

The 25 respondents (13 mothers and 12 fathers) generated a total of 944 scorable responses (not including omissions). The three judges, scoring independently, achieved perfect agreement on 841 responses for an 89% interrater reliability estimate. The responses under dispute were then placed in the category in which two out of the three judges had classified them.

Three clinical psychology graduate students, experienced in scoring and interpreting sentence completion tests and other projective devices, acted as judge-scorers.

Results

The 25 parents of autistic children who expressed their concerns and reactions in the SCF are young (mean age of mothers = 35.80; mean age of fathers = 36.48), well-educated, financially stable, and occupy middle-level to executive positions in their professions. Their families are small (average number of children is 3), urban, and nuclear. The autistic sons and daughters they speak of range in age from 4- to 9-years old.

Emotional Concerns of Parents

Parents expressed a variety of reactions to the initial pronouncement that their child was autistic. These reactions ranged all the way from the violent dismay experienced by one mother who felt "the world had crumbled" to the rational statement of one father who "decided that we should do everything to make her well." The majority, however, were *distressed* emotionally (Table 1). The predominant feelings were depression and sadness for both parents. As one father put it, "that was the saddest moment in my life." Six mothers were stunned and unbelieving, five felt very sorry for their child, and three were, in the words of one of them, "guilty and disturbed." These last three reactions of shock, pity, and guilt were rare in the fathers, who seemed more concerned about seeking immediate assistance from professionals, or knowing, and reading more about autism.

Table 1. How Parents Initially React to the Diagnosis

Response Category	Mothers	Fathers	Total
I was emotionally distressed.	25	13	38
. . . depressed/sad	9	10	19
. . . angry/ frustrated	2	2	4
. . . guilty	3	0	3
. . . pity/sorry for child	5	0	5
. . . shocked/incredulous/ refused to believe	6	1	7
I sought help immediately.	3	6	9
I became interested in autism.	2	2	4
Others	1	3	4
Total	31	24	55

Three or 4 years have elapsed for most parents since this initial diagnosis. How do parents presently feel about their child's condition? Nine of them are still emotionally upset at this time (Table 2). One mother replied that whenever she thinks of her autistic child, "I begin to cry." Mothers feel "lonely and worried;" "sad and low," while one father said that he had "mixed feelings." More than half of the parents voiced their puzzlement at the child's behavior, "sudden outburst of laughter with no reason"; "I feel he likes very much to talk but cannot do it." Thrice as many mothers than fathers wonder "how it happened or what the causes are"; "why she is a child with autistic-like symptoms" or "why he became so."

In spite of the seemingly unsolvable question of what causes autism, parents have their own beliefs as to its origin in their own child (Table 3). An almost equal number of parents attributed the disorder to either the events surrounding pregnancy or delivery ("the depressing atmosphere my wife experienced during her pregnancy"; "my difficulty in giving birth") or to the child's early traumatic experiences ("sibling rivalry"; "a traumatic experience with an ill-tempered temporary help"). One mother blamed herself directly ("my negligence") while a father believed that his son's autism

Table 2. How Parents Presently Feel about Their Child's Condition

Response Category	Mothers	Fathers	Total
I am emotionally upset/depressed/lonely/guilty.	5	4	9
I wish and pray hard that my child will be normal.	3	3	6
I think of my child's future.	3	3	6
I wonder why it happened to us/What the precise cause of the problem is.	6	2	8
I am puzzled by my child's behavior/development.	6	8	14
Others	4	1	5
No response	0	3	3
Total	27	24	51

resulted from "inborn characteristics whereby nobody is to be blamed." Another father even denied that his child was autistic, claiming that the condition "is not really autism."

Table 3. Parents' Beliefs--
What Caused the Child's Condition?

Response Category	Mothers	Fathers	Total
Mother's experiences during pregnancy/delivery	5	2	7
Child's early traumatic experiences	6	2	8
Physiological/genetic explanations	1	1	2
I don't know	1	2	3
Others	0	2	2
No response	0	3	3
Total	13	12	25

Table 4. What Parents Find Hardest to
Accept about Their Child's Condition

Response Category	Mothers	Fathers	Total
My child will never be normal/will always remain autistic.	10	11	22
The defects, the symptoms themselves (lack of speech, tantrums, etc.).	17	8	25
My child will always be dependent/cannot fend for self/will not recognize danger.	4	8	12
What will happen to my child if I am not around anymore.	6	2	8
How can we ever cope with child's special needs (education, health, expenses).	2	7	9
How others can accept my child.	3	0	3
Why did it happen to us.	3	1	4
Others	4	4	8
No responses	3	6	9
Total	52	48	100

The Stresses

Of the stresses experienced by these parents, the most difficult they have had to face and accept differ for mothers and fathers (Table 4). For the mothers, the defects and disabilities associated with autism itself bothered them most—"his tantrums"; "her hyperactivity"; "his speech"; "they behave irregularly in public and cause people to stare"; "he won't be able to appreciate some of the things I enjoy like having friends...." For the fathers, the fear that the child will never be normal is most prevalent; "the fact that in spite of all the care, he is autistic"; "he might never get well ever"; or even worse, "my child's condition could deteriorate."

Twice as many fathers as mothers are also anxious that the child will always be dependent, "the prospect that he will grow up not being able to fend for himself," and that the family may not be able to meet all the child's special requirements, "fear itself that we cannot cope with A. and his needs." Mothers, on the other hand, worry to a great extent about what will happen to their child if *they* are not around anymore, "if I die ahead of him"; "when she gets old and I will no longer be with her"; "who will take care of him when I am gone?" Three mothers are still unable to accept the fact that it happened to her child. "Why my child?" is the plaintive cry of one of them. Another father, however, stated outright, "I got no fears, I have a strong feeling that he will recover soon, with lots of love and God."

Given that most parents are primarily stressed by the child's handicaps and symptoms, which among these do they perceive as the most difficult to overcome? Mothers and fathers consistently pinpoint the area of communication as the child's biggest obstacle (Table 5), followed by interpersonal relations, and then the child's experiences of frustrations when his or her needs are not met or comprehended. Three fathers perceived the siblings as a potent source of problems for the autistic child, "when his younger brother annoys him"; "when he is fooled by his brother." In the "Others" category, some parents mentioned specific items of daily routine like "brushing teeth," "eating with fork and spoon," and "irregular bowel movements."

How Do Parents Cope

Faced with the child's handicaps and the

Table 5. What is Most Difficult for the Autistic Child?

Response Category	Mothers	Fathers	Total
Speech/communication	10	9	19
Getting along with other people/with other children	3	4	7
When child can't have what he/she wants/When child's needs can't be understood by us	5	2	7
When siblings annoy child	0	3	3
Loud noises/sirens	2	0	2
Eating/Sleeping problems	2	2	4
Others (unusual surroundings, etc.)	4	3	7
No response	0	1	1
Total	26	24	50

stresses they feel about his or her condition, how do families cope with their autistic child? Mothers and fathers are agreed upon two general coping strategies (Table 6). First, family life is adjusted such that the autistic child becomes the primary consideration in terms of time, effort, attention, and even expenses: from fathers—"give him first priority in most things"; "see to it that he gets the best of everything we can afford"; and from mothers—"set aside some time everyday to have some activities with him and make it our special time together" or "be absent from my office to have more time with her."

Table 6. How Families Cope with the Special Child

Response Category	Mothers	Fathers	Total
Learn to be extra patient and understanding of child/ accept and love as he/she is.	7	8	15
Adjust priorities so that child is primary consideration in terms of time/money/ effort/ attention.	8	8	16
Make a lot of sacrifices/ give up a lot of things/ (career, material things, etc.)	5	1	6
Work harder to attend to child's needs.	0	4	4
Cooperation and communication in the family.	2	0	2
Others (read books on autism, etc.)	3	2	5
No response	1	1	2
Total	26	24	50

Secondly, the family members have to learn to relate to the child with extra patience and understanding. For many, this involved being able "first to accept the tragedy..." and "learn to accept him as he is" so that they can give "more of myself—love, understanding, patience, kindness, gentleness, etc."

Some differences between the responses of mothers and fathers of autistics are nevertheless observed. Mothers spoke of their coping efforts more in terms of giving up certain things and making sacrifices: "give up my career"; "give up a lot of material things." One can almost hear the sigh in one mother's reply as she wrote, "I had to give up many, many things." Fathers, on the other hand, spoke more in terms of exerting greater effort in their work; they realize that they "will have to work harder to attend to all her needs."

Some unusual responses were also noted; one mother felt her family can cope only by "treating him like any other member of the family" contrary to the majority of the parents. Another mother honestly stated that she had to "be truthful to myself about how I feel about him" perhaps as an initial step toward accepting her autistic son.

Perceptions of Other Family Members

Majority of the young couples in this sample have small children; and their autistic son's or daughter's siblings mostly range in age from 5 to 8-years-old. From the parents' viewpoint, how do these siblings feel and react toward the autistic child?

Based on the information that they themselves have imparted to the children, seven parents claim that their normal children know that the autistic sibling is "sick somewhere inside of him (Table 7)." At the same time, 10 parents assured their normal children that "we're taking him to doctors and teachers so

Table 7. Siblings' Perceptions of the Autistic Child

Response Category	Mothers	Fathers	Total
They know the truth that their sibling is sick.	4	3	7
They know that their sibling cannot talk yet.	5	6	11
They understand and accept their sibling's condition and are reassured that he/she will soon get well.	5	5	10
They know they have to take care/be more patient/talk/ play with and teach their sibling.	6	7	13
They don't know anything yet/They are too young to understand.	4	0	4
Others	3	1	4
No response	29	27	56
Total			

he'll get well" or "he will soon catch up" and "he will be normal soon." Most siblings are only aware though, that their brother or sister cannot talk yet. This is also how they explain their autistic sibling's condition to others.

Apart from the knowledge of their autistic sibling's condition (at least of his or her speech handicap), the normal children are made aware, at their young age, of their responsibility to help the afflicted child. They are often told that "he's special so he should be taken care of"; and encouraged "to give extra patience to his *kuya*"; "to talk and play with her very often"; "to understand her and be kind to her"; "to be ready to defend him from whoever would criticize."

Four mothers believe that their normal children do not know anything yet about their sibling's condition or "is still too young to understand why." One mother, however, tells her other children, "nothing is really wrong with him, that's really his attitude" when referring to her autistic child.

The attitude of other family members toward the autistic child are also important to consider. According to parents, the most common reaction of relatives and close friends is to articulate their concern for greater professional help and more family attention for the autistic child (Table 8). They advise the parents to "explore all means so he'll get the best treatment we could afford"; "bring him to the U.S." and even "to go to faith healers." One mother was told "to stop working and concentrate more on my daughter" while fathers were admonished to "give him a lot of love and affection" and "be more patient with my child."

Table 8. What Relatives and Close Friends Think of the Autistic Child

Response Category	Mothers	Fathers	Total
Child is just delayed but is like any other child.	1	3	4
Child needs more attention and help from professionals and family.	6	9	15
They are hopeful that child will get well/will be normal soon.	6	3	9
Child was spoiled/overprotected/neglected when he/she was a baby.	1	3	4
Child is unfortunate, "sayang," pitiful, abnormal.	3	1	4
Child brings good luck/ fortune to family.	1	1	2
That I should not worry too much/relax.	2	0	2
Others	3	1	4
No response	3	3	6
Total	26	24	50

While a greater number of mothers than fathers see relatives as hopeful and optimistic about the child's chances of recovery, more fathers perceive implicitly negative attitudes from relatives such as the child being a "spoil [sic] brat" or "neglected when he was a baby."

Pity is also expressed (the child is "*sayang*, cause he is really handsome") and misunderstanding (they think "he is just delayed, they don't understand what autism is").

Outside of the Family

The parents favored talks with parents of other autistic children by a wide margin of 23 to 2 (Table 9). Approving parents considered these talks helpful, first, for the simple catharsis of being able to share experiences; and secondly, for the learning and advices they can exchange:

Table 9. Do Parents Feel Free to Discuss Autistic Child with Others?

Response Category	Mothers	Fathers	Total
With parents of other autistic children:			
yes... to share experiences/achievements/anxieties	7	5	12
yes... to gain moral support knowing we are not alone	2	1	3
yes... to get advices/learn from one another	5	4	9
yes... to know what to expect from my own child	1	1	2
no... we will just pity each other	1	1	2
Total	16	12	28
With friends and neighbors:			
yes... because I am not ashamed of my child	3	1	4
yes... they might be able to help	2	6	8
yes... so that they will understand my child better	4	1	5
no... they don't understand what autism is	1	2	3
Others	2	0	2
No response	0	2	2
Total	12	12	24

"We can help each other" and "compare strategies/approaches. . . ." Emotional support may also be gained in the process. As one father wrote, "It helps parents to see that they are not alone."

The lone dissenting couple gave this reason: mother—"the feeling of pity to the child is there"—to which the father concurred, "discussion will end up giving pity to our own children."

Talks with friends and neighbors do good, according to six fathers, because "I like to get some good ideas from them" and they might "give referrals for handling the education of autistic children." Four mothers feel that through these discussions, "knowledge leads to understanding" of the autistic child, other people are made to "understand him better," and "treat my son normally." Three other mothers defiantly state that they feel free to talk about their child because there is really "nothing to be ashamed of."

Three parents were reluctant to talk about their child because "it is very difficult (for others) to understand autism."

When in public, how do parents perceive the reactions of others toward themselves and the child? Parents are equally divided among four responses (Table 10). For nine of them, other people are always ready to offer sympathy, and even "tend to be apologetic" or "feel sorry for you." Eight parents reveal that other people don't even notice the child is autistic "unless he shows his autistic-like tendencies which is seldom in public"; "(only) when she would act her natural self"; "only when he screams with delight or irritation." In fact, seven parents claim that strangers often remark on the child's attractiveness—"say he is cute and stout"; ". . . is beautiful and very active"; "say that she's a pretty girl"; "notice his handsomeness."

Table 10. How People React to the Autistic Child in Public

Response Category	Mothers	Fathers	Total
They are sympathetic/they pity us/they offer help.	4	5	9
They don't notice child is autistic until he/she acts out autistic behaviors/symptoms.	3	5	8
They notice child's attractiveness.	3	4	7
They don't understand what child is doing/they are curious/puzzled and ask why child is behaving like that.	7	1	8
They stare and get irritated.	3	1	4
Others	3	3	6
No response	3	5	8
Total	26	24	50

Seven mothers but only one father stated that people do not understand what the child is doing, they are "puzzled because of his actuations..." and "curious about his attitude, like shouting and sometimes he's laughing. . . ." The only father who felt the public's bewilderment stated that they "tend to understand that the child has a mental disorder like persons confined at the Philippine Mental Hospital." Some public reactions are even negative, like people who "think that he is totally an abnormal"; "get irritated when he screams and roams around"; but only four parents reported these.

Mistakes Parents Can Make

When queried about the mistakes that other parents make in raising an autistic child (Table 11), this group responded that resignation was the most harmful such as "giving up on the child so easily," "leaving matters as is without seeking help" and thinking that "nothing can be done about his condition." Not getting involved in the child's treatment is also frowned upon by the autistics' parents. "It should be the school and the home relationship combination," and "There should be a close coordination between the specialists and parents," asserted two parents firmly. Three parents also declared it is a mistake to "hide the truth from other people" or "confining her inside the house."

Table 11. Mistakes Parents Make in Raising an Autistic Child

Response Category	Mothers	Fathers	Total
Hiding them at home/hiding the truth.	2	1	3
Giving up on the child/not doing anything about their condition.	2	3	5
Leaving treatment solely to the specialists/not getting actively involved in the child's treatment.	2	2	4
Pampering/spoiling the child.	3	0	3
Losing patience with the child.	3	0	3
Others	2	3	5
No response	0	3	3
Total	14	12	26

Thinking about the Future

Finally, turning now to parents' thoughts about the future, some interesting differences between mothers and fathers of autistic children emerge (Table 12). More fathers than mothers feel definitely optimistic and positive that the future is "bright" and even "challenging." On the other hand, more mothers than fathers acknowledge the uncertainty of the future ("blurred as of this time . . . ") and waver between hopefulness ("I pray and hope a lot") and insecurity ("I can't help [but] feel insecure").

Table 12. Parents' Thoughts about the Future

Response Category	Mothers	Fathers	Total
The future is bright... I am definitely optimistic and positive.	5	8	13
The future is uncertain... but I am hoping for the best.	9	5	14
The future is bleak... I am afraid and worried.	7	4	11
I don't think of the future...	4	1	5
Others	1	3	4
No responses	0	3	3
Total	26	24	50

Eleven parents (seven of whom are mothers) foresee the future as bleak, are "scared" and "think of the obstacles I have to encounter." Five parents do not even dare to look to tomorrow; "I go blank," "we just take a day at a time" said the two mothers. The only father who responded this way wrote "I don't want to think about it."

When asked about their hopes for their special child (Table 13), parents immediately wished for their child's complete recovery, for

Table 13. Hopes and Wishes for the Autistic Child

Response Category	Mothers	Fathers	Total
For my child to become normal/get well/completely heal.	16	16	32
For my child to become independent/capable/self-sufficient.	7	3	10
For my child to know that he/she is loved and accepted.	3	2	5
For my child to enjoy life/be happy as he/she is.	4	4	8
For my child to go to school/have a career/find a job.	7	6	13
Others	1	3	4
No response	1	2	3
Total	39	36	75

him or her to "break out of that shell." One father emphatically wished, almost demanded, "for him to be normal *NOW*." And one mother, as if in desperation, wrote "never mind if he's *bobo* or clumsy or if he's not very smart, just normal." Another mother wanted her autistic son "to become like us soonest."

Half of the parents in the autistic sample also manifested some concrete aspirations for their children, "learning proper grooming," "being able to talk," all the way to being able to "continue his studies the best he can"; "pursue a career"; "do good in the field of his choice"; possibly be "a professional in the future" and even "to be successful like an ordinary human being."

Mothers asked for their child to become independent, self-supporting, and to feel that "he is a capable person even in a small way." They also expressed the wish that their children will "know and feel that he is loved and treasured as any other child in the family" or become aware that "he matters, not only to his family, but to the rest of humanity." Eight parents were hopeful that the child "will always be happy with whatever he is doing" or simply "to be happy as he is."

Discussion

Judging from the SCF responses of the 25 mothers and fathers who participated in this study, the diagnosis of early infantile autism (a disease they only understood at that time as one that is hopelessly incurable) was fraught with tremendous emotional distress. Depression and sadness, disbelief and anger, guilt and pity for the self and the child, are reported in retrospect, as the parents tried to characterize what Ferber (1963) has hypothesized as a "tragic crisis," precipitated at the time of diagnosis especially in high SES parents, that resembles bereavement as ideals and expectations for children are demolished. This period of mourning was marked in most mothers in this study by overt depressive signs, crying spells, sleeplessness, and lack of appetite; while the fathers reported a generalized state of worry, discomfort, unease, and distractedness.

The length of mourning is variable, each family grieves at its own pace. There is evidence that for some parents in this group, it may not be over yet. Two to 3 years after the diagnosis, a third of the parents still report being beset with worry and anxiety, and experiencing many levels of sorrow, or "mixed feelings" as one father put it. This is captured in the responses of two parents who wrote, "(I) feel lonely and worried because of his condition but also happy that he is improving"; "(I) feel depressed and lonely but I realize God is giving me strength."

In their lives as parents of autistic children, the most stressful and most difficult to accept are the disabilities and symptoms associated with autism itself. This is parallel to the findings of Bristol (1979) and Gallagher et al. (1983) where level and type of parental stress were seen as related to child characteristics such as "difficult personality" or "degree of physical incapacitation." In the local context, similar results were obtained in a Philippine Mental Health Association survey (1976) among parents of mentally retarded, physically disabled, and anti-social children.

When these behaviors are lived with and experienced in their entirety and intensity, the result is the next most profound worry of parents—"Will my child ever be normal?" Twenty-two of the 25 parents voiced this fear in the SCF, and when later asked to make a wish for their child, unanimously wished for him or her to be normal, to "become like us," an "ordinary human being." Perhaps the most salient information received by parents at the diagnosis (and sometimes the only one that really registered in their minds) is that autism has no cure. They have been told over and over again, that "we can only hope to maximize his potentials," "try to make him as near normal as possible" but that "no case ever improved." Thus, as they do their best in managing and coping with the everyday stresses generated by the child's difficult characteristics, the underlying but close to the surface anxiety is embodied in the thought that the child will never get well.

Almost as if this frightful idea is too difficult to accept, denial in its many subtle forms are present in this sample of parents. One form it takes is the dominant perception that speech is the only major handicap of the child, and that if he or she can speak, somehow everything will be normal. To a large extent, the idealism and too high aspirations of a few parents involve elements of denial, too.

Consider for instance, the goal of Anton's father (who has an MBA and is a vice president in one of the country's biggest multinational banking corporations) for his autistic son to become better than him. Or Allan's father, who contested his son's diagnosis in the SCF "(it) is not really autism"; in the interview, he claimed that he does not consider his son handicapped because "there is no visible physical defect."

The rest of the parents, however, are seen to vacillate between unrealistic despair and equally unrealistic optimism, sometimes contemptuous of certain books ("I didn't like *Son-Rise*, it gave parents false hopes."), yet often bolstered by success stories heard from other parents.

One final observation about the parents' stress data—although eight parents (mostly fathers) in the SCF expressed some worry about the family's ability to meet the child's special needs, conspicuously minimal in their list of stresses are anxieties about expenses or financial difficulties.

There are several explanations that may be offered for this. The most obvious one is that these parents are financially secure; apart from their independent incomes, extended family support is also available. Secondly, given the general tendency to speak of child-related problems rather than their own, parents may have been reluctant to discuss in detail the financial aspect of raising the autistic child. Thirdly, it has already been hypothesized that these parents react to the child's autism as if to a "tragic crisis," typical of other high SES parents. Low SES parents, on the other hand, were hypothesized by Farber (1963) to react to a child's handicap or retardation as if to a "reality crisis" where the dominant anxieties are related to expenditures, child-care arrangements, treatment, or health. The stress data, taken as a whole, lead us to surmise that the sample fall along the patterns of a "tragic crisis" more common to the middle and upper classes. One may be more confident in this hypothesis if the experiences of a corresponding set of low SES parents were also investigated. This, however, was not made possible in the present research. It is very clear though that for these 13 families, despite the strain and pressures, very rarely do they not fully accept the *responsibility* of caring for the autistic child. In order to cope, however, two strategies were identified by the parents in the SCF and validated in the interviews.

The first one involves the adjustment of family priorities such that family time, effort, attention, and resources are made to revolve around the autistic child and his or her condition. In matters ranging from the parents' social life, family recreation, career orientation, day-to-day time budgeting, and financial goals, the autistic child's condition is given consideration in all major decision-making. Mothers give up their jobs, fathers get more involved in child-rearing (and work harder, too), special *yayas* are engaged, and family activities are organized around the autistic's regular visits to a clinic. In a sense, in order to cope, these families have become truly *child-centered*, with the autistic child as the center around which the wheel of family life revolves.

Several issues may be brought to bear upon this first finding. One is the relative ease in which most of the families (at least, as inferred from most of the *members* who participated in the study) moved into this kind of child-centered family configuration. One plausible explanation is that Filipinos are acknowledged to be child-loving, in nature, and that children do occupy a central place in families, and even believed to keep marriages intact (Sevilla, 1982).

Another question that arises is whether this kind of coping is more maladaptive in the long run. Some indications of the psychological costs of this kind of imbalance in the family system already appear and are recognized by the parents themselves. Spouses have lesser time for each other, siblings crave for attention, mothers are told by relatives to relax and think more of themselves. Undoubtedly, other factors will come into play to determine whether coping by chanelling all family energies and resources to the autistic child is more harmful in the end.

A third question, closely related to the second, is whether this kind of coping simply represents a stage in the family's socialization to the role of "family of handicapped child." The autistic children represented in this study range from 4 to 9-years-old. They are in a stage where even normal children are still dependent, although naturally, this dependency is exaggerated in the autistics' case. It is possible that as the autistic child grows older (and consequently change in his or her needs), families will also move to other forms of coping. A developmental, longitudinal approach, in which families of adolescent and even adult autistics are included in the research design, will certainly shed light on this question.

A second major coping strategy identified by these families concerns the direct interpersonal relationship of parent to child, and sibling to child. Parents spoke of family members having to learn to relate to the autistic child with more patience, understanding, love, gentleness, and tolerance. Parents self-defined these efforts, when taken together, as learning to "accept the child for what he or she is." "Acceptance" is in itself a concept that is most frequently used in family research with the handicapped, but also the most poorly-defined and ambiguous (Wolfensberger, 1967). It is recognized that a multiplicity of factors can affect the degree of family acceptance of the handicap, including sex, age, and ordinal position of the index case, family structure variables, parental intelligence, personality and attitudes, societal attitudes, and even cultural factors. Undoubtedly, all of these were operating in the present study and have largely been left uncontrolled.

Conclusions

An intense family drama begins to unravel at the moment when parents are told that they have a child who is autistic—a child devoid of human contact, unable to relate, to speak, to learn, or to ever live like a normal person. For the parents of the 13 autistic children in this study, the early scenes of the drama were suffused with pain, sorrow, shock, and disbelief. Clearly, the diagnosis of autism was a *stressor* that provoked *crisis* (Hill, 1965; Parad & Caplan, 1965) in these families—it created a situation for which the family had little or no preparation. Furthermore, it was a "tragic crisis," as the sense of loss for the normal child, they may never have descended upon the family. But while grief and mourning took place, bereavement did not paralyze these families into inaction. Parents immediately engaged in active information-seeking regarding the disease as a preparatory cognitive effort to understand the tragedy. As the harsh realities of autism came to light in the books they read and the doctors' explanations they heard, and then became alive in their child's disturbing behaviors and disabilities, family resources were mobilized to confront the problematic situation. Family members undertook the necessary instrumental and emotional tasks, first, to respond to the child's needs for treatment and special education; second, to rear the child at home. The instrumental aspects included, among others, seeking appropriate professional assistance for the child (therapy, medication, schooling) and maintaining these, implementing parental intervention programs as part of the child's treatment plan, and learning techniques for more effective daily management of the child. The emotional aspects involved primarily, an acceptance of the child and the irreversible handicap, and dealing with the myriad feelings this process generated—denial, confusion, anger, tolerance, gentleness, patience, and love. The enactment of these instrumental and emotional skills were self-defined by these parents as *coping*. Today, 4 to 5 years after the initial shock of the diagnosis, both instrumental and emotional coping are effectively in place (to combat current stresses associated with the child's disabilities) as a result of changes in family configuration, role patterns, and possibly, family values, to accommodate the centrality of the autistic child's presence in family life. The availability of resources, inside and outside the family, such as good financial capacity, extended family support, and professional assistance satisfactorily facilitated these families' coping efforts.

To conclude therefore, these families are seen to have accepted the tragedy of autism as woven into the fabric of their lives and their future. But the sadness and anxiety they still report at present, and the bleak outlook they have of the future, strongly suggest that this strategy still involves them directly, and exerts a powerful influence on their lives.

Recommendations

The present research is limited in the size of its sample and the manner in which the respondents were selected. Since the index children they represented belong to a clinic sample, the data and inferences from these families cannot be generalized to the population of families of autistic individuals. Families who have an undiagnosed autistic child, or a confirmed autistic who is not in therapy are not represented in the present sample. The dynamics of stress and coping in families not utilizing therapeutic or educational services may necessarily be dissimilar to what was described in this study.

Various aspects of the testing methodology need refinement. For instance, social desirability may be lessened and independence of spouse ratings may be assured if the SCF is administered in a standardized manner.

This exploratory study had barely begun to tap the complex family dynamics involved in facing a shared family trauma such as the condition of an autistic child. The entire research data consisted of projective and interview data and clinical observations. The next data, hopefully, should include the translation of these clinical impressions and hypotheses into a form that can be examined more systematically.

In particular, the study identified at least three potentially useful variables which may be pursued in subsequent studies of families of autistic children. The first of these is *socioeconomic status*, an important family variable that may be a pervasive determinant of the quality of stress and coping experiences of families in crisis. A study that can look into the dynamics of families across socioeconomic levels may provide definite leads to differentiate adequate from inadequate coping and bring to light the unarticulated needs of poor families who are unable to benefit from therapeutic and educational services for their handicapped child.

Secondly, a *developmental* research on families of autistics of varied age-related groups can create a significant view of the different developmental stages of a family's continuing adjustment to the handicap. Studies in which the autistic children can be followed up through critical transition stages will help define periods in the developmental sequence where families need specific kinds of support.

Third, the hypothesized *instrumental and emotional aspects of coping* with family trauma should be tested by designing a more refined, objective instrument, a checklist type of questionnaire that can incorporate items referring to these two aspects. The item pool may be generated through the projective data of the present study, as well as from a more detailed literature review of these two components.

Finally, the data of the present study readily points to a stronger theoretical commitment to an interactive view of family stress and coping (Andolfi, 1979; Carandang, 1987), for it is clear that handicap does not occur to or reside in individuals alone. It is an event that involves and includes the total family unit. Whether it is a chronically-ill member, a serious accident, or a sudden death that confronts the family, it is within this system with its capacity for understanding and change and mutual support, that members can live out the tragedy, and perhaps even grow from it.

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