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ABSTRACT

Mothers' coping mechanisms and adaptations to having a handicapped child were analyzed through extensive structured interviews with mothers of eight preschool-aged Down syndrome children and a language impaired child. Three illustrative case studies are presented, and general conclusions are drawn. Mothers of Down syndrome children go through the initial stage of denial, disbelief, and grief upon learning that their newborn infant is not normal. But, in retrospect, they feel that the shock could have been less traumatic had physicians and hospital staff handled the situation more positively and with a greater store of information concerning community resources. Other factors contributing to positive coping on the part of new parents include extent of parental knowledge, a supportive social network of family and friends, and community resources. In general, mothers' adaptation to the child's handicapping condition depends on the past history of interaction between mother and child (before diagnosis as handicapped), mothers' reaction to the handicapping label, extent and quality of knowledge of intervention and rehabilitation programs, and the child's personal characteristics (e.g., physical appearance, level of responsiveness to stimulation). (JW)

Coping strategies and adaptation of mothers of children with handicapping conditions

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Running Head: Coping Strategies

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A substantial amount of literature exists describing the stages of adjustment presumed to characterize parents' response to the birth of a child with a handicap (Wolfensberger, 1967; Farber, 1968; Emden & Brown, 1978; Searl, 1978; Featherstone, 1980; Paul, 1981). Blacher's (1984) review of literature points out that the stage concept is utilized mainly to categorize parents' emotional reactions to a handicapped child's birth. From examining the existing literature, she identified three major stages: (a) initial crisis, (b) emotional disorganization, and (c) emotional organization. The first stage is characterized by shock, denial, and disbelief; the second stage by guilt, disappointment, anger, or lowered self-esteem, and the final stage by adjustment and acceptance.

Blacher (1984) raised several methodological questions regarding the validity of research pertaining to the study of parental adjustment to the birth of a handicapped child. First, most researchers have employed open-ended interviews, resulting in a lack of uniform content. Consequently, the findings have limited comparability. Also, since the sample sizes have been small, the validity of the stages delineated needs further verification by utilizing more systematic and objective methods with larger sample sizes. Ideally, one would like to employ a structured interview with standard questions and a set of statistically reliable categories, so that responses could be coded easily and administered to a larger sample. Presently, there is no scale available in the literature to measure the parents' initial emotional reactions, and the long-term adaptation of the family. A first step in developing items for such a scale would be to use the structured interview approach. Such an approach would be less problematic than open-ended interviews and would still allow the subjects to respond freely to a set of well-defined and objective questions.

Secondly, most of the reported results are not very specific about the nature and the severity of the child's handicapping condition(s). One would expect that the family's adjustment to the birth of a handicapped child would be related to the degree and the nature of the child's handicapping condition(s). Consequently, these factors should be taken into account.

Thirdly, the emphasis in the previous studies has been mainly on "negative reactions" such as guilt, denial, shock, and so on. But, the birth of a handicapped child may also have a "positive" impact on the family. The existing research does not address the whole range of the possible impacts that a handicapped child may have on his/her family. Furthermore, the effect of services available to such families, due to Public Law 94-142 (1975), has not been fully investigated. It seems that, with more resources available, the impact and the stages of "emotional reactions" that a family goes through might have been altered.

Finally, there is a lack of clear definition of coping in the previous studies. For example, a researcher may say that the parent of a handicapped child is coping adequately if there has been no divorce in the family, or if the parent is shopping around to find the best available program for the child, or if the parent is involved in different community programs for handicapped children. Therefore, it is essential to come up with an operational definition in order to study the coping process in a more systematic and comprehensive fashion. The present report is part of a larger study which has been designed to avoid the shortcomings of previous research. The results of the larger study should be valuable in understanding the nature of different stages of the family's adaptation, providing a better picture of the types of resources which are more helpful in promoting a more satisfying adjustment in raising a handicapped child in a home environment, and providing a conceptual base for defining coping.

Primary Study

The broader study is designed to investigate and compare the coping strategy and language interaction within and among three groups of children (non-handicapped, Down Syndrome, and language-impaired) and their mothers. It targets 40 mother-child dyads in each group. Between March and December 1985, we have collected data on 20 Down Syndrome and 17 language-impaired children and their mothers. The mother-child dyads were recruited through several school districts in the Dallas/Fort Worth Metroplex, the Down Syndrome Guild, and the Callier Center for Communication Disorders of the University of Texas at Dallas.

The mean age for the mothers of both groups was 36.0 years (SD=6.0; Range=20 to 45 years for mothers of Down Syndrome children and SD=4.8; Range=26 to 45 years for mothers of language-impaired children). The educational level of both groups ranged from a minimum of partial college to a maximum of B.A. or B.S. Degree. The mean family socioeconomic level was 51.0 (middle-class) for both groups on the Hollingshead Index of Social Status (1975). The mean number of children was 2.8 for families with Down Syndrome and 2.0 for families with language-impaired children.

The mean age of Down Syndrome children was 61.8 months (SD=23.6; Range=38 to 107 months). The Adaptive Behavior Composite (ABC) on the Vineland Adaptive Behavior Scale (VABS, 1984) was 40.0 months (SD=16.6; Range=18 to 70 months). The mean Communication Sum (CS) on VABS was 35.0 months (SD=18.0; Range=13.0 to 72.0 months). Down Syndrome children were significantly delayed in their adaptive behavior and communication functioning $t=7.94$ and 7.14, respectively $Ps > .01$. According to karyotype, 19 Down Syndrome children were diagnosed as Trisomy 21 and one as Mosaic. The mean age of language-impaired children was 45.2 months (SD=10.0; Range=32.0 to 69.0 months). The mean ABC on VABS was 40.0 months (SD=9.7; Range=21.0 to 64.0 months). The mean CS on VABS was 36.0 months (SD=10.0; Range=18.0 to 49.0 months). For language impaired children, it was found that there was no significant difference between the means of their age and ABC. Their communication functioning was found to be significantly delayed $t=2.29$, $Ps < .05$. The language-impairment of subjects was attributed primarily to middle-ear infections, cleft palate (surgically corrected), and nonspecified causes. One of these children was diagnosed as mentally retarded.

Procedure of the primary study

Two female observers made two visits to the homes of participants. In the first visit, the Vineland Adaptive Behavior Scale (1984) and a demographic inventory were administered. Mothers were asked to fill out the Family Environment Scale (Moos, 1981) and the Parental Attitude Research Instrument (Shafer and Bell, 1958). In the second visit, language samples during mealtime, playtime, and storytime were videotaped. Each event was videotaped for 20 minutes. In the final phase, the investigator conducted structured interviews with the mothers using the Maternal Coping Questionnaire (MCQ).

A pilot study was carried out to identify the relevant items in the MCQ. Six mothers (2 from each group) were interviewed individually by utilizing an open-ended questionnaire based on the Scale of Parental Adaptedness to Birth of Impaired Child (PABIC) (Stahlecker, 1983) and items derived from the literature on stages of parental adjustment. Each mother was interviewed for about three hours in her home by the investigator. All interviews were audiotaped on a compact cassette recorder. A total of 18 hours of interviews were completed over a one-and-a-half month period.

The interview transcriptions were content-analyzed (Hooshyar, 1978) to generate a set of categories which describe the major themes contained in mothers' interviews. Four categories were added to the previous scales and one was deleted, resulting in a questionnaire consisting of 9 categories: (a) Pregnancy and birth, (b) Early period in the home with the child, (c) Parent's reaction to the problem, (d) Retrospective information, (e) Prospective thoughts, (f) Personal change/adaptations, (g) Parenting skills, (h) Parent's physical health and emotional stability, and (i) Husband's expectations. These were further subdivided into a set of 47 questions which were utilized in the structured interviews to measure the mother's coping and adaptation to the birth of the child.

Subsequently, nine non-handicapped, 12 Down Syndrome, and four language-impaired children's mothers were interviewed by the investigator. Each interview lasted about 5 hours and was conducted at the home of the participant. A total of 235 hours of interviews were completed over an 8 month period. All interviews were audiotaped.

The present report was based on selective transcriptions of the structured interviews of the mothers of 1 language-impaired and 8 Down Syndrome children. It contains the case studies and interpretations drawn from them. Later reports will focus on the entire sample with 40 in each group. Statistical analyses will be employed to clarify some of the issues raised in this study.

Preliminary Analysis

To obtain a better understanding of the nature of the raw data, short summaries of 3 transcribed interviews were prepared and are presented below. These summaires are intended to present mothers' perspectives which will enable us to code the MCQ. Subsequent to the coding of these categories, statistical analyses will be possible. In the following case studies, all the names are fictitious and the statements are not exact quotations. However, they illustrate the essence of the interview and some of the feelings, concerns, and problems these families were confronted with.

Illustrative cases

Case 1

Demographic Characteristics: Shelly is a 6 year and 7 month old female Down Syndrome child. She lives with her twin sister and her natural parents in a comfortable middle-class home. Both of her parents have graduate degrees. Shelly's father is a manager in a company and her mother is a homemaker. Shelly obtained age equivalent scores of 5 years and 4 months on ABC and 4 years and 3 months on CS of the VABS (1984).

Interview Summary: Early in my pregnancy, I found out I was expecting twins. I thought maybe God is giving us two babies to make up for the one we lost. A couple of days before the babies were born, I saw a double rainbow in the sky. One of the rainbows was not completed. I thought, "Son of a gun, that is an omen. One of the babies is not going to be all right." So, I was not terribly surprised when Shelly was born.

The moment I saw Shelly, I knew she was a Down. I was repulsed by her. Her skin was peeling, she had the protruding tongue, long fingernails, and all her hair stood up in one puff on the top of her head. I wanted this either not to be true or somebody adopted her.

A priest/psychologist friend wrote us a letter. He said he knew we would love Shelly even though she might never be able to love us in return. I thought, "good Lord, dog's love you. Are you telling me this child is not even going to function at a dog's level?" I was horrified. From reading the literature on Down Syndrome, I envisioned living in some little house with this creature sitting in the corner in diapers when I was sixty-five years old. This being who did not respond, did not understand, nor did anything except sit and rock. I was hoping against hope that it might be something else.

I wished my doctors had given me more information than what they did. The pediatrician gave me a little booklet about crippled children that had no pertinence to Down Syndrome at all. He did not have any information on schools or programs in the area. I wish they had come in with a lot of information. Because, first of all, it would have given us something else to think about. Secondly, it would have conveyed the idea to us that there was help available to us, that we did not have to do this with no guidance from anybody.

The night before her Baptism, a nurse friend suggested we cut Shelly's hair. That made all the difference in the way she looked. I started to see her as a person, an an individual, not as a stereotype thing I had in my mind. She was a lovely baby. She ate well, she slept well, and responded when I talked to her. When Shelly was six months old, I found out about the child development center through my second pediatrician. All of a sudden, I discovered the speech therapist, the occupational therapist, and all the women who had Down Syndrome children who were living! That was wonderful.

Our parents and my husband have been a great support right from the very beginning. We have tried to combine as much help for Shelly as we can with a normal family life. She is exposed to the whole spectrum of little children's life: birthday parties, movies, plays, symphony, swimming, soccer, library, and school. We have always been concerned that everybody else's life not revolve around Shelly's life. We did not want to become distorted and have Karen's life distorted because of Shelly's problem. We give Shelly as much as we can without making Down Syndrome the focus of our lives.

I would like to see Shelly learn to read at as high a level as possible. I think she is perfectly capable of working in an office as a file clerk or typist. I would not be adverse to seeing her get married. I would never want her to have a child because according to what I read, the children of Down Syndrome mothers have Down Syndrome. I do not think she would be capable of taking care of a child with Down Syndrome and making sure the child got what it needed to prosper. I can see her having her own apartment, maybe with a roommate and have a social worker come in every couple of weeks to help them with their budget or grocery shopping or whatever needed to be done. I don't see her living with us much past the age of 21 or 22. I would encourage her to become independent because Shelly will have to be sooner or later. I would rather have Shelly do it while we are around and able to give her a hand. I do not see her living with her sister. Karen has a right like anybody else does to have her own life and not have to be responsible for her handicapped sister.

Shelly has made me a practical and result oriented person. I am more tolerant of other people, not just their colors and religions, but also the way they think. As a family she has made us more sensitive and aware of situations outside the family in which we can be helpful.

Investigator's comments: It appears that three factors influenced this mother's negative reactions to the birth of her Down Syndrome daughter: (a) physical appearance of the child, (b) ill advice of a friend, and (c) lack of preparation of the medical and hospital staff to handle a patient like her. However, once she discovered the available community resources and made a change in her daughter's physical appearance, coupled with the support of the immediate and the extended family, she began to relate to her daughter as an individual, not as a textbook stereotype.

Case 2

Demographic Characteristics: Roberta is a 7 year old female Down Syndrome child. She lives with her natural parents and four sisters in a comfortable middle-class home. Roberta is the youngest child in the family. Her mother has a partial college education and her father has a B.S. Degree. Her mother is employed full-time as a registered nurse and her father is an accountant. Roberta obtained age equivalent scores of 4 years and 9 months on ABC and 5 years and 8 months on CS of the VABS (1984).

Interview Summary: I was very much disgusted with the hospital staff. The obstetrician and the pediatrician were very evasive. A neighbor told us to place Roberta in an institution for retardates. This upset me very much.

I tried to convince myself that Roberta was normal. My husband confronted me and said I must be sensible. The fact is that Roberta is Down Syndrome, and it will not help her to have false hopes. This helped me to be somewhat realistic. But, there were days that I felt sorry for Roberta, especially when I thought about how cruel people and children could be. It took me a couple of months before I was finally ready to deal with the fact that Roberta was a Down Syndrome child.

Right after we came home from the hospital, we looked around to see which state has the most resources available to these children. We moved to this city because it had the most services available for Down Syndrome children. From the family of a three-year-old Down Syndrome boy, who spoke in three different languages and was a whiz at math, we found out about a special program which views Down Syndrome as some kind of brain injury that can be cured by neurological stimulation. Since our main concern is to make Roberta lead an independent normal adult life, we have enrolled her in that program. Through this program Roberta will overcome her disability and will be able to function as a normal human being. I would like her to get married, have children, and hold a job.

When I was a teenager, my family lived near an institution for retarded children. I found them repulsive. When Roberta was born, I thought this was God's punishment for the way I felt about these children. I have come to be much more tolerant of children, not just Down Syndrome, but children with any disabilities, whether mental or physical. Robert has made all of us more understanding of children with problems.

Roberta has not altered the routine of the family life. As a family, we go shopping, to movies, and on picnics. For years, I had a lot of problems with my family. There was absolutely no contact between us. My father passed away, and I wrote to my mother about Roberta. Suddenly, all the old griefs were forgotten and my mother came to visit us. That was nice. I am thankful to Roberta.

The thing that still bothers me is the intolerance of people. In the shopping mall, people stare at Roberta. In a Bible camp, I overheard some children saying, "children like Roberta should be shot to death." These things are painful.

Investigator's comments: This mother seems to attribute having a Down Syndrome child to God's punishment of what her feeling used to be toward such individuals. She appears still to be angry at the physicians and the hospital staff for their lack of knowledge about Down Syndrome infants and seems to resent peoples' intolerance. She thinks of Down Syndrome as a form of brain injury that can be cured by neurological stimulation. She appears to be determined that through a special program her daughter will overcome this disability.

Case 3

Demographic Characteristics: Tom is a 4 year old language-impaired child. He was diagnosed as mentally retarded at the age of 3. Tom lives with his natural parents and a 6 year old brother and an 8 year old sister in a comfortable middle-class home. His mother is full-time self-employed and his father is a salesman. Both of his parents have B.A. degrees. Tom obtained age equivalent scores of 2 years and 11 months on ABC and 1 year 8 months on CS of the VABS (1984).

Interview Summary: At age three, Tom was diagnosed as language-delayed. Shortly after, he was diagnosed as retarded. When I heard that word, I cried. I saw language-delay as a physical problem that could be corrected in two or three years. But, being retarded, I realized that he would never function as a normal person.

I talked to my husband and a couple of close friends. But, talking to the psychologist at the Callier Center about children with severe learning problems made a lot of difference. I also learned about the services available at the public school for these children. Now, I have a lot of confidence about the whole situation. I am not ashamed of Tom or his problem. This summer, he went to four different Bible schools. I know it was hard on the people to have him, but I needed some time to myself. I feel allright about it.

I am not concerned as such about Tom's future. I know of a friend's niece who has similar problems. She went to a special school and took courses at college. Now, she has a job and is working for a degree. Tom may grow up to be like her.

I have learned to be calm when everything gets rough. I value time a great deal, and I have become more persistent and aggressive. I spent a lot of time helping Tom on his language drills. This leaves very little time to be spent with my husband and our two other children. Tom is also hyperactive. This makes it very difficult to take him places like restaurants and amusement parks. I do not feel comfortable taking-out the other children without Tom. Therefore, we do not have many outings.

Investigator's comments: Tom was not diagnosed as mentally retarded at birth. Thus, his mother had a chance to establish a relationship with him based on Tom's personality, not on a preconceived idea about certain handicapping conditions such as Down Syndrome. Also, Tom was enrolled in programs for language-impaired children. Through these programs, she had worked with different professionals dealing with language-impaired and mentally retarded children. She had had positive experience working with these professionals.

Discussion and conclusion

Any definite statement about the coping strategies of the mothers of Down Syndrome and language-impaired children should await till all data are collected and analyzed. However, based on the three illustrative and other cases that I have analyzed so far, it seems reasonable that a profile like the following may emerge. In general, mothers of Down Syndrome children go through the initial stage of "denial, disbelief, and grief" upon learning that their newborn infant is not "normal." But, in retrospect they feel that the shock and its consequences could have been less traumatic, if the physicians and the hospital staff had handled the situation differently. According to these mothers, the medical staff quite often gave them a bleak picture of life for these children and often recommended their institutionalization. Furthermore, the physicians and the hospital staff lacked information about other possible community resources. To reduce the initial shock, mothers recommended that (a) the physicians give the accurate news as soon as possible in the presence of both husband and wife, (b) the physicians and other hospital personnel should coordinate their activities and put mothers in touch with appropriate community agencies to get information about the physical and cognitive development of these children and the advances made in the areas of education, health-care, and alternative community living. The mothers further stated that the nurses should treat them as they treat mothers who have given birth to "normal" children. That is, the nurses should carry-out the ordinary routine of the hospital and should not automatically assume that the Down Syndrome child is an unwanted child. It seemed that the hospital staff was not prepared to handle such situations.

Another important factor that seemed greatly to diminish the initial shock and the anxiety for taking-care of and raising these children was the availability of (a) personal resources (e.g. parental belief system, parent's prior knowledge about Down Syndrome), (b) social network (e.g. the support and understanding of the extended family and friends), (c) community resources (e.g. infant stimulation program, Down Syndrome Guild).

These mothers reported having a handicapped child had made them more tolerant of individual differences, not only in terms of physical and mental, but also religion, race, and social class; more compassionate, calm, and patient. In some cases, the handicapped child has had a positive effect on bringing the extended family closer and making them more supportive of each other.

In the three illustrative and other cases, we did not find the three definite segmented stages. Although we saw some of the characteristics of the three stages mentioned in the literature, but they did not follow in a definite sequence as has been implied by supporters of the stage model. This preliminary finding seems to be in agreement with Allen and Affleck's (1985) study.

Finally, comparing the two groups of mothers it appears that mother's adaptation to the child's handicapping condition depends (a) on the past history of the interaction between mother and child, (b) mother's perception of the label mentally retarded, Down Syndrome, language-impaired, and so on, (c) extent and quality of mother's experiences with different intervention and rehabilitation programs, and (d) child's characteristics such as physical appearance, levels of responsiveness to stimulation, and behavioral repertoire for communication.

It should be noted that the preliminary coping profile presented in this report was based only on the mothers' perspectives. In order to construct a complete profile of the coping strategies, it is essential to study not only the mothers' experiences, but also the fathers', siblings', physicians', and other professionals working with these cases.

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