

MOTHERS OF DISABLED CHILDREN: A STUDY OF PARENTAL STRESS

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INTRODUCTION

Parents of a child with a disability have an expanded and exaggerated role. Both mother and father are expected to fulfill societal requirements in being parents, as well as being expected to meet the specific needs arising due to the disability. This child demands more time and attention. Acceptance of the child is difficult, being hindered by accompanying feelings of guilt, anger, depression, self-blame and/or blaming the spouse (Copel, 1973). Society expects the parents to cope with having a disabled child, holds the parents responsible for socializing a disabled child to be like other children and yet expects the child to know his place among the "not normal", the stigmatized (Goffman, 1963).

The mother is the primary socializing agent of the child. She must help the child learn to conform in his social behavior and to learn the skills of daily living even when the child is handicapped. Yet she is not provided with supports when her child is not capable of achieving the same as the non-handicapped child.

This study was designed to gain understanding into the mother's perception of her experience vis-a-vis her child, given that her perception determines her emotional state, her attitude toward her child, herself, and her family, and dictates her current intervention with this child.

REVIEW OF THE LITERATURE

A woman prepares herself for her role with her child during pregnancy (Blum, 1980). The mother anticipates her future role and begins social and psychological adjustment to the role by learning the expectations of the role (Thornton & Nardi, 1975). The mother, and the father, separately develop an image of the ideal child. After the birth parents resolve the differences between the ideal and the real child (Solnit & Stark, 1961). This becomes a difficult task when the infant deviates from the normal, societally acceptable baby. The shock

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of having an abnormal child may make it difficult for a parent to accept the child (Crout, 1979). Parents grieve the loss of the normal child while acceptance of the defective child begins. This grief is reactivated throughout the life of the parent at significant developmental stages (Olshansky, 1962). Crout (1979) traces this chronic sorrow through school age, as parents become more aware of the stigma attached to the child's abnormality and on to adulthood, when care becomes more difficult for the aging parents who worry about the child after their death.

The mother is particularly vulnerable when a child is handicapped (Featherstone, 1980). Typically the mother is closer to the situation, is more aware than the father of the disability, and feels more responsible (Marcus, 1977). The mother is the primary care giver and the main object of attachment for a child and her attitudes are in large part determined by the characteristics of the child (Blumberg, 1975). Her sense of achievement rests far more on her children's physical and emotional perfection than does her husband's (Featherstone, 1980). A mother hopes others will see her child as socially worthwhile, productive and accepted. The mother's perception of the situation and her infant's and others' response to her in her role influence her behavioral responses toward the child (Russell, 1974). Adaptive maternal behavior is influenced favorably by the mother's perceptions of the amount of positive support she receives (Mercer, 1981).

Feelings of anguish, guilt, shame, self-degradation, self-blame, and depressive attitudes are common among mothers of infants with any kind of physical defect whether congenital or acquired after birth (Copel, 1973). She does not receive the positive feedback, the smiles, the passing of developmental milestones, the social amenities afforded the parent of a healthy child. Developmental and emotional progress is slower, and time, energy and money don't seem to pay off in comparison to the energy invested in the handicapped child (Tyler & Kogan, 1972).

Klaus and Kennell (1976) identify that society has no customs, traditions, or rites to support parents when they need it most, when they have a baby who is abnormal. This, in part, has resulted from rapid urbanization and industrialization which have altered the role expectations, decreased access to the extended family, and have compounded the isolation and practical difficulties experienced by families in caring for the severely handicapped (Darling, 1979; Crout, 1979). Without norms governing parent-child interactions and expectations when the child is different, the mother has no criteria by which to evaluate herself in her role as a mother of a handicapped child (Strom et al., 1981).

The lack of societal guidelines in parenting a handicapped child, the loss of a normal child, and unrealistic expectations placed on the mother led this investigator to ask the questions guiding this study:

1. What is the mother's perception of her role in parenting a disabled child?
2. What are the stresses associated with the mother's role in parenting a disabled child?
3. Are there specific factors which act as supports to the mother of a child having a disability?

METHODOLOGY

An ethnographic study was developed for the purpose of exploring the experience of female parents of children with disabilities. A qualitative approach was taken so that women would tell about how their lives were influenced by their child who was different from the 'norm'. The study occurred over eight months in 1981 and was conducted by this investigator.

Setting

Participant observation occurred at a small university based clinic which provided services to the public in corrective therapy for orthopedic problems resulting from neuro-muscular dysfunction. Interviews were done in the mother's home and, on occasion, at a restaurant upon a mother's request.

Population

Twelve mothers, each having a child with cerebral palsy, consented to serve as informants for the study. The mothers comprised the total population of mother-child dyads attending the clinic. The study was approved by subject's rights committee of the university.

Participant observation

Eight hours per week over the eight months were spent by the investigator in interacting with, observing, and recording the mother's behaviors while at the clinic. Fieldnotes were taken on maternal-child-therapist interactions, on staff attitudes toward the mothers and children, on nonverbal and verbal communication, and on the mother's behavior toward her child and the therapy. This information served to give the investigator insight into the mother's experience and was necessary for developing interview questions. Observations were used in conjunction with informant interviews (Pelto & Pelto, 1978).

Interviews

Each mother was interviewed outside of the clinic for two hours per month. Three questions were asked at the initial interview. What services have you attended because of your child? What did you expect from each service? What did you think was expected of you at each service? Demographic information was also obtained at this interview. This was the only structured interview and was developed in order to obtain chronological information about the mother's experience. Questions 2 and 3 came into being because the word "expect" was frequently heard by the investigator at the clinic, being used by therapists and mothers.

The remaining interviews were either semi structured or unstructured and evolved from observations at the clinic and from content taken from prior interviews as well as focusing on topics of the mother's choice. Fieldnotes were taken during the interviews.

Analysis of Data

Demographic information was collected and tabulated to identify characteristics of this population. Information on services attended and expectations of these services, as well as observations from the clinic, served as input into interviews and as such are not included in this report. A componential analysis was done on the interviews to discover the psychological reality of the informant's world. Interviews were searched for contrasts in themes and entered into a paradigm. This process occurred for each interview and the information was shared with the informants who validated and added further information (Spradley, 1979).

FINDINGS

Demographic information revealed a relatively homogeneous population. All families were of European background, intact, nuclear, with both biological parents present. All parents had completed high school with 60% of mothers and 80% of fathers holding college degrees. 90% of mothers were between the ages of 27 and 35.

Information about the disabled children is seen in Table 1. The children ranged in age from 3 to 17 years with nine children below the age of seven. Ten were male. Two children, both male, were considered to be subnormal in intelligence and were being mainstreamed in schools. Five were youngest children, three were oldest and four were only children, with nine being first born. Only two had more than one sibling and these two children were both oldest. No child had younger and older siblings.

Table 1
Characteristics of the Disabled Child

Sex		Age at Diagnosis		Current Age in Years			Number of Siblings				Rank Order of Siblings	
Male	Female	Birth	8-9 mos	3-5	6-10	11-17	0	1	2	3+	older	younger
10	2	5	7	7	4	1	4	6	1	1	5	3

Six mothers stated that they were afraid to have any more children although four of these had one younger child; two having only one child. "There's no guarantee of having a normal child." "We waited seven years to have him. Nothing should have gone wrong." "We're afraid to try again." The responsibility of caring for another child and the need to focus on self was also expressed. "That's it! I want to go back to work," and "I have no time for myself now!"

Each mother stated her reason for the disability. These included: intra-uterine hemorrhage, intrauterine infection from working in a viral lab, "poor facilities" (the family was working in a remote village in South America), no MD present at time of delivery, high forceps delivery, no oxygen available and Rh incompatibility. Only one mother stated that there was no reason. All mothers in the study were familiar with the literature on cerebral palsy, and that the etiology could be traced to physical maternal factors. These mothers assumed the responsibility (guilt) for the disability.

Componential analysis revealed that mothers of children with a disability saw themselves as being under stresses unique to the female parent role. This tacit premise permeated all interviews and interactions and was the major cultural theme of the paradigm. Positive attributes/supports were also identified which helped mothers cope with their situation. Table 2 summarizes the results of the study as related to the cultural theme of stress.

Mothers delineated and placed in priority six major sources which resulted in stress. There was 100% agreement on the identification and ordering of this list. Stress was seen as something negative which made life more difficult for the mother. Each source generated specific stresses which placed demands on the mother. Mothers then identified positive attributes that were helpful in alleviating stress. It should be noted that of these attributes many had not been personally experienced, as seen by the numbers in Table 2, but all attributes had been identified as ideals and were optimistically relied upon to make life better for both mother and child.

Table 2
Components of the Cultural Theme of Stress

Major Sources of Stress	Specific Stresses Experienced	Positive Attributes/ Supports
1. SELF	Feelings of guilt (12) Being the main care giver (12) Having an abnormal child (12) Feelings of stagnation/ isolation (12) Unrealistic expectations of self and others (12) Inadequate energy to meet own and others' needs (12) Low self-concept (12) Inability to return to work as planned (8 out of 8)	Maintaining a hopeful attitude (11) Having healthy children (8) Sharing self with spouse (5) Satisfaction with role and responsibilities (6) Setting realistic goals (5) Previous experience in coping with stress (4) Realistic grieving (8)
2. CHILD (DISABLED)	Lack of acceptance by others (11) Meeting physical demands/ pain, discomfort of the child (12) Inability to communicate with the child (7) Slow progress (12) Concern about the child's future (12)	Personality of the child (11) Strengths within the child (11) Reciprocating of needs (11) Belief in the sanctity of life (12) Being MY child (12)
3. HUSBAND	Lack of communication and support (11) Financial burden (12) Needing his support (11) Lack of intimacy (11)	Sharing responsibility (5) Communicating openly (1) Providing monies (12) Male companionship (7)
4. PROFESSIONALS	Inaccurate/inconsistent information (12) Lack of support (12) Fragmentation of services (12) Emphasis on negative aspects of the disability (12)	Not harming child (3) Providing support for mother (5) Providing information, alternatives and outcomes about treatment (7)
5. SOCIETY	Lack of customs/supports (12) Imposed isolation and roles on mother and child (12) Stigmatization of child (12) Superstitions about disability (12)	Treating the child fairly as a unique individual (3) Acceptance of mother and child (2) Parent support groups (10)
6. FAMILY & FRIENDS	Lack of support/acceptance/ understanding (12) Inadequate time and energy for others (12) Being isolated from others (12)	Support and acceptance of mother and child (8) Valuing father's involvement with child (7)

NOTE: Numbers indicate the number of mothers having actually experienced each dimension of stress and of support.

Mothers identified themselves as the major stress causing agent and their child as the second most important source. Two themes reoccurred consistently in the interviews. The first was that mothers blamed themselves as being the direct cause or contributing to the cause of the disability. Self blame and guilt were reinforced every time the mother was made aware of the child's deviation from the norm, the mother being constantly reminded that this child would never be the socially ideal child. The second theme that continuously generated stress was that mothers felt themselves to be the primary, and often only care giver. Rarely could these mothers physically and emotionally release themselves from their child and entrust the child's care to another.

The only positive attribute stemming from within each mother was hope. Two levels of hope were identified. One level was considered to be realistic. All mothers had faith that others would accept the disability, hoped for autonomy, happiness and productivity in the child's future. The second level was considered to be unrealistic, that of a reversal of the disability or at least of some of its effects.

Mothers were able to assess the positive attributes of the child and placed the negative attributes of the disability in perspective, focusing on the whole child. Mothers were also cognizant that the child fulfilled needs within her.

Husbands were identified as the third most common source of stress. Only one mother spoke positively about her husband, attributing this to good communication between them. Attitudes are best summarized by one mother who stated, "He has retreated into his work. He only hears about the outcomes but never experiences what I have to go through when we get more bad news or when our son cries because he's afraid or in pain."

Worth noting is that 10 of the children were male. Mothers were uncertain whether this influenced fathers' involvement, although they thought it might. Two mothers made specific reference to this. "He tries but he's just not sure what to do for this child of ours. He wanted a son so badly." Another father, the parent of a severely retarded child, had never touched his son in the five years since birth, although he was very affectionate to a younger female child.

Anger was expressed toward some husbands for not being involved in the labour and delivery of the child. One mother states, "He just left when things were getting tough. That's when I really needed him." This anger remains with her after eight years.

Health and education professionals were identified as the fourth source of stress. Mothers were asked to identify the most difficult ex-

perience in having this child. All responses referred to the helping professions. Being given conflicting diagnoses, being told the child was mentally retarded when he was not, being told to institutionalize the child (none of the children in this study had been institutionalized), and not being given hope, were common complaints. To quote: "I've been disappointed over and over in professionals," "Professionals! I guess they mean well, but they don't understand how to help," and "They've never really helped me."

The mothers who brought their children to the physician at eight or nine months already knew something was wrong because the child could not stand. One mother brought her child to a family physician who had the child examined by a team of specialists. "On Friday he called to tell me the team had bad news and that my husband and I were to come to his office Monday morning. Well! You can just imagine the type of weekend I had."

Mothers were asked about the usefulness of professionals. Mothers wanted help, but acknowledged that what they needed as help, and what professionals saw as being helpful and necessary, were frequently quite different things. "You see, again I have to fight with them to make them understand what my child needs. Why won't they listen to me. I know my child."

The final areas identified as generating stress included society, and family and friends. All mothers found it difficult to tell others about the disability. There was little social conversation about the child. People would not ask about the child and mothers did not receive positive feedback. Friends and relatives appeared to be uneasy around the child and mother. Talking on the phone and visiting or being visited decreased after the diagnosis of the child in all instances. Society has no traditions to support parents when they need it most, that is, when they have a baby who is abnormal. A mother pointed out, "When you've got a normal baby everyone has advice to give. But that's not when the advice is needed."

All mothers described a self-imposed isolation. This was done to conserve resources. "I just can't handle not talking about him as if he didn't exist." Mothers would look toward the husband for the support once provided by friends. When this support was not forthcoming mothers turned to their relationship with their child.

The most helpful support was the parent support group. These were self groups made up mostly of mothers with disabled children. The orientations of the groups were social with secondary psychological and educational objectives.

DISCUSSION

All mothers in this study saw themselves as alienated and isolated from society. They were above all else mothers of children for whom society had no significant, inclusive or consistent support. Mothers were expected to fulfill the female parent role with no outside direction, or alteration in expectations in parenting for the special needs of this child.

This study is limited by the homogeneity of the population, sample size and non-random selection of informants. However, the results of the study as seen in Table 2 and through the quotations in this report demonstrate complex psychodynamic and sociocultural factors acting on the female parent. Statements were made by mothers that reflected their view of life. Whether experiences occurred years ago or yesterday made little difference. What happened in the past, both stress and support, became an intricate part of the present. Current perceptions are based on the past. The mothers in this study did not develop an inclusive list of stress and support. They recalled what was meaningful to them now.

One of the responsibilities of nursing is to work within the framework of any given individual to assist that individual to maximize health, according to his or her definition of health, and to achieve the highest state of quality of life within his or her capability and desire. However, as individuals and professionals we, like the people we serve, are bound by our society, and, as such, are frustrated by the lack of guidelines available to the parents of handicapped children. The framework that guides our interventions is nebulous. The mothers in this study begin to give us the guidelines in what they found made life more difficult for them and in what they found, or would like to have available to them as supports.

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RÉSUMÉ

Mères d'enfants handicapés: étude du stress chez les parents

L'éducation de l'enfant handicapé physique est une responsabilité à laquelle la plupart des parents sont mal préparés. Les besoins spéciaux de l'enfant handicapé sont à l'origine d'un stress additionnel chez les parents; il s'agit par ailleurs d'un stress auquel peu de parents peuvent faire face efficacement. Les modes d'adaptation existants sont mis à l'épreuve chez chaque mère ou père.

Le présent article traite de l'expérience subjective de la mère et examine sa vie face à son enfant. Une étude ethnographique a été réalisée pendant huit mois auprès de douze mères d'enfants atteints de paralysie cérébrale. L'analyse des notes recueillies sur le terrain fait apparaître un thème culturel de stress unique chez la mère. Les mères ont raconté comment elles prenaient soin de leurs enfants et elles ont identifié six sources de stress: la mère elle-même, l'enfant infirme, le mari, les spécialistes, la société, enfin la famille et les amis. Les sources ont été analysées et l'on a identifié des stress spécifiques émanant de chaque source. Les mères ont également identifié les points forts ou les attributs positifs de chaque source. Les résultats de l'étude sont résumés et des citations pertinentes soulignent les observations utiles dans le contexte clinique.