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PREVIEW

**MATERNAL PERCEPTIONS OF PARENTING INFANTS
WITH CONGENITAL HEART DISEASE:**

IMPLICATIONS FOR EARLY INTERVENTION

by

Barbara Berke Meyers

**A Doctoral Project Submitted in Partial Fulfillment of the
Requirements for the Degree of Doctor of Psychology in the
Department of Psychology at Pace University**

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ABSTRACT

This study explored how mothers perceive their parental role and cope with the chronicity of their child's congenital heart disease (CHD). Sixty-four mothers were selected to complete the Parent Perception Inventory (PPI) and the Parent Role Questionnaire (PRQ). The PPI was used as a needs assessment tool to identify mothers' perceptions of their concerns, needs, and coping strategies when raising a chronically ill infant. The PRQ was used to assess whether the impact of an infant's chronic illness has an effect on a mother's parental role perception at different stages of her child's development. Responses from 31 mothers of infants, diagnosed with congenital heart disease within the first six months of life, were compared with the responses from a control group of 34 mothers of healthy infants.

This study found that mothers' stress reaction to their infant's illness is related to perceptions of the long-term prognosis of the cardiac defect. The presence of illness, severity of condition, and the accuracy of a mother's perceptions of the severity of her infant's cardiac condition was not associated with degree of stress.

Although mothers of CHD infants did not experience a significantly greater degree of stress than mothers of healthy infants, there was significant variability in the number and types of concerns that each group held. Mothers of CHD infants are significantly more concerned with the needs of their infant, (e.g., his/her care and prognosis) than non-CHD mothers. Mothers of healthy infants focused their concerns on how the birth of their infant impacted on their

needs and self-concerns. In both groups, marital satisfaction was related to stress, and unrelated to maternal age, income, and marital status. Both groups also agreed on their perceptions of their parental role and acknowledged that this role changes at different stages of their child's development.

The aim of this study was to study maternal perceptions about parenting CHD infants. This study may sensitize health care professionals in their ability to identify maternal concerns and coping strategies, in order that interventions can be developed which meet their specific needs. Prior research shows that facilitating parenting and adaptive interactions within families has a positive impact on the developmental outcome of at-risk infants (e.g., enhances social and cognitive competence).

PREVIEW

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I would like to express gratitude to those who have influenced my personal and professional growth. There are many people who have touched my life and my heart in profound ways.

First, I would like to express thanks and appreciation to my family. To my parents I am grateful for their love and unending confidence in me. They taught me to respect life, believe in myself, value learning and that you can meet any of life's challenges as long as you have the love and support of a loving family. I was additionally blessed with a wonderfully supportive husband, Michael, whose encouragement, wealth of knowledge and experience as a doctor, who works with children and families with CHD, inspired my admiration and interest in these families. His support, respect, and love were never ending even when it meant cold dinners and endless hours on the computer. Completing my family is my daughter Rebecca whose birth was a "miracle" and who provides me with endless hours of pride and enjoyment as I watch her grow into a beautiful caring and loving young woman. She was always an inspiration to me as she continually encouraged me to persevere with my training even when things got difficult and it meant other mothers having to drive her to activities.

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Additional thanks to the mothers who took the time to participate in this study.

DEDICATION

This Doctoral project is dedicated to the memory of my mother Rose N. Berke who passed away shortly before my graduation.

Although my mother battled a chronic illness for over 35 years, she dedicated her life to lovingly raising a family and pursuing the highest academic goals for herself. She dedicated her professional life to the education of children and her personal life to her husband and children. She taught me to be independent and to pursue my dreams no matter how difficult the obstacles may seem. It was her love, independent spirit, strength, and courage that have seen me through some very difficult life events and which I hope to pass on to my daughter.

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CHAPTER I

PURPOSE OF STUDY

This study considered the concerns, stresses, coping abilities, and perceptions of parental role of mothers of infants who are born with congenital heart disease (CHD). More specifically, this study examined maternal perceptions of stress and coping and its impact on parenting and compared these perceptions with mothers of non-CHD mothers. The purpose was to examine stress and coping specifically in mothers of CHD infants. This research has the potential of assisting early intervention professionals in developing an understanding of the unique needs of families who have infants with CHD.

Background

The birth of a child and the anticipation of parenthood brings about changes and stress in the lives of all family members (Miller & Sollie, 1980). While birth is usually responded to as a positive change, many of the accompanying life changes (e.g., increased financial expense, less time to self, additional household work and caretaking responsibilities, altered sleep patterns, and possible job and income loss) may be viewed as negative aspects by family members, particularly by new mothers. More specifically, research indicates that parental reaction and adaptation, in response to the birth of a child, is influenced by a variety of factors (e.g., the interface of child and parent characteristics, quality of the parent-infant interactions, stress and the quality and availability of support systems (Crnic, Greenberg, Robinson, & Ragozin, 1984).

Raising a chronically ill infant, and living with the uncertainty of the child's future, creates even greater stress and changes in the family system. Belsky (1984) found that the birth of an infant at-risk places additional stress, and demands on the family, and places the family as a whole, and the individual family members, at risk for ineffective coping. The emotional system and coping abilities of the entire family are challenged. This study looked at a group of mothers who were faced with the increased challenge of parenting an infant born at risk with CHD.

At least 8 to 10 of every 1,000 infants born annually have a heart defect (one percent of all live born infants). Sometimes the defect is so mild that there are no outward symptoms, but in other cases the symptoms are so severe that the newborn becomes ill soon after birth. CHD is amongst the most common class of birth defects, and children with CHD constitute the largest single patient population in many pediatric inpatient services. Of the more than 30,000 infants born annually with CHD, more than one-third will require cardiac surgery early in life (American Heart Association, 1991). As mortality rates for corrective cardiac surgery in infancy have declined, long-term follow-up of survivors and neurological, developmental, and psychological outcomes are now being examined. Pediatric neurology and developmental pediatric departments often receive referrals to assess neuropsychological sequelae arising from CHD. Damage to the heart of a newborn, even if early repair is done, often results in behavior, adjustment, and cognitive difficulties (Ferry, 1990).

Cooper (1959) wrote of the need for pediatricians and family physicians to approach the child with CHD as a total person. He additionally stated that these children are more at risk for significant psychological sequelae to which numerous articles on CHD fail to acknowledge. He felt that these psychological sequelae might be influenced by a variety of factors, such as co-

existing congenital defects, physical and/or psychological stresses; directly associated with their heart disease and its treatment, disturbed parent-child interactions, and/or peer relationships.

Auer, Senturia, Shopper, and Biddy (1971) followed up 28 children, ages 6-11, who were diagnosed early in life with the same cardiac lesion, ventricular septal defects (VSD). Although only half required surgical intervention early in life, all had one or more catheterizations. Looking at subsequent childhood adjustment, between the ages of 6-11, they found that operated children demonstrated significantly more impairment of intellectual functioning than those children with VSDs who were not operated on. Although there was no significant difference in the incidence of emotional disturbances in the entire group of 28 children with VSDs, children diagnosed with VSDs were more similar emotionally to children in a psychiatric clinic group than to those in a control group (healthy children). The duration and number of hospitalizations were significantly associated with maternal stress and anxiety. The greater the duration and number of hospitalizations, the more profound was a mother's anxiety; this, in turn, they found to be positively related to impaired social adjustment and clinically demonstrable emotional disturbances in these children.

Chandler (1975) found that individual differences in the development of high risk infants could not be solely accounted for by early risk factors. Rather, environmental factors (e.g., caretaker characteristics) influence children's developmental outcomes. A mother's perceived level of stress and availability of social support were found to be significant predictors of maternal attitudes and of the quality of their interaction with their infant.

The relationship between maternal stress and adaptation, child cognitive behavior, and mother-child attachment and interaction were examined by

Hanson and Hanline (1990). They conducted a three-year longitudinal study of three disability groups (i.e., Down's syndrome, hearing impaired, and neurologically impaired) when the children were age 2, 3, and 4. They found a significant relationship between maternal stress and parenting experience (coping). Mothers who reported higher levels of stress scored lower with respect to satisfaction with parenting and availability of social supports than mothers who reported lower levels of stress. Similar to the previous study by Cooper, their findings show that a significant relationship exists between maternal stress and child characteristics. Although it appears that some children with disabilities and chronic illnesses pose a greater challenge to their parents and families than others, child characteristics (e.g., more frequent hospitalizations, developmental complications, treatment changes, different or problematic temperamental and behavioral characteristics), socioeconomic status, the quality of the spousal relationship, as well as maternal characteristics, were all found to be more significant in determining family difficulties than the presence of a particular type of disability or illness.

Parent-child interactions have been found to be one of the best predictors of developmental outcome. Outcome is not only affected by the severity of an illness, but also by how effectively a family deals with their infant's illness as well as the quality of the parent-child interaction (Lewis & Khaw, 1982).

Although being a parent is a difficult and stressful job, research has consistently shown that parents of chronically ill children experience more stress than parents of healthy infants. Goldberg (1990) found that parental stress changes over time and is effected by the characteristics and course of an illness. When she compared responses of parents of infants with cystic fibrosis and those with CHD, with parents of healthy infants, she found that parents of

chronically ill infants consistently reported more stress than parents of healthy infants. Additionally, parents in the CHD group reported higher levels of stress than the other two groups. CHD represents many different diagnoses and prognoses, but in general the threat to life and the greater degree of uncertainty about outcome is more immediate at the time of diagnosis than with the diagnosis of cystic fibrosis.

Goldberg (1990) found that a parent's psychological well being is affected by a child's illness. Parents of ill infants reported more problems with depression and a lowered sense of competence when compared with mothers of healthy infants. Frequently these parents experienced their infant's failure to thrive or continued illness for several months before an accurate diagnosis was made. Chronically ill infant's are also frequently more unpredictable and difficult to parent. Kazak and Marvin (1964) found that these experiences negatively impact on a parents feelings of efficacy and satisfaction in their parental role. They also found that mothers of at-risk infants report, early on in their parental role, feelings of depression an helplessness.

The presence of an infant's illness therefore appears to cause immediate and profound changes not only in the functioning of a child but in all members of the family. These changes have been found to appear regardless of illness severity. Lirde, Rasof, Dunn, and Rabb (1966) found that maternal anxiety and stress were related to presence rather than to severity of their child's identified heart condition. They report that since parents do not possess the sophisticated medical knowledge to accurately assess the severity of their child's cardiac lesion and can only partially grasp the prognostic implications, the mere diagnosis of 'congenital heart disease' sets into motion complex changes in the family system. These changes affect a family's approach to the cardiac child as well as to his/her healthy siblings. Although this is an old study

and diagnosis and knowledge about CHD in infants is more sophisticated, a parent's extreme overestimate or underestimate of the severity of his/her infant's condition may be an important clue to parental difficulties in adjusting to their infant's condition.

Kong (1986) found that maternal anxiety did not always disappear after corrective heart surgery. The psychological state of the parent often affects his/her ability to process information about the infant's condition accurately and without distortion. Even if the defects of these infants are medically corrected, many still remain difficult to care for and parent. In a study by Gudersmith (1975), mothers of infants who were born with CHD and were between the ages of 2-21 months old, reported difficulties in establishing comfortable social interactions with their infants. Goldberg (1991), using the "Strange Situation" (Ainsworth, 1969), also assessed the effect that CHD had on early social relationships. She identified significantly fewer infants with CHD having secure relationships with their mothers in comparison with healthy peers. More specifically her longitudinal study investigated mother infant relationships and found that severity of an illness "may" have a variable effect on parent child relationships. She used four of the five diagnostic groups that are used in this study (i.e., ventricular septal defect (VSD), atrial septal defect (ASD), coarctation of the aorta (COA), tetralogy of Fallot (TOF), and transposition of the great arteries (TOF). These groups differ with respect to prognosis and severity. Goldberg's study assessed infant mother relationships at 2 months and again at 18 months of age. By comparing observations of 42 mothers of CHD infants with those of 40 mothers of healthy infants, she found more insecure-avoidant infants in the CHD group than in the normal group. The infants in the CHD group showed minimal distress at their mothers departure and ignored and/or avoided her upon return. Some even demonstrated friendlier responses to

strangers than to their own mothers. More specifically, she found that the individual diagnostic group correlated with the quality of parent child relationships. TOF and VSD groups had significantly fewer attached infants. In both of these groups, parents experienced more uncertainty about their child's condition. In the former, the infants face an indeterminate number of surgeries, and, in the latter, the parents are told that they must take a wait and see approach to their infant's condition. In the TGA and COA groups, parents are told that the defect is correctable and many parents feel that their infants are fixed at an early age. Therefore, it may be the uncertainty that interferes with the formation of secure attachments, rather than the illness itself.

Linde et al. (1966) looked at certain aspects of parenting that contributed to later child adjustment. They found that maternal pampering and protectiveness were significantly greater in the CHD group than in the normal group. This group of children was found to be significantly more anxious and made a poorer social-emotional adjustment by latency than their normal peers. Linde et al. found this to be related to maternal anxiety and pampering rather than to severity of illness or child incapacity.

Protectiveness by a mother of a cardiac child is a combined response to a reality based on a real illness of the child, as well as to a mother's anxiety and guilt about her damaged child. The negative correlation Linde et al. found between pampering and adjustment is critical in assisting parents early on with parenting. He found that mothers of CHD infants were unable to separate pampering from protectiveness and, as a result, the more pampered child was later found to be more easily frustrated, unhappy, anxious, and dependent. Conversely, with normal children a positive correlation existed between pampering and adjustment. Some pampering (greater attention on the part of the mother) correlated with better adjustment. They attributed these findings to

the hypothesis that parents of a well child are better able to realistically separate attitudes of pampering and protectiveness (i.e., balance concern about the physical care of the child with establishing consistent parameters for discipline). Therefore, they are able to facilitate, rather than interfere with, a child's developmentally appropriate autonomy strivings.

Therefore, because it has been shown through research that diagnosis alone may not be predictive of the quality of the mother-infant relationship, a more complicated pattern of mutual influence needs to be considered when one does an assessment. Additionally, because it has also been found that children with CHD have more behavioral difficulties than their healthy peers (Heller, 1985), it is critical that early attention be given to assisting parents in establishing positive relationships with their infants, so that they can facilitate their infant's social development. With increasing research showing that medically compromised infants fare better emotionally, physically, and cognitively in securely attached mother-infant relationships, it is critical that professionals focus their efforts on providing attention and support to parents of at-risk infants in their more difficult caregiving and parenting responsibilities. According to Belsky (1981), responsive parenting enhances the intellectual, social and emotional development of the child with CHD. Early intervention and support with caregivers has also been shown to provide psychological benefits to the entire family.

As a result of the increasing recognition that family members have a profound and dynamic effect on one another, early intervention services have been concentrating on addressing the entire family. To promote optimum functioning of the high risk child, it is essential that early intervention strategies recognize the strengths and needs of the larger family system. The recently enacted Federal Law PL 99.457 recognizes this, and emphasizes the

contribution and critical importance of the family system to early intervention and developmental outcome with high risk infants. Through the development of an Individualized Family Service Plan (IFSP), families are assisted in identifying their needs in order to assist them in coping and accessing services for their special-needs-infants. The emphasis on "individualized", in the IFSP, calls attention to the variance in coping. There are individual differences between and within families in their perceptions of whether they are in crisis, as well as in the quality of their resources and needs. In order to individualize and develop services and strategies for promoting the well being of the family as a whole, early intervention professionals need to learn to identify and evaluate the needs and strengths of families in areas that contribute to their ability to function adequately. In order to become more effective in assisting family service planning, psychologists need to recognize the reciprocal influence that family members exert on one another, as well as the influence that the at-risk infant has on parenting and on the operation of the family system, and become skilled at facilitation and intervention.

The significant psychosocial and intellectual problems that many studies found upon follow-up of children with CHD warrants further studies of children with CHD and their families. Children with CHD present unique care needs. As psychologists, it is important that we recognize and investigate this growing population in conjunction with their parents in order to support and provide early intervention services. The aim of this study is to identify maternal concerns and coping strategies, in order to develop interventions that will facilitate parenting and adaptive family interactions. Adaptive family functioning can enhance compliance with treatment and conceivably reduce vulnerability to adjustment reactions, anxiety disorders, and affective disorders that may be triggered by the stress of an illness.

This study explores how mothers' perceive their parental role and cope with their infant's CHD. By comparing mothers of health infants, with mothers of CHD infants, this study aims to identify the impact of an infant's CHD on maternal concerns, needs, coping strategies, as well as on parental role perceptions at different stages of their child's development.

Research Questions

1. What concerns and stressors do mothers of CHD infants have and are they greater than and/or different from those of mothers of healthy infants?
2. Are mothers of CHD infants under greater stress than mothers of healthy infants?
3. What factors are associated with maternal stress in both groups, e.g., income, marital status, marital satisfaction, and age of mother.
4. Is there a relationship between perceived severity of an infant's illness and maternal stress? Do mothers' perceptions of the severity of their infants' illness agree with documented medical status reports? Do mothers of CHD infants tend to overestimate, underestimate, or accurately estimate the severity of their infants' illness?
5. What strategies (emotion-focused vs. problem-focused) do mothers of CHD infants employ to cope with their infants' difficulties, and are they different than those of mothers of healthy infants?
6. How do mothers of infants, born with CHD, and mothers of healthy infants, compare on the perceptions of their parental roles and how the roles change at different stages of child development?

Hypotheses

1. Mothers of CHD infants have a significantly greater number of concerns than mothers of healthy infants
2. Mothers of CHD infants are under greater stress, as measured by the PPI Stressor scale (subscales: HELP, SELF CONCERN).
3. In both groups of mothers maternal stress will be related to income, marital status, marital satisfaction, and age of mother.
- 4a. There is a relationship between the perceived severity of an infant's illness and maternal stress.
- 4b. Mothers who overestimate the severity of their infants' illnesses will score higher on the PPI Stressor scale than mothers whose perceptions agree with documented medical status reports.
5. Mothers of CHD infants who are experiencing stress employ emotion-focused coping strategies to a greater degree than mothers of healthy infants.
- 6a. Mothers of both groups will agree in their acknowledgement of the six characteristics of the parental role as defined by the PRQ Questionnaire.
- 6b. Differences will exist between the perceptions of mothers of infants born with CHD and those of mothers of healthy infants regarding their parental role at different stages of their respective children's development.