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UNIVERSITY OF ALBERTA

RELATIONSHIP BETWEEN THE IMPACT OF HAVING A VISUALLY IMPAIRED CHILD AND PARENTAL COPING BEHAVIORS

BY

BARBARA JEAN ASTLE ©

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND
RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA
FALL, 1990

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ISBN 0-315-64836-8

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DEPARTMENT OF PEDIATRICS
Pediatric Ambulatory Care Division

Mailing Address
Bronx Municipal Hospital Center
Jacobi Hospital
Pelham Pkwy. & Eastchester Rd.
Bronx, New York 10461

July 17, 1989

Barbara Astle
Apt #1106
9740 - 106th St.
Edmonton, Alberta T5K-2P8
Canada

Dear Ms. Astle:

Thank you for your request regarding the Impact on Family Scale used by our group in studying chronic illness in children. Because of the rising number of requests for the instrument and the need to supply psychometric data on the instrument as well, we have developed a standardized packet of information regarding the measure.

Unfortunately we do not have support to cover the costs of handling these requests and are therefore forced to charge a processing fee of $25.00 for the Impact on Family Scale. This covers the cost of preparation, duplication, and mailing the information. The check for this fee should be made out to "PACTS PAPERS/AECOM" and sent to Dr. Ruth Stein, Room 1N17 at the above mailing address.

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The packet has been prepared based on our experience with a particular population of inner-city children with chronic physical health problems and in some instances on other populations as well. While the instrument has also been used in still other populations, we cannot describe or guarantee their properties in those situations. We are sure you realize this would be a standard caution with the use of any instrument.

Many thanks for your interest.

Sincerely,

Ruth E.K. Stein, M.D.
Professor of Pediatrics

REKS/lr

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Barbara J. Astle, RN, BScN
#1106, 9740 - 106 Street
Edmonton, Alberta
CANADA T5K 2P8

Dear Ms. Astle:

✓ I am pleased to give you my permission to use the **CHIP: Coping Health Inventory for Parents** instrument. We have a policy to charge $5.00 (one time charge only) *per instrument* to individuals who seek permission. We apologize for this necessity. We also ask that you please fill out the enclosed abstract form and return it to this office.

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Sincerely,

Hamilton I. McCubbin
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DEGREE: MASTER OF NURSING

YEAR THIS DEGREE GRANTED: 1990

Barbara J. Astle
(Student's Signature)

#1106, 9740 - 106 Street
(Student's Permanent Address)

Edmonton, Alberta
CANADA T5K 2P8

Date: September 28, 1990

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SUBMITTED BY: BARBARA JEAN ASTLE

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE

DEGREE OF MASTER OF NURSING.

Marion Allen

M. N. ALLEN, PhD., RN. (Supervisor)

Louise Jensen

L. A. JENSEN, PhD., RN.

G Drummond

G. T. DRUMMOND, MD.

Date: Sept 27, 1990

DEDICATION

To my dear husband, Bill, who shares with me a committment and concern for a better understanding of families having a child(ren) with a visual impairment. I am thankful for my husband's unyielding patience, support, constructive suggestions, and the time that he unselfishly gave to me throughout my program. I could not have done it without him.

To all of the mothers and fathers who willingly allowed me to come into their homes and share with me their experiences of having a child(ren) with a visual impairment; I am very grateful. I hope this study leads to a better understanding of your situation and in some way will help other families in the future.

ABSTRACT

Families increasingly face the long-term care of children with various chronic conditions, such as a visual impairment. This situation can be a very stressful, demanding, and challenging experience for both the parents, and the entire family. However, empirical research is lacking concerning the impact on parents of having a child who is visually impaired, and the coping behaviors they use to deal with this situation. The purpose of this study was to discover what the relationship was between the impact of having a child who is visually impaired and parental coping behaviors among parents of these visually impaired children. In addition, the relationship between specific influencing factors and the impact/parental coping behaviors of having a child who is visually impaired was also explored. The descriptive correlational design was used to examine the relationships between the two variables of impact and parental coping behaviors.

Two self-report questionnaires and a background information form were administered individually to 23 sets of parents (both mothers and fathers from the same household) having a visually impaired child, three years of age or younger. The two self-report questionnaires measured the variables: impact and parental coping behaviors, while the background information form collected biographical data about each parent.

The impact on parents having children who are visually impaired, was greater when the child's level of impairment was more severe. Differences were found between mothers and fathers in the level of impact, and the usefulness of particular coping behaviors. Overall, mothers reported higher impact, and used more coping behaviors which dealt with communicating with other parents and consulting with the health care personnel, as compared with fathers. With both mothers and fathers, relationships were identified between the impact of having a visually impaired child and parental coping behaviors. The knowledge of the impact of having a visually impaired child and

coping behaviors used by these parents, may better assist nurses with their individual assessments of the needs of these families. Further research is suggested for examining other family types, and conducting a longitudinal study exploring the impact among families at the time of diagnosis through to adulthood.

ACKNOWLEDGEMENTS

There are a number of people I would like to thank sincerely for assisting me in completing my thesis. First, there are the members of my thesis committee, my Thesis Supervisor, Dr. Marion N. Allen, and committee members Dr. Lousie A. Jensen, and Dr. Garry T. Drummond. Dr. Marion Allen graciously offered me constructive input, continuous positive encouragement, and enthusiasm as I proceeded with each new phase of the study and the writing of my thesis. Dr. Louise Jensen guided me to a better understanding of my data by sharing her statistical expertise with me. In addition, her willingness to assist me and her encouraging smile made the process that much smoother. Dr. Garry Drummond's expertise in Pediatric Ophthalmology allowed me to view various aspects of my study from another perspective. The input that each of my thesis committee members shared with me was invaluable and I thank them very much.

The following individuals assisted me with obtaining subjects for my study for which I am sincerely grateful, Sylvia Miller, Dr. Garry Drummond, and Dr. William F. Astle from the University of Alberta, Division of Pediatric Ophthalmology and Adult Strabismus, and Jennifer Stopsen from the Canadian National Institute for the Blind (CNIB).

I am indebted to Dr. Terry Taerum, University of Alberta, Computing Services who patiently assisted me with creating the statistical programs required to analyze my data.

I am also very thankful to my husband for his enduring patience, my family, and my friends in the Faculty of Nursing who gave me unyielding encouragement, support, and inspiration to proceed.

During the course of my personal life and nursing career, there have been numerous individuals that have positively influenced me, and to all I thank you.

Finally, I must acknowledge and thank the Alberta Foundation for Nursing Research for their financial assistance in providing me with a student research bursary.*

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* The Alberta Foundation for Nursing Research is not necessarily supportive of any of the ideas and findings of this study.

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CHAPTER I

Introduction

It has been estimated in Canada that there are approximately 780,000 children and youths between birth and 19 years of age with a chronic health problem or chronic illness (Rosenbaum, 1988). This increase in the prevalence of children with a variety of chronic conditions (Gortmaker & Sappenfield, 1984; Rosenbaum, 1988; Stein, 1989) during the past two decades has led to a definite change in child health care. There are various reasons contributing to this increased prevalence rate and the apparent changes in providing care for these children. One major reason frequently cited in the literature, is the continuous introduction of technological advancements and improvements occurring within the health care delivery system (Rosenbaum, 1988; Stein, 1989). In addition, North American society has experienced various philosophical, political, and attitudinal changes toward the rights and needs of this group (Rosenbaum, 1988). As a result, the health care delivery system has been increasingly faced with the role of overseeing the care of more families and children with chronic conditions (Hanson, 1987; Hobbs, Perrin, & Ireys, 1985; Pless & Pinkerton, 1975; Stein & Jessop, 1984; Stein, 1989; Thomas, 1987a; Travis, 1976) and is not necessarily equipped with the knowledge to help them cope over the long-term (Stein, 1989). In order to better assist these families and control escalating health care expenditures, health care professionals must help families realize that the responsibility for the health and well-being of its members ultimately resides within the family (Burr, 1985; Hobbs et al., 1985; Masters, Cerreto, & Mendlowitz, 1983; Sargent, 1983; Scharer & Dixon, 1989; Thomas, 1987b). Therefore, families become the primary group responsible in caring for children with chronic conditions (Austin, 1990; Beckman, 1983; Thomas, 1987b).

As a result of these current changes in health care delivery, there has been increasing interest by researchers to study how families manage stressful situations such as children having a chronic condition (Cauble, 1988; Doherty, 1985; Doherty & McCubbin, 1985; Hymovich, 1981; McCubbin et al., 1980; Scharer & Dixon, 1989). The impact upon a family faced with the long-term care of a child with a chronic condition can present the family with new challenges, demands, hardships, and stresses (Burr, 1985; Gibson, 1984; Hobbs et al., 1985; Kazak & Marvin, 1984; Patterson, 1988; Rolland, 1987; Sargent, 1983; Singer & Farkas, 1989; Thomas, 1987b; Warnick, 1969). However, empirical research is lacking concerning the impact a child's chronic condition has on the family's active ability to cope with the stresses of a child who has a chronic condition (Deatrick & Knafl, 1990; Hymovich, 1981; McCubbin & Boss, 1980; Shapiro, 1983; Thomas 1987b). It is not clear why some families handle such a situation better than others (Hansen, 1987; Hymovich, 1981; Katz, 1988; McCubbin & Huang, 1989; Stein & Reissman, 1980; Thomas, 1987b). In the researchers' clinical practice, working with families who have a visually impaired child, it became increasing apparent that some families appeared to manage the stress of caring for their child better, while others appeared to have more difficulty.

Nursing is in an excellent position to assess the impact of a child's chronic condition on the family and to ascertain the coping behaviors used to actively manage this stressful situation (Austin, 1990; Deatrick & Knafl, 1990; Hanson, 1985; Holaday, 1984; Hymovich, 1981; Hymovich & Baker, 1985; McCubbin et al., 1983). Increasingly, nursing is acknowledging the importance of understanding how a child with a chronic condition influences the health of other family members (Burr, 1985; Thomas, 1987b). In the past, however, nursing has had major difficulty in assessing the impact of a child's chronic condition on the family and the coping behaviors employed to manage this situation because of a lack of comprehensive measurement instruments (Hymovich, 1981, 1983, 1984; McCubbin, 1979; Stein & Riessman, 1980).

This study focuses on the impact parents face in having a child with the chronic condition, visual impairment, and the related coping behaviors used to manage this stressful situation. This chronic condition has not been previously examined in this way. It is suggested in the literature that more studies are needed to examine not only how a childs' chronic condition impacts upon the family, but to further examine the specific coping behaviors parents employ to manage this situation (Deatrick & Knafl, 1990; Patterson, 1988). Such knowledge may increase nurses' understanding of these family situations for developing intervention strategies to enhance positive family coping of each family member. Therefore, nurses may be better able to assess, reinforce, and strengthen the variability of coping behaviors that individual family members employ to cope with the impact of a stressful situation such as visual impairment (Hymovich, 1984).

Purpose

The purpose of this study was to discover what the relationship was between the impact of having a child who is visually impaired and coping behaviors among parents of these visually impaired children. The relationship between specific influencing factors and the impact/parental coping behaviors of having a child who is visually impaired was also explored.

Research Questions

It is suggested in the literature that when families are confronted with a stressful event, there is a variation in the impact. Coping behaviors that families use to manage the impact of the stressful event, directly influence family functioning. In addition, other specific influencing factors, such as, socioeconomic status, education level, and religious beliefs affect ways in which families respond to the impact of the stressful event and the coping behaviors employed. Based upon a review of the literature the following research questions were derived:

1. What is the impact upon parents of having a child who is visually impaired?

2. What are the parental coping behaviors parents use with a child who is visually impaired?

3. What is the relationship between the impact of having a child who is visually impaired and parental coping behaviors?

4. What is the relationship between specific influencing factors on the impact of having a child who is visually impaired and parental coping behaviors?

5. What are the similarities and differences in impact among mothers and fathers with having a child who is visually impaired?

6. What are the similarities and differences in coping behaviors mothers and fathers use to manage a child who is visually impaired?

Definition of Terms

The following terms were used to describe the meaning of the two main variables, impact and parental coping, and the specific pediatric group who have a visual impairment and their parents.

Impact: was defined as "the effects of a child's illness on the family system" (Stein & Riessman, 1980, p. 466) as measured by parents responses to the effects on family life of having a visually impaired child, as determined by scores obtained on the 33 item Impact on Family Scale self-report questionnaire (Appendix A).

Parental Coping Behaviors: was defined as the collective or personal efforts to manage the difficulties with health problems in the family (McCubbin et al., 1983) as measured by parent's perceptions of behaviors that they use to assist them in family life with a visually impaired child, as determined by scores obtained on the 45 item Coping-Health Inventory for Parents (CHIP) self-report instrument (Appendix B).

Parents: was defined as including both mothers and fathers living in the same household, who are the legal caretakers of a visually impaired child three years of age and younger.

Visual Impairment in Children : was defined as children who have a significant chronic and/or permanent disease or condition causing a decrease in their level of vision to a point that the involved eye(s) is/are not capable of useful levels of vision as determined by the examining ophthalmologist. Specifically:

(1) Any disease or condition resulting in unilateral or bilateral irreversible visual acuity loss to a level estimated by the referring ophthalmologist to be at the 20/60 level or worse in the involved eye(s).

(2) Any disease or condition which may be partly reversible with improvement of visual acuity, but requiring either surgical intervention such as cataract extraction, and/or prolonged home therapy of longer than six months.

The definitions for visual impairment are numerous and varied because of the many degrees and types of visual impairment (Jan, Freeman, & Scott, 1977; Velleman, 1990). The definition of legal blindness used by many governmental agencies to manage the services provided to those classified into this group, bases its definition on visual fields and visual acuity (Velleman, 1990). Such a definition tends to neglect other individuals with other causes of blindness or types of visual impairment that affords them some vision. As a result, the definition for visual impairment in children, as stated above was specifically defined to include other types of visual impairment that does affect vision to some degree and is found in the pediatric age group, which was the group chosen to be examined in this study.

The diagnosis of visual impairment is difficult in this age group and cannot be accurately measured by one specific test as performed with adults or older children (Friendly, 1989; Isenberg, 1989; Kivlin, 1984; Robinson, Jan, & Kinnis, 1987; Taylor, 1983). To obtain a visual acuity level estimate in these children, the ophthalmologist must consider the patient's history, employ estimating techniques for visual acuity testing, and especially rely on physical findings as a prognosticating factor for future visual acuity attainment (Isenberg, 1989; Weiss, 1983). In this study, the list of ophthalmologic conditions/diseases included, but was not limited to the following: congenital/acquired cataracts, optic nerve atrophy, congenital nystagmus, retinopathy of prematurity, congenital glaucoma and its variants, chorioretinitis, retinal detachment, albinism, retinitis pigmentosa, high refractive errors, colobomas, retinoblastomas and/or other tumors of the eye, diseases of the ocular adnexa and visual pathways, and all causes of cortical blindness (Weiss, 1983).

Significance of Study

It is suggested in the literature that increasingly more families are faced with the long-term care of children with chronic conditions. One such chronic condition is visual impairment, in which there is a gap in the literature concerning the impact a child's visual impairment has on the family's active ability to cope with such a situation. The findings from this study will add to nursing knowledge about families dealing with children having a visual impairment. With a better understanding of the relationship between the impact and coping behaviors that parents use to deal with having a visual impaired child, nursing will be able to provide intervention strategies that will improve and maintain the outcome of positive family functioning.

CHAPTER II

Literature Review

In this chapter, the literature discussion is divided into two sections based upon the two main variables of impact and parental coping behaviors being examined in this study. There are numerous chronic conditions found in children that are relatively rare as compared with adults (Patterson, 1988). As a result of their low prevalence rates, this can have major implications for families in terms of meeting other families to talk to, professionals skilled to care for the child's condition, and information about the condition. Visual impairment is one condition that has a relatively low prevalence rate (Jan & Robinson, 1989; Robinson et al., 1987). However, Jan and Robinson noted that the prevalence rate for visual impairment in children may be rising because of an increase in cortical visual loss and retinopathy of prematurity in children. However, empirical literature available concerning children having a visual impairment and how these families cope remains limited. Therefore, the forthcoming literature review reflects an examination of other chronic conditions as they relate to the chronic condition of visual impairment.

Impact Among Parents Having a Child with a Chronic Condition

Much of the literature concerning the impact of a childhood chronic condition on families has been descriptive and retrospective, although increasingly more empirical studies have been done examining the impact on the family in relationship to other variables, such as developmental gaps and coping (Gibson, 1984; Schliemann, 1988). In addition, much of this literature has focused on mother's responses and less on father's (Sabbeth, 1984; Singer & Farkas, 1989). In this first section, parental reaction to the initial diagnosis of having a child with a chronic condition, and factors influencing the impact of having a child with a chronic condition will be addressed. In addition, an examination of the impact among parents having a child with a visual impairment, and a summary of the impact literature will be presented.

Parental Reaction to the Diagnosis of a Childhood Condition

The diagnosis of a child with a chronic condition creates a stressful situation for the entire family (Kazak & Marvin, 1984; Mac Keith, 1973; Mardiros; 1982; Shapiro, 1983). Parents may exhibit a mixture of feelings such as sadness, helplessness, and bereavement at the loss of a normal child before accepting the actual child as born (Solnit & Stark, 1961). These feelings in turn may lead to depression (Mac Keith, 1973), self-blame, and /or blaming their spouse (Mardiros, 1982).

Several researchers suggest that when parents first learn of their child's chronic condition, they react by proceeding through various stages comparable to the grieving process, before accepting and/or adjusting to the situation (Bristor, 1984; Butani, 1974; Drotar, Baskiewicz, Irvin, Kennel, & Klaus, 1975; Fortier & Wanlass, 1984; Parks, 1977; Solnit & Stark, 1961; Young, 1977). However, other researchers disagree with a staging process (Searl, 1978), or suggest that parents, in addition to the grieving process, may experience a permanent response of sorrow to their child's chronic condition (Olshansky, 1962; Wikler, Wasow, & Hatfield, 1981). In an autobiographical account, Searl (1978) describes the experience of raising his retarded child as a mixture of unresolved, even contradictory feelings of guilt, shock, and bitterness that persisted over time, and did not follow specific progressive stages toward acceptance. He implied that these conflicting feelings, which he had also observed with other parents of retarded children, did not suggest that he was not adjusting or accepting his child, but was his way of dealing with his childs' chronic condition. Other reseachers, such as Olshansky (1962) found in his personal and professional counselling experiences with parents of mentally impaired children that these parents experienced a pervasive psychological reaction called "chronic sorrow". Chronic sorrow meant that the sorrow of this permanent situation was always present, and would vary in intensity over time.

Individual variations of chronic sorrow between mothers and fathers and from one family situation to another were also noted. More recently, building upon the concept of chronic sorrow, a retrospective study (Wikler et al., 1981) found that parents had periodic sorrow that peaked according to their mentally impaired child's inability to successfully meet developmental milestones, rather than grief that was time bound. Wikler et al., suggest that chronic sorrow was a normal reaction to a stressful situation, allowing parents to grieve periodically.

Factors Affecting the Impact of a Childhood Chronic Condition

It is suggested in the literature that a child's ongoing chronic condition places significant strain upon the family, although there remains no definitive concensus about the impact of a childhood condition on a family (Jessop & Stein, 1989). In the literature there are personal accounts and studies describing the numerous psychological, interpersonal, and financial demands placed upon a family's adaptation to their situation. In addition, similarities and differences between family members, such as mothers, fathers, and siblings have been examined and described. The array of factors effecting mothers and fathers having a child with a chronic condition will be analyzed and described below.

Selected characteristics of children with chronic conditions such as the severity of the impairment, whether a neurological deficit was present or absent, and other characteristics of the child's responsiveness which may result in additional or unusual caregiving demands, influenced the amount of stress reported by mothers (Beckman, 1983; Schlomann, 1988; Singer & Farkas, 1989), fathers (Cumming, 1976), and both mothers and fathers (Athreya & McCormick, 1987; Cauble, 1988; McCubbin, 1988). In a study examining the extent to which specific kinds of behaviors and characteristics of handicapped children were related to the level of stress reported by mothers, Beckman (1983) found that additional caregiving demands of the child accounted for the greatest amount of stress in mothers. Beckman's findings supported the work of Athreya and

McCormick (1987) who found that limitations in the activities of a child with a chronic condition contributed to greater parental strain and increased impact than the specific medical diagnosis. This greater level of parental impact was based upon the lack of available financial and physical resources to the parents.

A study examining fathers (Cummings, 1976) with separate groups of chronically ill, mentally impaired, and healthy children, revealed that the psychological impact on these fathers raising both chronically ill and mentally retarded children was similar. However, there was a slightly greater negative psychological impact upon fathers having mentally impaired children as compared with fathers of chronically ill children. Some of these fathers of mentally impaired children demonstrated depressive feelings, lower self-esteem, and a need for compulsive ordering of their situation, suggesting the early development of neurotic tendencies in these fathers.

Developmental gaps of children with delays in motor skills, were found to be related to a positive impact on the family as reported by the mother, whereas delays in cognitive-psychosocial skills produced a negative impact upon the family (Schlomann, 1988). In a similar vein, Singer and Farkas (1989) found that mothers of children with long-term tracheostomies reported greater stress when their child had even the slightest degree of a neurological problem. When there was an absence of a neurological problem in their child, Singer and Farkas reported that these mothers demonstrated a high level of positive mastery related to the caregiving demands. When examining the increasing severity of an impairment, such as children with myelomeningocele, McCubbin (1988) found that the level of family system involvement increased which contributed to the child's health outcome. Such findings suggest the importance of examining other types of children's chronic conditions to best determine the needs of these children and their families.

There are other demographic characteristics of the family members themselves that have been found to contribute to increasing impact among parents of children with a chronic condition, such as, occupation level of parents, single parent versus two parent families, education level of parents, and income level. It was found that families experienced less impact when the head of the household had a higher occupation level as compared with low occupation level families (Schlomann, 1988). Beckman (1983) found that households where there was only one parent, such as a single mother, reported greater stress than an intact two parent household. Schilling, Kirkham, Snow, and Schinke (1986) noted that single parents when compared with married parents, differed primarily on social and economic factors. Time pressures, dissatisfaction with having a lower income, and education level, rather than specific areas related to their child's chronic condition were the single parents' major concerns. They concluded that while single parents face additional challenges, some commonalities exist with married parents and thus interventions may be examined jointly.

It is suggested in the literature that the education level of parents can result in both lower (Athreya & McCormick, 1987; Jessop & Stein, 1985; Schlomann, 1988) and higher degrees of impact (Gibson, 1984; Singer & Farkas, 1989). Singer and Farkas suggest in their study of mothers with children having long-term tracheostomies, that the higher education levels of these mothers contributed to greater stress, because of their understanding of the long-term consequences of their child's neurological problems. In addition, Gibson also reported parents of children with cystic fibrosis experienced greater impact because they appeared to be more concerned about the future as compared with parents of lower education levels. Low family income has been associated with increased impact (Athreya & McCormick, 1987; Gibson, 1984; Jessop & Stein, 1985; Singer & Farkas; 1989), however, Singer and Farkas, recently reported that even families of a higher social class also experienced greater degrees of impact. Singer and Farkas suggest that this increased level of impact may be due to the fact that higher social class families assume more of the financial burden of caring for their chronically ill child as compared with lower income families that are financially subsidized.

Impact of Having a Child with a Visual Impairment

In the literature, there are primarily descriptive accounts of how parents react to the diagnosis of having a visually impaired child. Many of the descriptions are autobiographical accounts written by parents outlining their experiences with raising a visually impaired child as difficult, challenging, and inspiring (Barton, 1984; Bryden, 1990; Ende, 1972; Froyd, 1973; Matthew, 1979; Schultz, 1980; Scott, Jan, & Freeman, 1985; Tuttle, 1986; West, 1981). Seven phases of an adjusting process through which parents with visually impaired children may proceed have been described (Tuttle, 1986). Tuttle suggests that there is no ultimate state of adjustment, rather all family members of a visually impaired person will continually adjust to visually impaired related issues throughout the person's life. A retrospective study (Hancock, 1988) found that mothers with visually impaired children reported difficulties following the diagnosis such as disbelief, anger, concern for their child, disappointment, and denial. These are similar findings reported in another study done with both mothers and fathers with visually impaired children (Jan, Freeman, & Scott, 1977). However, Jan et al. noted that there were individual differences among parents, such as mothers reacting greater to the diagnosis than fathers. In addition, other responses included the expression of relief at confirmation of a suspicion that their child was visually impaired. Hancock, also noted that all the mothers emotional reactions appeared to vary according to their personalities and individual situations, although there were some commonalities in these emotional reactions.

The Institute for Families of Blind Children in Los Angeles (1989) has produced a videotape entitled "Heart to Heart" where both mothers and fathers verbally express their experiences and reactions during and after being told that their child was blind or visually impaired. These parents expressed feelings of helplessness, denial, fear, uncertainty, and loss similar to the findings in the empirical studies of Hancock (1988) and Jan et al. (1977). Murphree, Horn, and Chernus-Mansfield (1990), in assessment of this videotape, noted that although individual reactions differed, there were some common underlying fundamental emotional reactions experienced by all of the parents, such as a stated desire to search for a reason for their child's visual impairment (Murphree et al. 1990). However, no studies could be found that measured the impact on parents of having a child with a visual impairment.

Summary of Impact on Family Literature Findings

It is outlined in the literature that parents possess similarities and differences to the diagnosis of their child with a chronic condition, such as proceeding through a staging process towards acceptance of their situation, or being in a state of periodic sorrow that persists over time. It is also suggested in the literature that there is no specific empirical data to support definitively one set of parental reactions over another. In addition, various characteristics of children with chronic conditions, and of parents have been suggested to influence the degree of impact parents experience. Therefore, it is evident that a child with a chronic condition can present major difficulties and challenges for not only parents, but the entire family (Beckman, 1983; Bennett, 1986; Gallagher, Beckman, & Cross, 1983; Holaday, 1984; Kazak & Marvin, 1984; Mardiros, 1982; Schlomann, 1988). However, gaps in the empirical literature exist about how other chronic conditions, such as visual impairment, are similar or different from the impact upon parents of children with other chronic conditions. To understand the impact that diagnosing a child as being visually impaired has on parents, one must acknowledge the parental expectations placed on the child's future from the parent's perspective (Marcy, 1989; Schultz, 1980). When the parent's original hopes and plans are shattered by the diagnosis of a visual impairment in their child, significant stress is placed upon the entire family.

Parental Coping

Research literature examining parental coping behaviors used by family members was limited prior to 1980 (McCubbin et al., 1980). Since that time, however, researchers have begun to study parental coping with childhood chronic conditions (Van Cleve, 1989). These studies have examined parental coping with healthy infants and children with various chronic conditions such as cystic fibrosis, spina bifida, Down Syndrome, and cerebral palsy (Cauble, 1988; Damrosch & Perry, 1989; Ellison, 1986; Gibson, 1988; Hymovich & Baker, 1985; McCubbin, 1984; McCubbin et al., 1983, Van Cleve, 1989; Venters, 1981; Ventura, 1982, 1986). In this second section, parental coping with healthy children, children having chronic conditions, and differences between mothers' and fathers' coping will be addressed. In addition, parental coping with visually impaired children will be discussed.

Parental Coping with Healthy Children

Parental coping has been examined in relation to new healthy infant temperament characteristics and parental functioning (Ventura, 1982). Three coping patterns evolved that parents used to manage their new situation: (a) a tendency to seek self-development and social support, (b) an attempt to maintain family integrity, and (c) to be religious, content and thankful with their situation. A variation of these coping patterns was used by mothers and fathers depending if they were depressed, anxious, or perceived their infant as having a pleasing or less pleasing temperament. Differences between coping behaviors used by mothers and fathers were also noted. For example, mothers found coping behaviors, such as, perceived social support, being religious and content, more helpful than fathers. These findings suggest that specific coping behaviors were indicators of adapting to being a new parent.

In a replication of this study, Ventura (1986) found compatible results, revealing similar coping behaviors to be helpful. Socioeconomic status was a significant factor in the Ventura (1982) study, whereas not in the second study (Ventura, 1986), suggesting that a larger more diverse sample may be required to verify this finding. The findings from both of these studies suggest that parental coping behaviors are indicators of a family's adaptation to normal healthy children.

Parental Coping in Children with Chronic Conditions

More recently, parental coping of parents caring for children with various chronic conditions has been examined. In one such study of mothers and fathers coping with a child's chronic condition of spina bifida, differences were found between low-coping and high-coping parents, as well as the coping strategies used by mothers and fathers (Van Cleve, 1989). Rather than using numerous coping strategies, high copers found the extensive use of particular coping strategies were more helpful. However, no significant differences were found in the stressor items reported, suggesting that both mothers and fathers were confronted with comparable stressors. In addition, significant positive relationships were found between coping and attending a support group, and between coping and marital satisfaction. There were no significant relationships between church attendance or religion and coping. Van Cleve, suggests that the instrument may not have been sensitive enough to measure this relationship. Demographic data concerning increased age of the parent and higher socioeconomic status were predictive of parental coping.

Other researchers, studying parental coping with cystic fibrosis, present interesting findings (Gibson, 1988; Hymovich & Baker, 1985; McCubbin, 1984; Venters, 1981). An exploratory study was conducted to determine if there was variation in long-term familial responses with a child having cystic fibrosis (Venters, 1981). Two major coping strategies were shown to be associated significantly with strengthening long-term family functioning. These were (a) sharing the burden of the illness with family or other outside members, and (b) endowing the illness with meaning either scientifically or religiously, or giving the illness a positive rather than a negative orientation.

Parental coping was also examined in another study of children with cystic fibrosis (Gibson, 1986, 1988). Gibson, found that these parents generally perceived themselves as coping well, despite experiencing stress related to the illness itself. These parents reported that uncertainty about the future, acceptance of the diagnosis, prognosis of the condition, and acceptance of the treatment regimen all contributed varying levels of stress for them. This study supported previous findings (Hymovich & Baker, 1985; McCubbin 1984; Phillips, Bohannon, Gayton, & Friedman, 1985; Ventura, 1982) concerning increased levels of stress encountered by both mothers and fathers caring for a child with cystic fibrosis. Various levels of social support, such as interacting with other families having children with cystic fibrosis and speaking with health care professionals helped promote positive coping (Gibson, 1986). A general feeling that treatment was progressing positively and attempts to maintain overall family stability were also found to help maintain and promote positive coping. Other resources found useful in coping with a child who had cystic fibrosis were strengths within the parents, such as their attitudes and beliefs, and a perception by these parents that they were managing their stressful situation normally. This perception of normality was also noted among parents of other children with chronic conditions who perceive themselves as coping well (Anderson, 1981). Anderson, found that the spouse and other family members were significantly important in helping the family cope with their situation and assisted with strengthening the family unit.

Differences between Mothers and Fathers Coping Behaviors

Despite an initial study suggesting that there were no significant differences between the ability of mothers and fathers to cope with the stress of having a child with a chronic condition (McCubbin, 1984), more recent researchers have found that both mothers and fathers used different coping strategies to manage their situation (Cauble, 1988; Damrosch & Perry, 1989; Gibson, 1986; Schilling, Schinke & Kirkham, 1985; Van Cleve, 1989). Gibson (1986) noted that mothers tried harder than fathers to maintain self-esteem, psychological stability, social support, and to have an optimistic outlook and to maintain family togetherness. Gibson acknowledges that the sample of fathers used was small, but states that such findings may suggest that fathers' perceptions of coping or their coping behaviors may differ from mothers'. Cauble (1988) found that parental coping, as it related to family functioning differed between mothers and fathers with a child who had cerebral palsy . Medical information and organization were two coping strategies that were more helpful to fathers than mothers. In addition, Cauble noted that, when fathers of children with cerebral palsy were experiencing greater stress and strain within the family, they found the coping strategy of maintaining family integration not very helpful. Cauble suggested that this finding may indicate that fathers use withdrawing or distancing as a coping response as compared to mothers who draw upon a larger repertoire of useful coping responses. In another study with parents having children with Down Syndrome, Damrosch and Perry (1989) found that perceptions dealing with a child's impairment differed between mothers and fathers. Specifically, Damrosch and Perry found that within the same family, mothers reported frequent periods of chronic sorrow in their adjustment to their child's condition. Conversely, fathers reported a steady, gradual level of adjustment. In addition, mothers and fathers differed in the coping behaviors that they found useful. For example, mothers reported that coping behaviors dealing with ventilating their feelings were more helpful to them as compared with fathers.

Successful Parental Coping

It is suggested in the literature that not all families function poorly, but that some families cope well with having a child with a chronic condition (Anderson, 1981; Bruhn, 1977, Longo & Bond, 1984; Phillips et al., 1985; Schulman, 1983). Gottesfeld (1979) noted that once parents have been told about their child's diagnosis, they will draw upon previous patterns of coping to manage their present situation depending upon a number of factors, such as, the severity of the illness, support systems available, and the meaning of the diagnosis to the individual. In a study of families having children with leukemia, Schulman (1983) found similar characteristics among families coping well with their situation. A history of prior good coping was a specific characteristic suggested to be an indicator of increasing the success of coping well with a new situation (Bruhn, 1977; Schulman, 1983). As well, treating the child as normal within the constraints of the chronic condition was another indicator of successful coping (Anderson, 1981; Schulman, 1983). Other characteristics of successful coping found in Schulman's study were a strong family and marital relationship, open communication, good support systems both inside and outside of the family, attitude of living in the present, and a perception of receiving quality medical care. These findings suggest that a better understanding of families' prior coping behaviors may assist health professionals with identifying those families that are suspected poor copers and high copers. As a result, appropriate early strategies and interventions may be employed to better assist these families with managing their situation.

More empirical study is required to determine what useful positive coping behaviors are employed by parents having children with other chronic conditions. The evidence reveals that variation exists between how parents cope with a healthy child versus a child with a chronic condition. Although the results from these studies are generalizable to the samples studied, the findings suggest that parents use various coping behaviors to manage the care of their children and maintain family functioning.

Parental Coping by Parents with Visually Impaired Children

No empirical studies could be found in the literature regarding coping behaviors employed by both mothers and fathers with visually impaired children. However, the literature does suggest that parents find it difficult to cope with the impact of such a diagnosis (Hancock, 1988; Miller, 1989; Murphree, Horn, Chernus-Mansfeld, 1990; Tuttle, 1986), and that it is a stressful situation (Hancock, 1988) followed by periods of transition as parents become more comfortable in caring for a child who is visually impaired (Kodadek & Haylor, 1988). With mothers who had a child 5 to 17 years of age with a visual impairment, Hancock (1988) identified that the mother's personality, the child's positive attitude, the child's accomplishments, and support networks (emotional or financial) were all factors that facilitated maternal coping. In addition, empirical research concerning the impact of having a visually impaired child and coping behaviors of both mothers and fathers to manage this situation is lacking. As previously stated, the prevalence of visually impaired children as compared with other chronic conditions is lower (Akeson, 1983; Jan & Robinsion, 1989). As a result, few health professionals have had the opportunity to obtain sufficient experience working with the visually impaired (Froyd, 1973; Jan & Robinson, 1989; Sonksen, 1983). However, with improved neonatal care, there is an increase in the number of premature infants surviving. Accompanying this increased survival, complications directly associated with prematurity are on the rise, such as the visual impairment, retinopathy of prematurity (Robinson, Jan, & Kinnis, 1987; Urrea & Rosenbaum, 1989). As a result, nurses may be encountering more of these children in a variety of health care settings. By examining the impact on parents of having a visually impaired child and the coping behaviors parents use, nurses will acquire a better understanding of their situation.

Summary of Literature Review

This literature review indicates that some commonalities exist concerning the psychological hardships, demands, and challenges families experience when faced with the diagnosis and long-term care of a child with a chronic condition. As well, individual differences are evident which can influence the impact among parents in their ability to cope with such a situation, such as characteristics of the child and the parents. In addition, the literature suggests that variations exist in the coping behaviors that mothers as compared with fathers find helpful. It is also suggested in the literature that what was once considered a major insult to the family, resulting in possible ineffectual family functioning and marital disruption, may in certain circumstances be a stressor that bonds and strengthens rather than one that weakens (Barton, 1984; Ende, 1972; Froyd, 1973; Hancock, 1988; Holaday, 1984; Marcy, 1989; Matthews, 1979; Scott et al., 1985; Thomas, 1987b; Tuttle, 1986; West, 1981). However, there still remains a dearth of information about the impact of a child's chronic condition on these families, especially concerning the resources and coping behaviors they use to manage their situation successfully, as opposed to those families who cope poorly (Patterson, 1988). There is a need to examine more families of children with chronic conditions, such as visual impairment, to determine what the impact is like among these families, and what the similarities and differences are in how these families cope.

CHAPTER III

Method

This descriptive correlational study was designed to examine, describe, and compare the relationship between the two variables: impact and parental coping behaviors with parents (including mothers and fathers from the same household) having a visually impaired child three years of age or younger. Despite the fact that these two variables have been examined with other chronic conditions (Gibson, 1984), the study design was chosen because a review of the literature revealed a lack of empirical knowledge concerning parental management of a visually impaired child. Data concerning both the parental impact when confronted with managing a visually impaired child and the coping behaviors parents may employ in this situation were examined and analyzed.

Sample

The subjects for this study were recruited from a University Pediatric Ophthalmology Clinic, private Ophthalmology offices, and a local organization for the visually impaired in a large urban centre in Western Canada. These various recruitment sites were chosen to allow the reseacher maximum accessibility to parents having children with a visual impairment who met the selection criteria and the specific definition for visual impairment. Sixty subjects (30 sets of parents) were approached to participate in the study. Fourteen subjects (7 sets of parents) refused; reasons included that one or the other spouse refused to participate, that they perceived their child's visual impairment was not a problem, or that they were already participating in other studies. A convenience sample of 46 subjects (23 sets of parents including both mothers and fathers) was obtained over a four month period who met the following selection criteria:

1. Parents (both mothers and fathers) living in the same household, who were the legal caretakers of a visually impaired child three years of age or younger. The age range of three years or younger for the visually impaired child was chosen to limit additional developmental intervening variables introduced by including older age groups. Visual impairment was not necessarily the child's only health problem. It has been estimated that approximately 50% of visually impaired children have additional medical impairments (Robinson et al., 1987). Single parent families were not included because the researcher was primarily interested in comparing parental responses between mothers and fathers within the same family and as a group.

2. Parents (both mothers and fathers) who agreed to participate at the same time were included in the study.

3. Parents (both mothers and fathers) were able to read and speak English.

4. Parents (both mothers and fathers) resided within a 25 mile radius of the city limits of the major urban centre.

All subjects for the study were obtained as follows. First, the Pediatric Ophthalmologists, Orthoptist, and Social Worker who had agreed to assist with the study, approached subjects in the clinic setting who met the selection criteria and gave them a copy of a brief letter that explained the study and their individual role(s) (Appendix C). This letter assured the researcher that similar information was being given to each subject at the beginning of the study. Subjects who were not approached in the clinic setting, but contacted by telephone by the Pediatric Ophthalmologists, Orthoptist, and Social Worker had the brief letter read to them. Second, subjects who verbally expressed interest in the study were asked if their name(s) could be forwarded to the researcher for further explanation of the study and possible enrollment. For those that agreed to be contacted for consideration in the study, the Pediatric Ophthalmologists, Orthoptist, and Social Worker then recorded in a log book the date, name, address, telephone number of the potential subjects, and their child's visual diagnosis. Third, the researcher contacted the subjects by telephone to explain the study in further detail and discuss their participation. The subjects who verbally agreed to participate in the study were visited by the researcher in their home at a mutually convenient time. In the subject's home, an explanation of the study was repeated followed by both the mother and father signing a written informed consent (Appendix D).

Setting

Studies using instruments to be completed in clinics or office settings reveal a tendency for a higher participation rate by mothers as compared with fathers (McCubbin, 1987). Therefore, the setting for this study was the subject's home rather than the clinic or office, as it facilitated easier participation by both mothers and fathers. All but one set of parents completed the questionnaires in the home. This set of parents completed the questionnaires in an ophthalmology office.

Data Collection

A total of 22 home visits and one office visit were conducted at a specific time and date that was convenient with both the researcher and subjects. The researcher gave verbal pre-determined instructions about the questionnaires and background information form that each subject was to complete (Appendix E). Both mothers and fathers individually completed the questionnaires and background information form. They were strongly encouraged to complete the questionnaires independently of one another, but were allowed to openly confer about the background information form. An envelope containing the two questionnaires, the Impact on Family Scale, the CHIP questionnaire, and the background information form were given by the researcher to each subject. During the completion of the two questionnaires and background information form, the researcher remained in the subjects' home to ensure that each subject completed the questionnaires independently of one another and to answer any questions. Once the subjects had completed the questionnaires and the background information form, they were returned to the researcher. The subjects took from 15 minutes to 1 hour to complete the questionnaires and the background information form.

Instruments

Two self-report instruments, the Impact on Family Scale, and the Coping Health Inventory for Parents were used to collect data on the two main variables: impact and parental coping behaviors (Appendix A & B). Permission to use the Impact on Family Scale was obtained (R.E.K. Stein, personal communication, July 17, 1989) and the CHIP instrument (H.I. McCubbin, personal communication, August 2, 1989). Biographical information about each subject and their child(ren) was also collected to assist with identifying specific characteristics of the sample (Appendix F).

Impact on Family Scale

The Impact on Family Scale is a 33 item Likert Scale self-report instrument, designed to measure the effects of a child's chronic condition on the family (Stein & Riessman, 1980; Stein & Jessop, 1985). Stein and Riessman (1980) were interested in developing a formal measure for quantifying the variable, impact. Initially, they theorized that the four dimensions of strain, economic burden, familial impact and social impact were relevant to examining the variable, impact. From these theorized dimensions, items were developed for the instrument based upon a review of the literature concerning families with chronically ill children, qualitative interviews with families having chronically ill children, clinical experience of the senior author (Stein), and interviews with health care workers experienced in caring for chronically ill children and their families. Items for the scale were reviewed by consultants and then redefined by factor analysis. The initial scale consisted of a 24 item Likert scale based upon a population of 100 inner city mothers of a lower social class and their children with chronic physical health problems. Further analyses and refinement of the scale was done on their entire Pediatric Ambulatory Care Treatment Study (PACTS) sample of 209 subjects. Stein and Jessop (1985) state that this scale has since been used for various studies with other populations which has increased their confidence that it is a reliable and valid measure. However, they state that the scale has also been used in still other populations, and at this time they cannot guarantee the properties of the tool with these populations because they have not analyzed these findings for their reliability or validity (R.E.K Stein, personal communication, July 17, 1989).

This instrument factors into four subscale scores that measure different dimensions of impact: General Negative Impact, Disruption of Social Relations, Coping-Positive, and Financial Support. In addition, there is a score that reveals an overall measure of impact, labelled Total Impact and a score for Sibling Impact. A description of the items for each dimension on the scale will now be outlined. General Negative Impact, consists of 10 items such as "Because of the illness, we are not able to travel out of the city." The Disruption of Social Relations dimension, consists of 9 items such as "People in the neighbourhood treat us as special because of my child's illness." The Coping-Positive dimension, consists of 4 items such as "Because of what we have shared we are a closer family." The Financial Support dimension, consists of 3 items such as "Additional income is needed in order to cover medical expenses." The Total Impact score consists of 19 items that include various items from the four subscale scores. The Sibling Impact dimension consists of 6 items such as "There is fighting between the children because of my child's special needs." The items in all of the dimensions stated above excluding the Coping-Positive dimension, ascribe to the negative effects on family life, whereas, the Coping-Positive dimension ascribes to the positive effects that may emerge from having a child with a chronic condition.

<u>Scoring of the Impact on Family Scale</u>. The subjects were asked to choose using a 4-point Likert scale where (1) equals <u>strongly agree</u>, (2) equals <u>agree</u>, (3) equals <u>disagree</u>, and (4) equals <u>strongly disagree</u>, their level of agreement or disagreement with the statement as it pertained to their present family situation. Scores were computed for each of the five dimensions, in addition a Total Impact score was

derived. Scoring guidelines were provided by the instrument developers outlining how to recode missing data to the modal category on that item and recoding various subscale items to the opposite direction (Stein & Jessop, 1985). The General Negative Impact, Disruption of Social Relations, Financial Support, Sibling Impact subscales, and the Total Impact scores generally reveal that high scores imply high impact and low scores represent low impact. The Coping-Positive Impact score reveals that high scores imply an inability to cope well and low scores represent an ability to cope well. Higher Total Impact scores are associated with, for example, low family income, low education, lack of social support, absence of a mother/father headed household, and poor functioning on the part of the child.

Reliability and Validity of the Impact on Family Scale. The five subscale scores and the Total Impact score have reported internal consistency reliabilities (Stein & Reissman, 1980; Stein & Jessop, 1985). Cronbach alpha coefficients have been calculated for ethnic and language subgroups. The Cronbach alpha coefficients for the non-hispanic English group are: general negative impact, .81; disruption of social relations, .80; coping-positive, .70; financial support, .66; sibling impact, .84; and total impact, .86 (Stein & Jessop, 1985). Internal consistency reliability was chosen over test-retest reliability to decrease the subjects' hardship in completing the questionnaire more than once (Stein & Jessop, 1980). The instrument has reported face and content validity on the test items (Stein & Reissman, 1980) and construct validity for the total Impact on Family Scale (Stein & Jessop, 1985).

Coping-Health Inventory for Parents (CHIP)

The Coping-Health Inventory for Parents is a 45 item Likert Scale self-report instrument, designed to assess parents' perceptions of behaviors that they presently use to manage family life when they have a family member who has a medical condition requiring ongoing medical care or is ill for a short period (McCubbin & Thompson, 1987). The instrument was developed from extensive studies of family responses to stress, family stress theory, social support theory, family health care support, and theories of the individual psychology of coping (McCubbin, 1987). Since the instruments' development, it has been used by numerous health care and behavioral researchers on subjects with a family member having a variety of chronic illnesses and/or debilitating conditions (McCubbin, 1987).

A hierarchical approach to the organization of behavior influenced the development of the CHIP instrument. As a result, two general levels of coping were derived, which are, (a) coping behaviors as derived from each item on the instrument, and (b) three coping patterns which are a composite of specific coping behaviors. The CHIP instrument originally had 80 items, but further factor analyses and refinement of the instrument was completed on a sample of 185 parents (90 fathers and 95 mothers) of children with cystic fibrosis, resulting in 45 items (McCubbin, 1987).

The instrument consists of specific coping behavior items that focus on such areas as family life and relationships with a chronically ill child, efforts by parents to develop relationships with other parents having a chronically ill child, and establishing relationships with health care professionals. These coping behavior items are categorized into three coping patterns with individual coping scores. A description of the items for the three Coping Patterns follows. Coping Pattern I, labelled as Family Integration, Co-operation and an Optimistic Definition of the Situation, consists of 19 coping behaviors, such as "Believing that my child(ren) will get better." Coping Pattern II, labelled as Maintaining Social Support, Self Esteem and Psychological Stability, consists of 18 items, such as "Becoming more self-reliant and independent." Coping Pattern III, labelled as Understanding the Health Care Situation Through Communication with Other Parents and Consultation with the Health Care Team, consists of 8 behaviors, such as "Reading more about the medical problem which concerns me."

Scoring of the CHIP Instrument. A 4-point Likert scale is used where (0) equals not helpful, (1) equals minimally helpful, (2) equals moderately helpful, and (3) equals extremely helpful. In addition, for each coping behavior that subjects do not use, in a column labelled, I do not cope this way because, the subjects could give their reason by choosing a response of (a) chose not to use it, or (b) not possible. The subjects were asked to choose (on a scale from 0 to 3) the helpfulness of the coping behavior in managing their present family situation. Scores for the CHIP instrument were computed for each of the three coping patterns by means of an unweighted summing of the scores. Scoring guidelines were provided by the instrument developers (McCubbin, 1987). The three coping pattern scores were analyzed separately for mothers and fathers by comparing them to normative data based upon a sample of 308 parents who have a chronically ill child with cerebral palsy or cystic fibrosis and a Profile of Mother's and Father's Coping Patterns with established normal ranges. Higher scores generally imply that a mother or father possess coping behaviors to manage the situation of having a chronically ill child. Lower scores may signify that a mother or father is not managing very well and that assistance may be required.

Reliability and Validity of CHIP. The three coping patterns of the CHIP questionnaire have reported internal consistency. The Cronbach alpha coefficients for Coping Patterns I, II, and III, are .79, .79. and .71, respectively (McCubbin, 1987). The CHIP questionnaire's content validity is based upon extensive and critical review of social support theory, studies of family responses to stress, family stress theory, theories of the individual psychology of coping, and family health care support (McCubbin, 1987). Concurrent validity has been performed using the CHIP questionnaire with two indices of the health status of cystic fibrosis children (pulmonary functioning index and height/weight index) and the Family Environment Scale, revealing positive correlations which further supports the CHIP questionnaire measurement (McCubbin, 1987). In addition, discriminant analysis between low and high conflict families with a child having cerebral palsy revealed that both mothers and fathers used all three coping patterns in high conflict situations. This suggests that families with higher stress levels actively manage their situation.

Background Information Form

A background information form was used to collect data concerning the biographical and demographic characteristics of the sample, such as age, socioeconomic status, and age of child at time of diagnosis (Appendix F). Anecdotal information, such as whether the child with the visual impairment had one or both eyes affected, was also recorded by the researcher after leaving the subject's home, to assist with planning for future research in this area and data analysis (Tornquist, 1986).

Data Analysis

Descriptive statistics using frequency tables outlining percentages, means and standard deviations describe and summarize relevant biographical and demographic characteristics of the sample (including mothers and fathers in the sample and their children), and responses to the two questionnaires. The Sibling Impact I subscale on the Impact on Family scale, was divided by the researcher into two groups, labelled as Sibling Impact I and Sibling Impact II for further indepth analysis. Sibling Impact I subscale referred to parents with other children older than 4 years of age. Sibling Impact II referred to parents with other children younger than 4 years of age.

The mean scores for the two groups of mothers and fathers on both of the instruments' subscales were compared using the paired t-test. To determine whether relationships existed between the Impact on Family and CHIP subscales, correlational analysis was performed with the Pearson Product Moment Correlation Coefficient (r) statistic. Contingency tables were used to compare the total responses between mothers and fathers on each of the instruments' subscales. To determine whether there was a difference between the mothers and fathers concerning the coping pattern scores and the impact scores in these contingency tables, chi-square analysis using Yates Correction for Continuity was performed. Multiple regression was performed using the individual subscale scores as the dependent variable with the introduction of the biographical and demographic data as independent variables. To test the internal consistency reliability of the two instruments' subscales, Cronbach alpha coefficients are reported. Correlational analysis using the Pearson Product Moment Correlation Coefficient (r) statistic was used to determine how scores on the instruments correlated with each other to support concurrent validity of the measures.

Protection of Rights of Human Subjects

The researcher received ethical approval from the University of Alberta, Faculty of Nursing Ethics Review Committee, the University of Alberta Hospital's Nursing Ethics Committee, and the University of Alberta Hospital's Special Services and Research Committee. Written approval was obtained from the Chairman, Department of Ophthalmology and the Pediatric Ophthalmologists involved in the study to access subjects (Appendix G). Subjects who agreed to participate voluntarily were informed about the details of the study, the purpose, benefits of the study and any forseeable risks. Each subject signed a written informed consent and was given a copy for their records (Appendix D). All subjects were informed that their participation in the study was voluntary, that they had the right to withdraw from the study at any time and that withdrawal from the study would not influence the care they or their child received. The identity of the subjects was known only to the researcher. All questionnaires and the background information form were coded to ensure anonymity.

The subjects' names, addresses, and telephone numbers will be destroyed when the final report is completed. A summary of the study findings will be sent to the subjects who participated in the study. If any subjects became uncomfortable and unable to cope during a home visit or family dysfunction was identified, the researcher was to seek permission to refer them back to their Ophthalmologist. None of the subjects required this type of intervention.

CHAPTER IV

Findings

In this chapter, the findings from the data analysis that were performed, will be described, focusing on the research questions to be answered. The study's purpose was to determine what the relationship was between the impact of having a child who is visually impaired and the coping behaviors among the parents of these visually impaired children. In addition, factors that may influence the impact of having a child with a visual impairment, as well as the parental coping behaviors used, were examined. First, descriptive statistics will be used to describe the characteristics of the sample (including mothers, fathers, and their children). Second, the percentages of agreement for mothers and fathers to individual items on the Impact on Family and CHIP scales will be described. Third, to determine if there were any significant differences between mothers and fathers on the Impact on Family and CHIP subscale scores, the $\underline{t}$-test statistic is reported. Fourth, to detect further meaningful differences in the total responses for the Impact on Family and CHIP subscale scores between mothers and fathers separated into specified groups, contingency tables and the chi-square statistic is reported. Fifth, the Pearson Product Moment Correlation Coefficient ($\underline{r}$) statistic is used to describe the relationships between the Impact on Family and CHIP subscales for mothers and fathers. Sixth, to determine the predictor variables of impact, as measured by the Impact on Family, and coping behaviors, as measured by the CHIP scale, multiple regression analysis is described. In conclusion, the internal consistency reliability and concurrent validity of the Impact on Family and CHIP scales is reported.

Characteristics of the Sample

The results of this study were based upon a convenience sample of 23 sets of parents (23 mothers and 23 fathers). In Table 1 the characteristics of the mothers and fathers in the sample are presented. Mothers ranged in age from 24 to 38 years with a mean of 31.78 years, and fathers ranged in age from 25 to 49 years with a mean of 33.48. Educational preparation varied for both mothers and fathers from some high school education to a university or college degree. Sixty-five percent of the mothers and 70% of the fathers had less than a university or college degree. At the time of completing the questionnaires, 48% of the mothers and 100% of the fathers were employed. Sixty-nine percent of mothers and 43% of fathers found their religion a source of support for coping with their visually impaired child.

In Table 2 the demographic characteristics of the parents in the sample are presented. The annual gross combined family income ranged from between $20,000 to greater than $100,000, with 22% reporting an income of under $39,999. The number of children in the family ranged from one to three children with 78% of the parents having more than one child. There was no specific birth order for the visually impaired child within these families, with approximately one third of the sample being their first, second, or third child. Nine percent of the parents had other children with either a visual impairment only or a medical problem only. The time period of parents living with their child who is visually impaired since the time of the diagnosis, ranged from 2 to 42 months, with a mean of 16.8 months.

In Table 3 the characteristics of the children who were visually impaired are presented. The sample consisted of 23 children (3 years of age or younger) who were visually impaired. The childrens' age at the time of diagnosis ranged from birth to 10 months with a mean of 3.65 months. Almost half of the sample of visually impaired children were female (52.2%) and half male (47.8%). Twenty-two percent of the children who were visually impaired had additional medical problems. In 65% of the children the visual impairment was present in both eyes. In Table 4 the types of visual impairments found in these children are summarized.

Table 1

Characteristics of Mothers and Fathers in the Sample

Variables	Mothers (n = 23)	%	Fathers (n = 23)	%
AGE: (Mean in years)	31.78		33.48	
EDUCATION				
University or College Degree	8	34.8	7	30.4
Some University or College Education	8	34.8	6	26.1
High School Graduate	5	21.7	9	39.1
Some High School Education	2	8.7	1	4.3
EMPLOYMENT				
Employed	11	47.8	23	100.0
Unemployed	12	52.2	0	0.0
RELIGION - SUPPORT				
Yes	16	69.6	10	43.5
No	4	17.4	5	21.7
Not Applicable	3	13.0	8	34.8

Table 2

Demographic Characteristics of Parents in the Sample

Variables		Parents (n = 23 couples)	%
Family Income (Combined)	$ 20,000 - $ 29,999	2	8.7
	$ 30,000 - $ 39,999	3	13.0
	$ 40,000 - $ 49,999	7	30.4
	$ 50,000 - $ 99,999	10	43.5
	$ 100,000 or more	1	4.3
Number of Children in Family	1 Child	5	21.7
	2 Children	11	47.8
	3 Children	7	30.4
Birth Order of Visually Impaired Child	First Child	8	34.8
	Second Child	8	34.8
	Third Child	7	30.4
Other Children in Family With -	Visual Impairment Only	1	4.3
	Visual and Medical Problem	0	0.0
	Medical Problem Only	1	4.3
	Not Applicable	21	91.3
Time Period Living with Visually Impaired Child (Months)	M	16.8	

Note: Visually Impaired Child refers to 3 years of age or younger.

Table 3

Characteristics of Children in the Sample

		Children (n = 23)	%
Mean Age of Child at Time of Diagnosis (Months of Age)		3.65	
Sex of Visually Impaired Child	Male	11	47.8
	Female	12	52.2
Visual Impairment Only		18	78.3
Visual Impairment and Medical Problem		5	21.7
Unilateral Eye Disease		8	34.8
Bilateral Eye Disease		15	65.2

Medical Problem	Children (n = 5)
Central Neurologic Disorders	3
Cleft Palate / Heart Disorder	1
Genitalia Disorder	1

Note: Visually Impaired Child refers to 3 years of age or younger.

Table 4

Summary of the Childhood Visual Impairments

Visual Impairment	Children ($\underline{n}$ = 23)	%
Cataracts	6	26.1
Glaucoma	2	8.7
Persistent Hyperplastic Primary Vitreous (PHPV)	3	13.0
Retinopathy of Prematurity (ROP)	1	4.3
Hereditary Retinal Degenerations	3	13.0
Albinism	3	13.0
Anophthalmia	2	8.7
Optic Nerve Atrophy / Hypoplasia	2	8.7
Cortical Blindness	1	4.3

Mothers' and Fathers' Agreement to Individual Items on the Impact on Family Scale

To determine the impact upon parents of having a child who is visually impaired, individual items on the Impact on Family scale were examined for both mothers and fathers. The Impact on Family Scale is a 33 item Likert Scale self-report instrument, designed to measure the effects of a child's chronic condition on the family (Stein & Riessman, 1980; Stein & Jessop, 1985). This instrument factors into four subscale scores that measure different dimensions of impact: General Negative Impact, Disruption of Social Relations, Coping-Positive, and Financial Support. In addition, there is a score that reveals an overall measure of impact, labelled Total Impact, as well as a score for Sibling Impact. The percentages of agreement with individual statements on the Impact on Family Scale for 27 of the statements for mothers and fathers are presented in Table 5. The percentages have been described in descending order for the mothers and then compared with the fathers. The percentages of agreement were computed using the total responses of strongly agree and agree, on the individual statements. The statements that applied to Sibling Impact I and Sibling Impact II subscales were excluded from this particular analysis due to the small sample size, where 12 families had other children older than 4 years of age and 6 families had other children younger than 4 years.

The mothers in this sample revealed a high level of positive coping with their child who is visually impaired. This was indicated by the high level of agreement among mothers' responses concerning the four items comprising the Coping-Positive subscale score, which measures the families' ability to master the stress of the condition. There was 100% agreement by all mothers for discussing their child's problem with their partner, and also trying to treat their child as if he/she was normal. In addition, 87% of the mothers reported that because of the experience of having a child who is visually impaired they were closer as a family, and also 83% indicated that learning to manage their child's condition had made them feel better about themselves.

It is important to note when comparing the mothers' responses with fathers', fathers' also rated the coping items as being very helpful in dealing with the impact of having a child who is visually impaired. Although not every father totally strongly agreed or agreed with all of the coping statements, the percentages of agreement ranged from 83% to 96%. The level of agreement between mothers and fathers concerning the coping statements indicated very little discrepancy between the two groups, revealing that the majority were coping positively with the experience of having a child who is visually impaired.

Statements related to the subscale measuring General Negative Impact, concerned with the psychological burden of the condition, revealed that both mothers and fathers had differences that were marginal, while others were more pronounced. Ninety-one percent of mothers and 96% of fathers generally agreed that relatives have been understanding and helpful with their child who is visually impaired and did not report this as a negative impact. However, over half of the mothers (65%) and fathers (57%) felt they lived on a roller coaster, depending upon the acuity and stability of their child's visual impairment status. Larger differences were noted between mothers and fathers about having more children and planning for the future. Eighty-three percent of mothers reported thinking about not having more children because of their child's visual impairment as compared with 57% of fathers. Thirty percent of mothers said that they lived day to day without planning for the future as compared with 7% of fathers. Fatigue was reported by 35% of mothers as being a problem because of their child's visual impairment, as compared with 22% of the fathers. Ninety-six percent of the mothers and 100% of fathers reported that travelling out of the city with their child who is visually impaired was not a major negative impact.

The subscale measuring Disruption of Social Relations Impact, concerned with how mothers and fathers interact with their family members and others outside the family, indicated that parents were influenced both positively and negatively by caring for their child who is visually impaired. Approximately half of the sample of mothers (52%) and less than half of the fathers (43%) contemplated the idea of whether their child who is visually impaired should be treated as special or as a normal child. However, there was strong agreement by 100% of the mothers and 91% of the fathers that they try to treat their child as if he or she was normal. In reference to these families' desire to go out and and spend time with their other children, less than a third of mothers and approximately a fourth of the fathers were negatively affected. In addition, only a quarter of the sample of mothers and fathers reported that they were seeing friends and family less because of their child's condition. Mothers and fathers differed in agreement concerning the family giving up things because of their child's condition, with 60% of fathers and 76% of the mothers not being negatively affected.

The subscale measuring Financial Impact is concerned with the economic consequences for the family having a child with a chronic condition. With families having a child who is visually impaired the financial impact scale revealed low impact. Eighty-three percent of both mothers and fathers reported that their child's visual impairment was not causing financial problems for the family. However, 30% of mothers as compared with 22% of the fathers stated that additional income was required to cover some of the medical expenses. The statement concerning employment outside of the home, negatively affected a quarter of the mothers as compared to fathers. Twenty-six percent of mothers reported they stopped working because of their child's visual impairment as compared to 0% of the fathers. In addition, over one-third of the mothers cut down the hours they worked outside the home to care for their child as compared to 9% of the fathers.

Table 5

Percentages of Agreement for Mothers and Fathers' Responses to the Impact on Family Scale

Impact Statement # of items = 27	Mothers (n = 23) (Strongly Agree & Agree)	Fathers (n = 23) (Strongly Agree & Agree)
My partner and I discuss my child's problems together.	100.0 %	91.3 %
We try to treat my child as if he/she were a normal child.	100.0 %	95.7 %
My relatives have been understanding and helpful with my child.	91.3 %	95.7 %
Because of what we have shared we are a closer family.	87.0 %	82.6 %
Learning to manage my child's illness has made me feel better about myself.	83.0 %	82.6 %
I think about not having more children because of the illness.	82.6 %	56.5 %
I worry about what will happen to my child in the future (when he/she grows up, when I am not around).	73.9 %	60.8 %
Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable.	65.2 %	56.5 %
Sometimes I wonder whether my child should be treated "specially" or the same as a normal child.	52.1 %	43.4 %
Time is lost from work because of hospital appointments.	39.1 %	43.5 %
I am cutting down the hours I work to care for my child.	39.1 %	8.7 %
It is hard to find a reliable person to take care of my child.	39.1 %	52.2 %
Fatigue is a problem for me because of my child's illness.	34.8 %	21.7 %
Nobody understands the burden I carry.	34.8 %	26.0 %
Traveling to the hospital is a strain for me.	34.7 %	26.0 %
Additional income is needed in order to cover medical expenses.	30.4 %	21.7 %

Table 5 - Continued

Percentages of Agreement for Mothers' and Fathers' Responses to the Impact on Family Scale

Impact Statement # of items = 27	Mothers (n = 23) (Strongly Agree & Agree)	Fathers (n = 23)
We have little desire to go out because of my child's illness.	30.4 %	21.7 %
I don't have much time left over for other family members after caring for my child.	30.4 %	21.7 %
I live day to day and don't plan for the future.	30.4 %	8.6 %
I stopped working because of my child's illness.	26.1 %	0.0 %
People in the neighborhood treat us specially because of my child's illness.	26.0 %	21.7 %
Relatives interfere and think they know what's best for my child.	26.0 %	21.7 %
Our family gives up things because of my child's illness.	26.0 %	39.1 %
We see family and friends less because of the illness.	21.7 %	17.4 %
The illness is causing financial problems for the family.	17.4 %	17.3 %
Sometimes we have to change plans about going out at the last minute because of my child's state.	17.4 %	17.4 %
Because of the illness, we are not able to travel out of the city.	4.3 %	0.0 %

Mothers' and Fathers' Agreement to Individual Items on the CHIP Scale

To determine the coping behaviors parents use with a child who is visually impaired, individual items on the CHIP scale were examined for both mothers and fathers. The Coping-Health Inventory for Parents is a 45 item Likert Scale self-report instrument, designed to assess parents' perceptions of behaviors that they presently use to manage family life when they have a family member who has a medical condition requiring ongoing medical care or is ill for a short period (McCubbin & Thompson, 1987). The instrument consists of specific coping behavior items that focus on such areas as family life and relationships with a chronically ill child, efforts by parents to develop relationships with other parents having a chronically ill child, and establishing relationships with health care professionals. These coping behavior items are categorized into three coping patterns with individual coping scores. The percentages of agreement with individual statements on the CHIP subscales for mothers and fathers are presented in Table 6. The percentages have been described in descending order for the mothers and then compared with the fathers. The percentages of agreement were computed using the total responses of extremely helpful and moderately helpful on the individual statements.

The first subscale, Coping Pattern I, comprised of coping behaviors dealing with integration, cooperation, and optimism, revealed notable differences between mothers and fathers concerning their belief in their child's medical care, belief in God, and care of medical equipment at home. The majority of mothers (96%) believed that their child was getting the best medical care possible as compared with 74% of fathers. The coping behavior of believing in God was not used by 26% of mothers as compared with 56% of fathers. Lastly, taking care of all medical equipment at home was reported to be used more frequently by mothers (61%) as compared to fathers (30%).

Believing that things will always work out was a coping behavior used by the majority of fathers (96%) and by most mothers (87%). The remaining coping behaviors reported similar agreement between mothers and fathers. The most important coping behaviors in this subscale centered around their own immediate family, for example, trusting their spouse to help support them and their child(ren), doing things with their children, and building a strong relationship with their spouse.

Coping Pattern II is comprised of coping behaviors dealing with support, esteem, and stability. Mothers and fathers choices of coping behaviors that they used to help them cope with their situation revealed differences. Generally, mothers more so than fathers reported that taking care of themselves and allowing their feelings to be shared and expressed were more useful to them. Mothers reported that developing themselves as a person and becoming more independent and self-reliant (83%) were useful as opposed to fathers who reported that being able to get away from responsibilities and home care tasks for some relief was most useful (83%). In addition, 61% of fathers reported that going out with their spouse on a regular basis was useful as opposed to 40% of the mothers. Seventy-four percent of mothers reported that talking to non-professionals about how they felt was useful as compared with 48% of fathers. However, there was 50% agreement between mother and fathers concerning coping behaviors reported as being of less importance, such as involvement with people and activities outside of their own family.

The last subscale, Coping Pattern III, comprised of statements dealing with medical communication and consultation, revealed that mothers reported using more of these coping behaviors as opposed to fathers. Mothers reported that talking to others, including both professional and non-professional individuals was more helpful than to fathers. However, there was strong agreement between mothers (87%) and fathers (83%) that talking with a variety of professional staff (nurses, social workers, etcetera) about their child's visual impairment was useful. Ninety-one percent of mothers reported that reading about their child's medical problem was useful as compared with 65% of fathers.

Table 6

Percentages of Agreement for Mothers' and Fathers' Responses to the CHIP Scale

Coping Behavior Statement # of items = 45	Mothers (n = 23)	Fathers (n = 23)
	(Extremely Helpful & Moderately Helpful)	
Coping Pattern I		
Believing that my child is getting the best medical care possible.	95.7 %	73.9 %
Trusting my spouse (or former spouse) to help support me and my child(ren).	91.3 %	87.0 %
Doing things with my children.	91.3 %	86.9 %
Believing that things will always work out.	87.0 %	95.6 %
Building a closer relationship with my spouse.	86.9 %	87.0 %
Talking over personal feelings and concerns with spouse.	86.9 %	86.9 %
Believing that the medical center/hospital has my family's best interest in mind.	82.6 %	82.6 %
Believing that my child(ren) will get better.	78.3 %	73.9 %
Telling myself that I have many things I should be thankful for.	78.3 %	73.9 %
Doing things together as a family (involving all members of the family).	78.2 %	78.2 %
Investing myself in my child(ren).	78.2 %	78.2 %
Having my child with the medical condition seen at the clinic/hospital on a regular basis.	78.2 %	65.2 %
Believing in God.	73.9 %	43.5 %
Showing that I am strong.	69.6 %	60.8 %
Trying to maintain family stability.	69.5 %	73.9 %
Taking good care of all the medical equipment at home.	60.8 %	30.4 %

Table 6 - Continued

Percentages of Agreement for Mothers' and Fathers' Responses to the CHIP Scale

Coping Behavior Statement # of items = 45	Mothers (n = 23)	Fathers (n = 23)
	(Extremely Helpful & Moderately Helpful)	
Getting other members of the family to help with chores and tasks at home.	60.8 %	47.8 %
Encouraging child(ren) with medical condition to be more independent.	56.5 %	47.8 %
Doing things with family relatives.	52.2 %	65.2 %
Coping Pattern II		
Develop myself as a person.	82.6 %	73.9 %
Becoming more self reliant and independent.	82.6 %	56.5 %
Keeping myself in shape and well groomed.	73.9 %	65.2 %
Talking to someone (not professional counselor/ doctor) about how I feel.	73.9 %	47.8 %
Being able to get away from the home care tasks and responsibilities for some relief.	69.6 %	82.6 %
Engaging in relationships and friendships which help me to feel important and appreciated.	60.9 %	47.8 %
Sleeping.	56.5 %	39.1 %
Working, outside employment.	52.2 %	56.5 %
Getting away by myself.	52.2 %	56.5 %
Building close relationships with people.	52.1 %	56.5 %
Concentrating on hobbies (art, music, jogging, etc.)	43.5 %	56.5 %
Allowing myself to get angry.	43.5 %	26.1 %
Investing time and energy in my job.	43.4 %	47.8 %
Entertaining friends in our home.	39.1 %	43.4 %

Table 6 - Continued

Percentages of Agreement for Mothers' and Fathers' Responses to the CHIP Scale

Coping Behavior Statement # of items = 45	Mothers (n = 23) (Extremely Helpful & Moderately Helpful)	Fathers (n = 23) (Extremely Helpful & Moderately Helpful)
Involvement in social activities (parties, etc.) with friends.	39.1 %	34.7 %
Going out with my spouse on a regular basis.	39.1 %	60.8 %
Eating.	26.1 %	26.1 %
Purchasing gifts for myself and/or other family members.	21.7 %	30.4 %
Coping Pattern III		
Reading more about the medical problem which concerns me.	91.3 %	65.2 %
Talking with the medical staff (nurses, social workers, etc.) when we visit the medical center.	86.9 %	82.6 %
Talking with the Doctor about my concerns about my child(ren) with the medical condition.	86.9 %	69.6 %
Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.	78.3 %	43.4 %
Talking with other parents in the same type of situation and learning about their experiences.	78.2 %	60.9 %
Talking with other individuals/parents in my same situation.	73.9 %	47.8 %
Explaining our family situation to friends and neighbors so they will understand us.	73.9 %	43.4 %
Reading about how other persons in my situation handle things.	69.6 %	34.7 %

Mothers' and Fathers' Impact of Having a Visually Impaired Child and Coping Behaviors

After examining spousal agreement to individual items on the Impact on Family and CHIP scales, further analysis was done to determine the similarities and differences in the impact between mothers' and fathers' with a visually impaired child and coping behaviors. Means and standard deviations are used to describe and summarize the Impact on Family and CHIP subscale scores between mothers and fathers. A paired *t*-test was carried out to determine if there were any significant differences between mothers and fathers on the Impact on Family and CHIP subscale scores. In addition, to determine other factors that may have influenced the impact between mothers and fathers with a visually impaired child and coping behaviors, means and standard deviations are reported for visually impaired children having one or two affected eyes, children having medical problems and/or visual impairments, birth order of a visually impaired child, and length of time since the diagnosis of a visually impaired child.

Impact on Family Subscale Scores for Mothers and Fathers

The means, standard deviations, and the *t*-values for the Impact on Family subscales for mothers and fathers are presented in Table 7. It is important to note that the statistics presented in Table 7 concerning the Impact on Sibling Subscale I are based upon a sample of 12 mothers and fathers and the Impact on Sibling Subscale II are based upon 6 mothers and 6 fathers. This division is important to acknowledge so that interpretation of the Sibling Impact results, comparing them with previous impact scale values will be meaningful. The Impact on Sibling I subscale examines families that have other children 4 years of age or older. Whereas the Impact on Sibling II subscale examines families that have other children, none of whom are 4 years of age or older. Five of the parents did not have any other children and therefore the Impact on Sibling score was not meaningful.

As seen in Table 7, the means for the Impact on Family subscales were slightly higher for the mothers as compared with fathers on the Total Impact, General Negative Impact, Disruption of Social Relations, Financial Impact, and Impact on Siblings I. However, the differences in means between mothers and fathers respectively, on the Financial Impact (M = 5.87, M = 5.69) and Impact on Siblings I (M = 13.00, M = 12.83) were negligible. The difference [illegible] on the Coping subscale was slightly lower for mothers (M = 6.39) as compared with fathers (M = 6.69), but again the difference was negligible. Fathers scored slightly higher on the Impact on Siblings II (M =23.83) subscale as compared with mothers (M = 24.66). A schematic representation comparing the mean scores between mothers and fathers for the Impact on Family subscales is presented in Figure 1. The reported means of all of the subscales for both mothers and fathers are lower as compared with previous impact values obtained with a Non-Hispanic English speaking sample. A paired t-test was performed to determine if there were any significant differences between mothers' and fathers' on all of the Impact on Family subscale scores (Table 7). Total Impact, which is the overall measure of impact on the Impact on Family scale, was the only subscale in which there was a significant difference between mothers and fathers (t (22) = -2.21, p = .037).

Table 7

Means, Standard Deviations, and t-Values for the Impact on Family Subscales

Score	# of items	Mothers	Fathers	Previous Impact Scale Values	*t*-Value
TOTAL IMPACT	19				
M		42.95	39.00	46.20	-2.21 *
SD		8.88	9.91	7.60	
n		(23)	(23)	(74)	
Range = 19 - 76					
GENERAL NEGATIVE (I)	10				
M		21.28	19.39	24.40	-1.97
SD		5.29	4.56	4.40	
n		(23)	(23)	(74)	
Range = 10 - 40					
DISRUPTION OF SOCIAL RELATIONS (II)	9				
M		19.43	17.91	19.90	-1.70
SD		4.20	4.47	3.80	
n		(23)	(23)	(74)	
Range = 9 - 36					
COPING (III)	4				
M		6.39	6.69	7.80	.91
SD		2.01	1.86	1.50	
n		(23)	(23)	(74)	
Range = 4 - 16					
FINANCIAL IMPACT (IV)	3				
M		5.87	5.69	7.60	-0.43
SD		1.93	2.05	1.90	
n		(23)	(23)	(74)	
Range = 3 - 12					

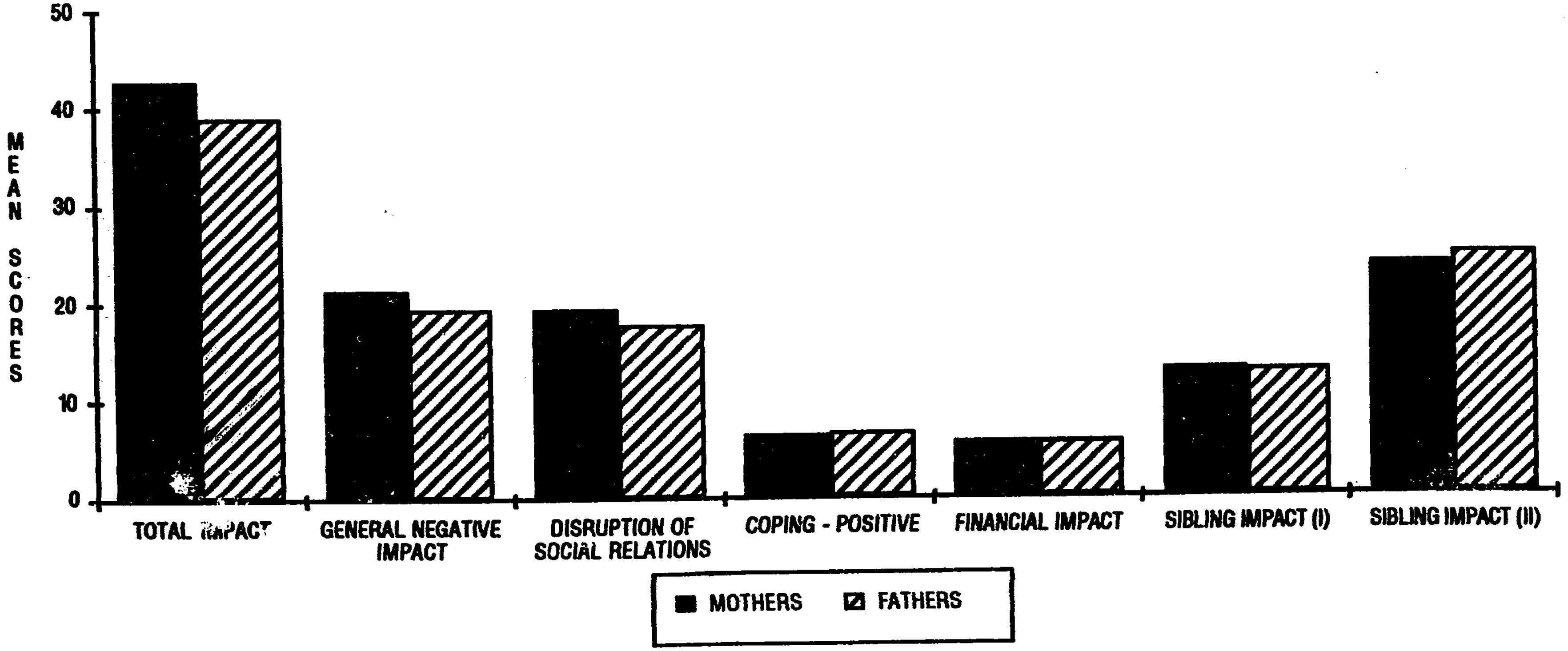
Table 7 (Continued)

Means, Standard Deviations, and t-Values for the Impact on Family Subscales

Score	# of items	Mothers	Fathers	Previous Impact Scale Values	*t*-Value
IMPACT ON SIBLINGS (I)	6				
M		13.00	12.83	13.10	
SD		3.49	3.81	2.80	-0.14
n		(12)	(12)	(40)	
Range = 6 - 19					
IMPACT ON SIBLINGS (II)	6				
M		23.83	24.66		
SD		1.47	1.50	N/A	1.54
n		(6)	(6)		(6)
Range = 22 - 26					

* $p < .05$, two-tailed

Figure 1. Comparison of mean scores between mothers and fathers for Impact on Family subscales.



CHIP Subscale Scores for Mothers and Fathers

The means, standard deviations, and the t-values for the CHIP subscales for mothers and fathers are presented in Table 8. The means and standard deviations for mothers and fathers were compared with established normative data of the CHIP subscales revealing that for both mothers and fathers all subscales were slightly higher than the norm, with the exception of Coping Pattern II for mothers, where the mean was slightly lower.(M = 26.82 vs. M = 28.00). A schematic representation comparing the mean scores and normative scores between mothers and fathers for the CHIP subscales is presented in Figure 2. A paired t-test was performed to determine if there were any signficant differences between mothers and fathers on the CHIP subscale scores. The only subscale in which there was a statistically significant difference between mothers and fathers was with Coping Pattern III, which deals with medical communication and consultation

(t (22) = -3.78, p = .001).

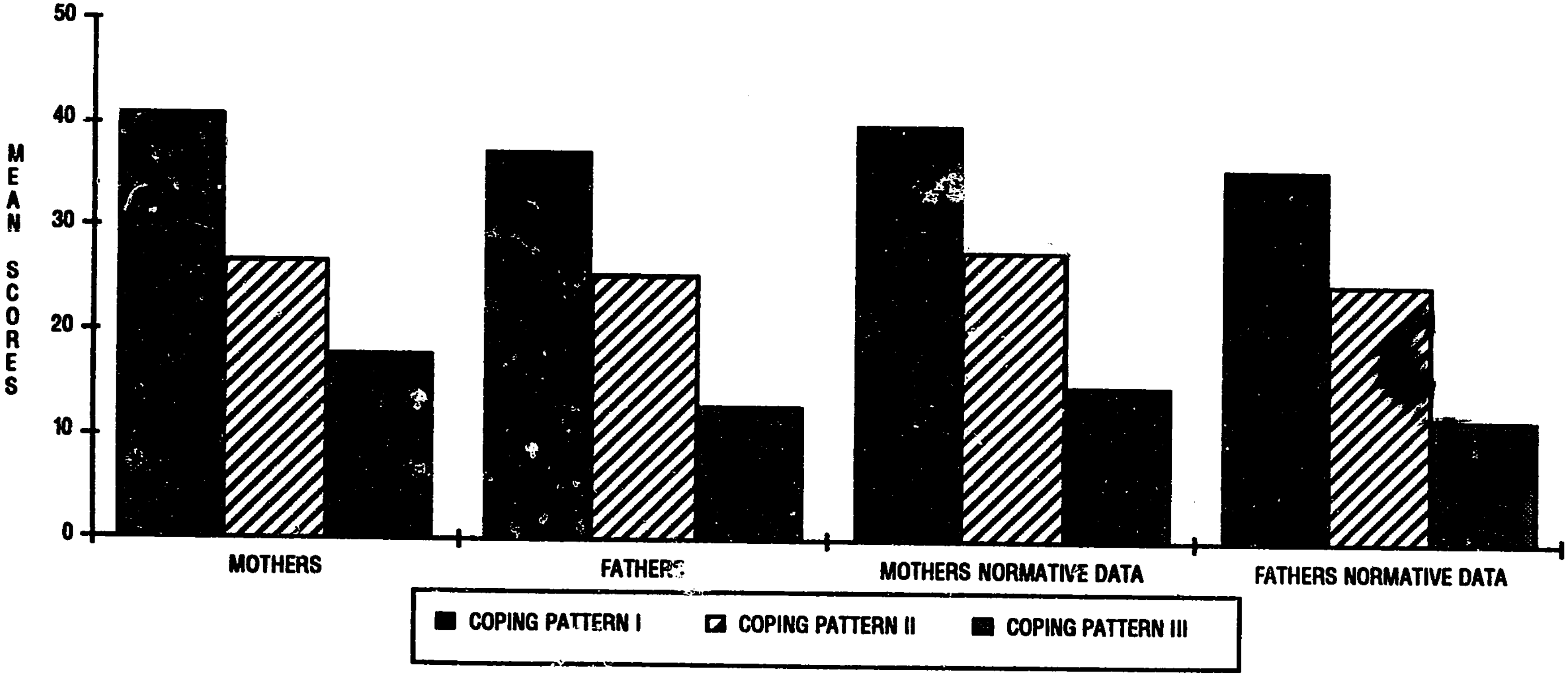
Table 8

Means, Standard Deviations, and t-Values for the CHIP Subscales

Coping Pattern	# of items	Mothers (n = 23)	Norm. Data (Mothers)	Fathers (n = 23)	Norm. Data (Fathers)	t-Value
COPING PATTERN (I) Integration, Cooperation, Optimism	19					
M		40.87	40.00	37.47	36.00	-1.04
SD		9.92	15.00	11.43	20.00	
Normal Range			25 - 55		16 - 56	
COPING PATTERN (II) Support, Esteem, Stability	18					
M		26.82	28.00	25.47	25.00	-0.48
SD		10.68	12.00	10.99	15.00	
Normal Range			16 - 40		10 - 41	
COPING PATTERN (III) Medical Communication and Consultation	8					
M		18.00	15.00	12.91	12.00	-3.78 *
SD		3.28	7.00	6.19	8.00	
Normal Range			8 - 22		4 - 19	

* $p < .05$, two-tailed

Figure 2. Comparison of mean scores/normative scores between mothers and fathers for CHIP subscales.



Visually Impaired Children Having One or Two Affected Eyes

The means and standard deviations for the Impact on Family subscales for mothers and fathers with a visually impaired child(ren) having one or two affected eyes are presented in Table 9. With children having one or two affected eyes, mothers as compared with fathers reported higher impact scores on Total Impact and Disruption of Social Relations Impact. The General Negative Impact mean score was the same for mothers and fathers with children having one affected eye (M = 18.00), however mothers reported a higher score (M = 23.03) than did fathers (M = 20.13) with children having two affected eyes. The mean scores for Coping-Positive and Financial Impact measured approximately the same for both mothers and fathers. As a group, both mothers and fathers with children having two affected eyes reported higher impact scores as compared with mothers and fathers with children having one affected eye. The means and standard deviations were not reported for Sibling Impact I and II because of the small sample size. A comparison of the mean scores between mothers and fathers for the Impact on Family subscales with children having one or two affected eyes is presented in Figure 3.

The means and standard deviations for the CHIP subscales for mothers and fathers with a visually impaired child(ren) having one or two affected eyes are presented in Table 10. With children having one affected eye, mothers reported using slightly more coping behaviors with Coping Pattern II (M = 30.37) as compared with fathers (M = 25.89). However, both mothers and fathers reported similar mean scores with Coping Pattern I and III. With children having two affected eyes, mothers reported a higher mean score on Coping Pattern I (M = 39.33) and III (M = 18.13) as compared with fathers (M = 33.86, M = 10.6), but similar mean scores on the Coping Pattern II. As a group, mothers and fathers with children having two affected eyes reported lower coping scores for Coping Patterns I and II as compared with mothers and fathers having children with one affected eye. Mothers with children having two affected eyes reported a slightly higher mean score for Coping Pattern III (M = 18.13) as compared with mothers with children having one affected eye (M = 17.75). Conversely, fathers with children having two affected eyes reported a much lower mean score for Coping Pattern III (M = 10.6) as compared with fathers with children having one affected eye (M = 17.25). A comparison of the means scores between mothers and fathers for the CHIP subscales having children with one or two affected eyes is presented in Figure 4.

Table 9

Means and Standard Deviations for the Impact on Family Subscales between Mothers and Fathers with Children having One or Two Affected Eyes

Subscales	1 Eye		2 Eyes	
	Mothers (n = 8)	Fathers (n = 8)	Mothers (n = 15)	Fathers (n = 15)
Total Impact				
M	38.12	35.00	45.53	41.13
SD	8.57	8.41	8.17	9.99
General Negative(I)				
M	18.00	18.00	23.03	20.13
SD	4.56	3.46	4.91	4.99
Disruption of Social Relations (II)				
M	18.37	15.87	20.00	18.80
SD	4.89	4.51	3.85	4.26
Coping-Positive (III)				
M	6.12	6.00	6.53	7.21
SD	1.72	2.00	2.19	1.71
Financial Impact (IV)				
M	5.25	5.50	6.20	5.80
SD	1.66	2.00	2.04	2.14

Figure 3. Mean scores for Impact on Family subscales between mothers and fathers with children having one or two affected eyes.

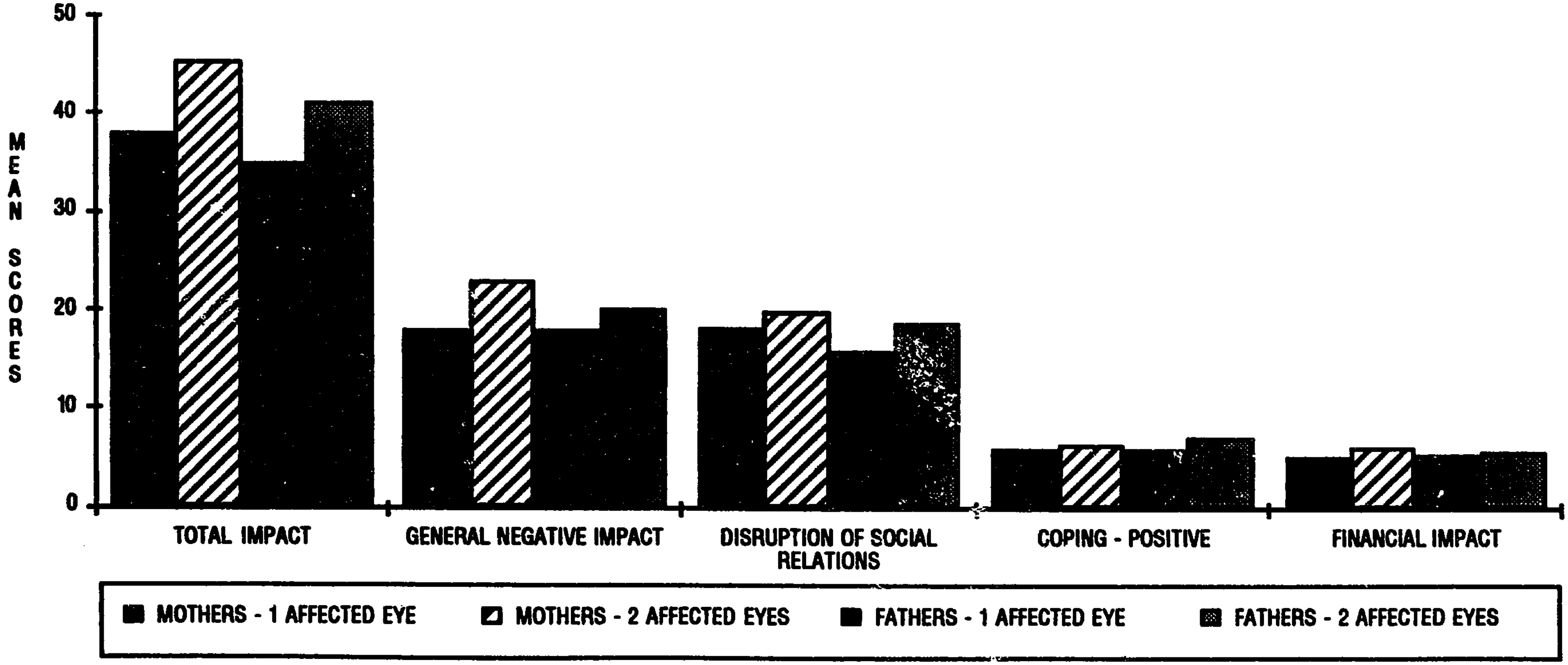
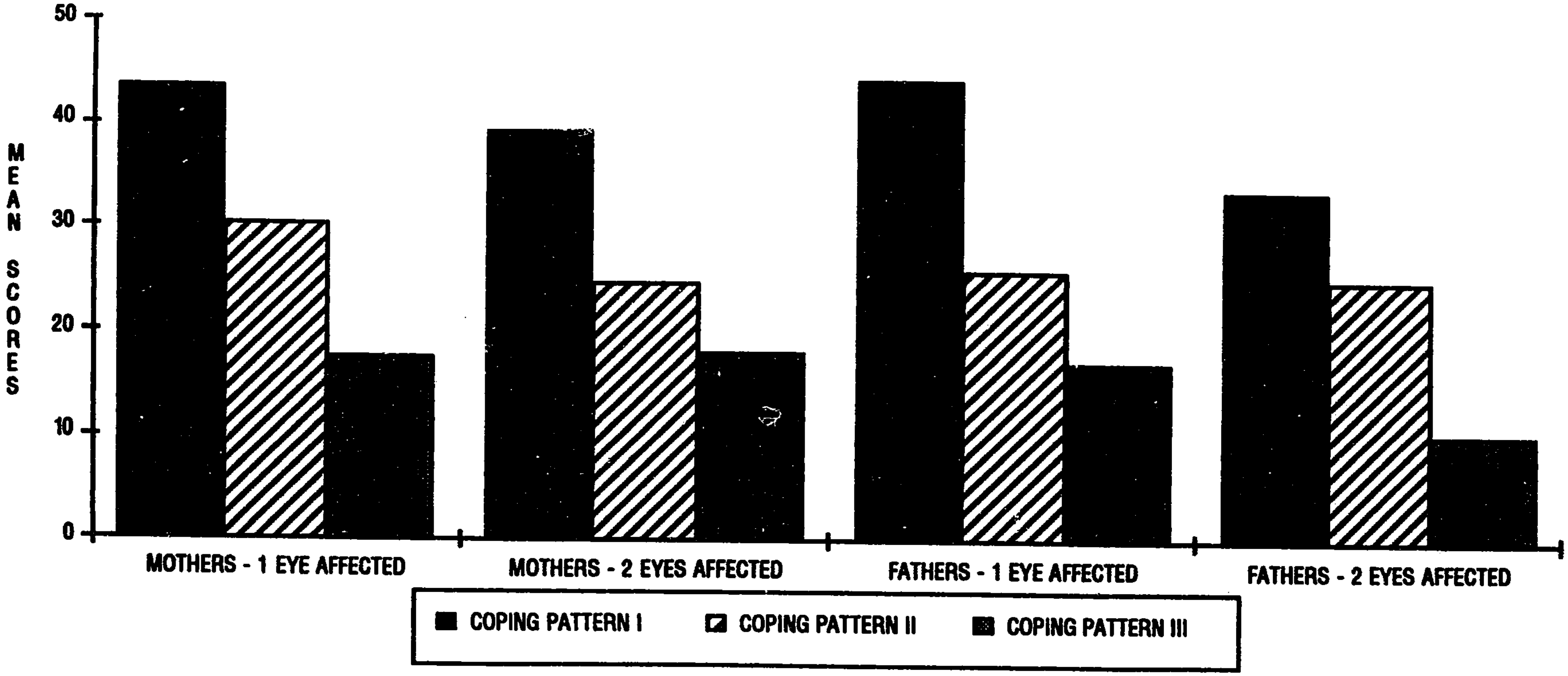


Table 10

Means and Standard Deviations for the CHIP Subscales between Mothers and Fathers with Children having One or Two Affected Eyes

Subscales	1 Eye		2 Eyes	
	Mothers (*n* = 8)	Fathers (*n* = 8)	Mothers (*n* = 15)	Fathers (*n* = 15)
COPING PATTERN I (Integration, Cooperation, Optimism)				
M	43.75	44.25	39.33	33.86
SD	5.62	5.44	11.47	12.26
COPING PATTERN II (Support, Esteem, and Stability)				
M	30.37	25.89	24.93	25.26
SD	10.30	10.78	10.72	11.47
COPING PATTERN III (Medical Communication and Consultation)				
M	17.75	17.25	18.13	10.60
SD	4.52	3.99	2.58	5.97

Figure 4. Mean scores for CHIP subscales between mothers and fathers with children having one or two affected eyes.



Children Having Medical Problems and/or Visual Impairments

The means and standard deviations for the Impact on Family subscales for mothers and fathers with children having other medical problems and/or visual impairments are presented in Table 11. The means and standard deviations were not reported for Sibling Impact I and II because of the small sample size. Mothers with children having a visual impairment only, reported similar mean scores for Coping-positive (M = 6.22) and Financial Impact (M = 5.55), as compared with fathers (M = 6.61, M = 5.39) respectively, but differed on the other Impact subscale scores. Mothers had slightly higher mean scores for the Total Impact, General Negative Impact, and Disruption of Social Relations Impact as compared with fathers. However, both mothers and fathers with children having a visual impairment plus other medical problems reported higher mean scores on all Impact subscales as compared with mothers and fathers having children with a visual impairment only. Within this latter group, mothers reported higher mean scores as compared with fathers except for the Coping-positive Impact score where their scores were similar. A comparison of the mean scores between mothers and fathers for the Impact on Family subscales with children having medical problems and/or visual impairment are presented in Figure 5.

The means and standard deviations for the CHIP subscales for mothers and fathers with a child having other medical problems and/or visual impairments are presented in Table 12. With children having a visual impairment only, and children having a visual impairment plus a medical problem, mothers reported higher mean scores on all three coping patterns as compared with fathers. However, as a group mothers and fathers with children having a visual impairment plus a medical problem, reported higher mean scores on all three coping patterns, with the exception for fathers on Coping Pattern III where a lower score was reported, as compared with mothers and fathers with children having a visual impairment only. A comparison of the means scores between mothers and fathers for the CHIP subscales with children having medical problems and/or visual impairments are presented in Figure 6.

Table 11

Means and Standard Deviations for the Impact on Family Subscales between Mothers and Fathers with Children having Medical Problems and/or Visual Impairments

	Visual Impairment		Visual Impairment with Medical Problem(s)	
Subscales	Mothers (*n* = 18)	Fathers (*n* =18)	Mothers (*n* = 5)	Fathers (*n* = 5)
Total Impact				
M	41.28	37.72	49.00	43.60
SD	8.94	9.10	6.04	12.42
General Negative(I)				
M	20.41	18.83	24.40	21.40
SD	5.30	4.22	4.39	5.68
Disruption of Social Relations (II)				
M	18.89	17.44	21.40	19.00
SD	4.42	4.46	2.88	4.85
Coping-Positive (III)				
M	6.22	6.61	7.00	7.00
SD	1.83	1.97	2.74	1.58
Financial Impact (IV)				
M	5.55	5.39	7.00	6.80
SD	2.01	1.85	1.22	2.59

Figure 5. Mean scores for impact on Family subscales between mothers and fathers with children having medical problems and/or visual impairments.

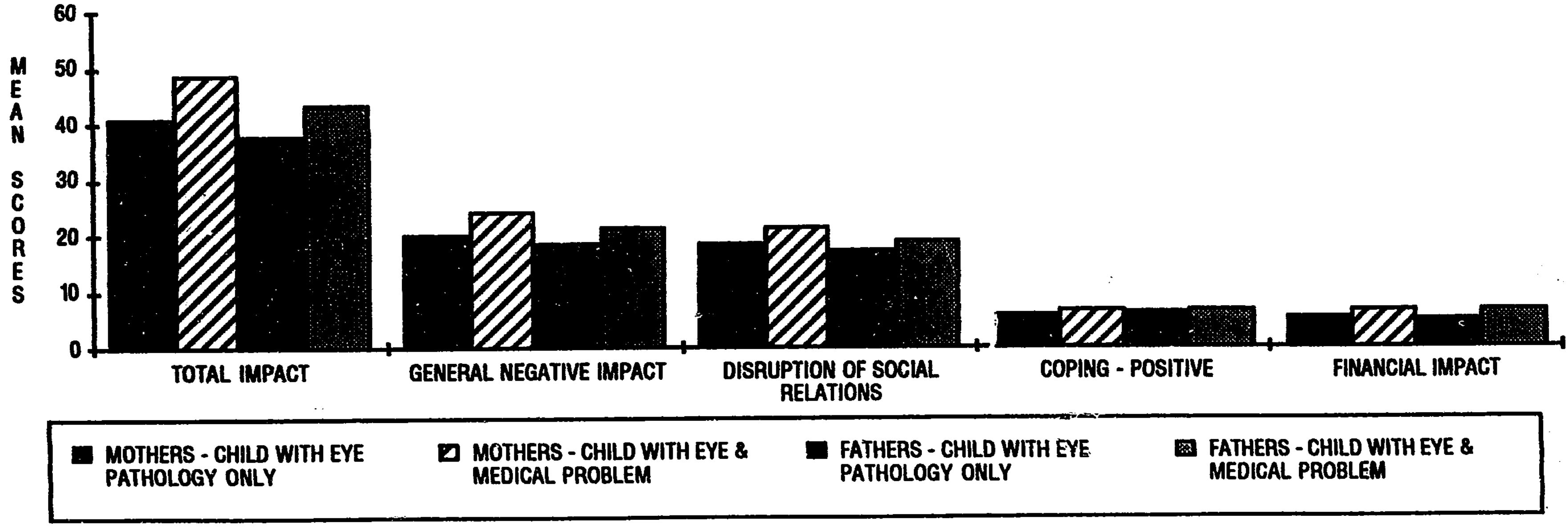
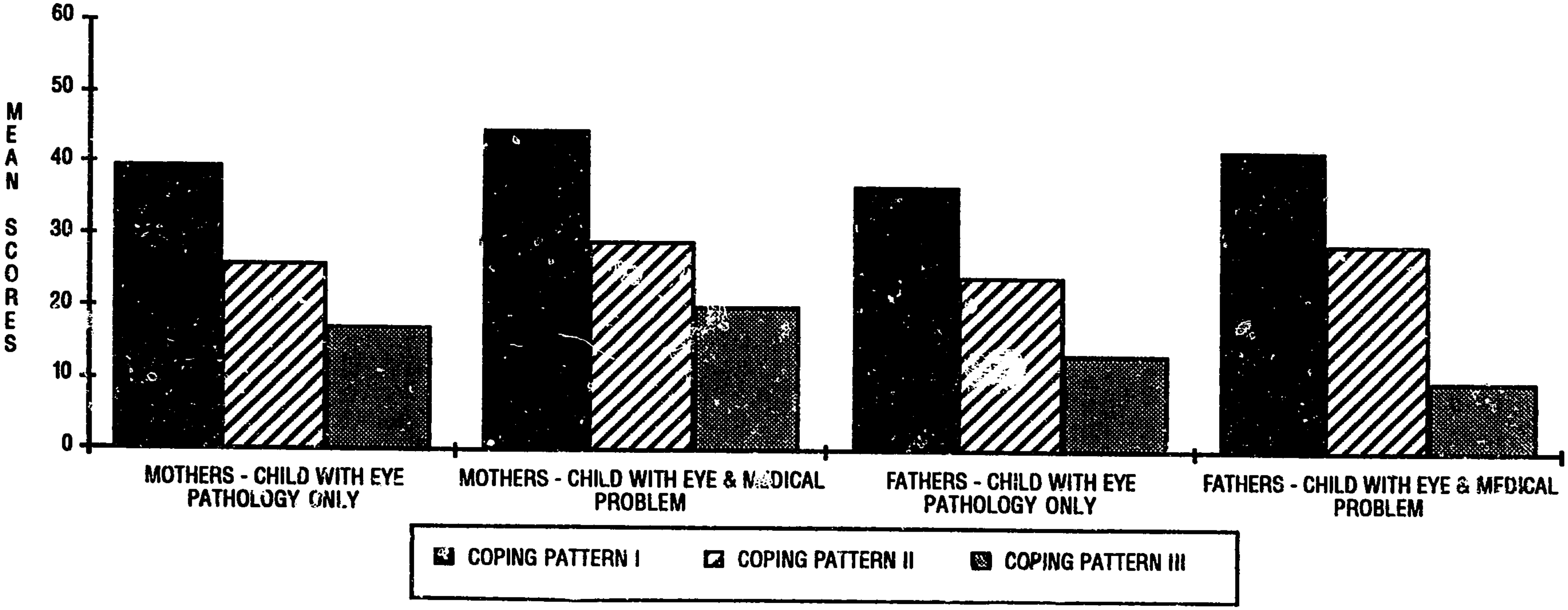


Table 12

Means and Standard Deviations for the CHIP Subscales between Mothers and Fathers with Children having Medical Problems and/or Visual Impairments

	Visual Impairment		Visual Impairment with Medical Problem(s)	
Subscales	Mothers (n = 18)	Fathers (n = 18)	Mothers (n = 5)	Fathers (n = 5)
COPING PATTERN I (Integration, Cooperation, Optimism)				
M	39.77	37.11	44.80	42.20
SD	10.80	12.00	4.54	8.34
COPING PATTERN II (Support, Esteem, and Stability)				
M	26.11	24.38	29.40	29.40
SD	11.10	11.03	9.60	11.10
COPING PATTERN III (Medical Communication and Consultation)				
M	17.40	13.66	20.20	10.20
SD	3.31	6.48	2.28	4.43

Figure 6. Mean scores for CHIP subscales between mothers and fathers with children having medical problems and/or visual impairments.



Birth Order of a Visually Impaired Child

The means and standard deviations for the Impact on Family subscales between mothers and fathers with the birth order of their visually impaired child are presented in Table 13. Mothers reported higher total impact scores, general-negative impact, disruption of social relations, and financial impact when the visually impaired child was their second or third child. However, fathers reported similar total impact scores, general-negative impact, and disruption of social relations when the visually impaired child was their first, or second child, with decreases in these impact subscales when the visually impaired child was their third. Both mothers and fathers reported similar comparison mean scores on coping-positive impact whether the visually impaired child was their first, second, or third child. A comparison of the mean scores for the Impact on Family subscales between mothers and fathers with the birth order of their visually impaired child is presented in Figure 7.

The means and standard deviations for the CHIP subscales between mothers and fathers with the birth order of their visually impaired child are presented in Table 14. Mothers reported using Coping Pattern III more consistently, regardless of whether the visually impaired child was her first, second, or third child, as compared with fathers. However, both mothers and fathers reported similar decreases in their mean scores of Coping Patterns I and II when their visually impaired child was their third child. A comparison of the mean scores of the CHIP subscales between mothers and fathers with the birth order of their visually impaired child is presented in Figure 8.

Table 13

Means and Standard Deviations for the Impact on Family Subscales between Mothers and Fathers with the Birth Order of their Visually Impaired Child

Subscales	Mothers			Fathers		
	1st Child (n = 8)	2nd Child (n = 8)	3rd Child (n = 7)	1st Child (n = 8)	2nd Child (n = 8)	3rd Child (n = 7)
Total Impact						
M	41.75	42.87	44.43	40.50	40.12	36.00
SD	9.05	8.63	10.15	9.59	12.11	8.16
General Negative(I)						
M	20.06	21.25	22.71	19.00	20.25	18.86
SD	5.14	4.59	6.55	2.51	6.63	4.02
Disruption of Social Relations (II)						
M	19.0	18.75	20.71	18.87	18.25	16.00
SD	3.96	4.62	4.35	5.14	4.37	3.87
Coping-Positive (III)						
M	5.87	6.00	7.42	6.12	6.87	7.14
SD	1.55	2.27	2.07	1.36	2.10	2.19
Financial Impact (IV)						
M	6.00	5.25	6.43	6.37	5.37	5.28
SD	2.32	1.39	2.07	2.26	2.26	1.60

Figure 7. Means and standard deviations for the Impact on Family subscales between mothers and fathers with the birth order of their visually impaired child.

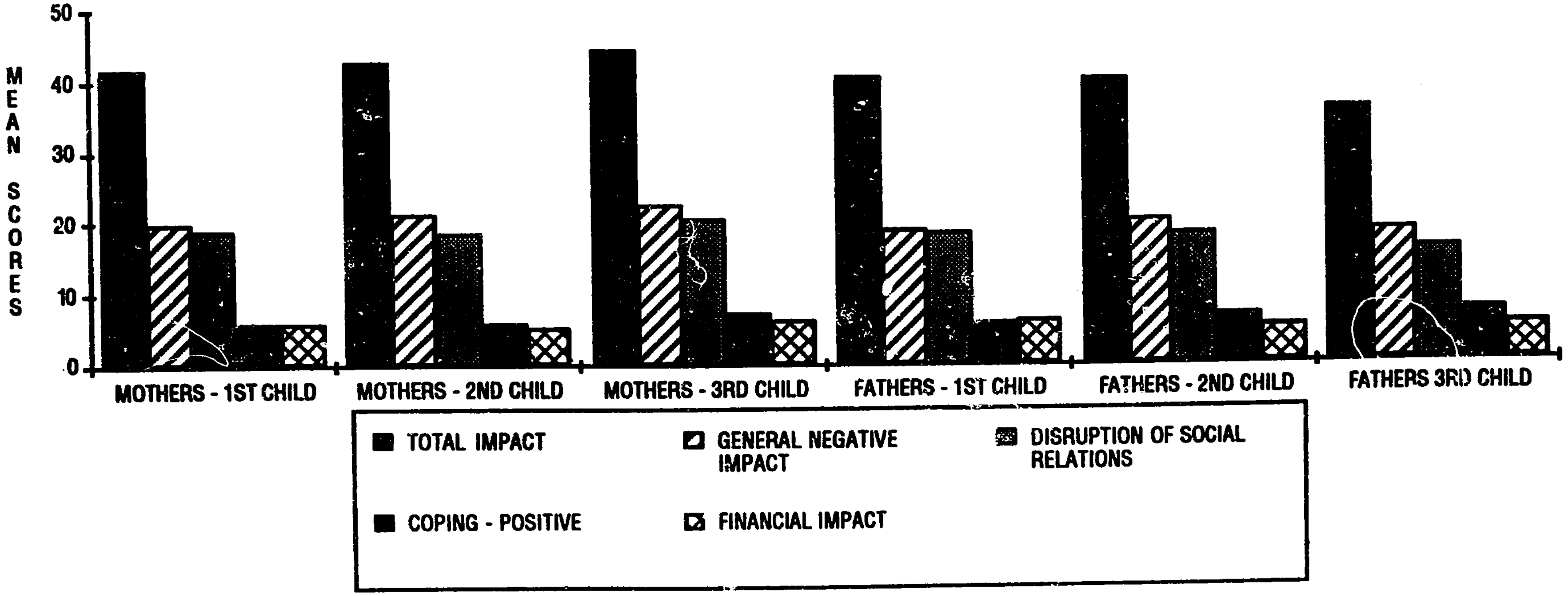
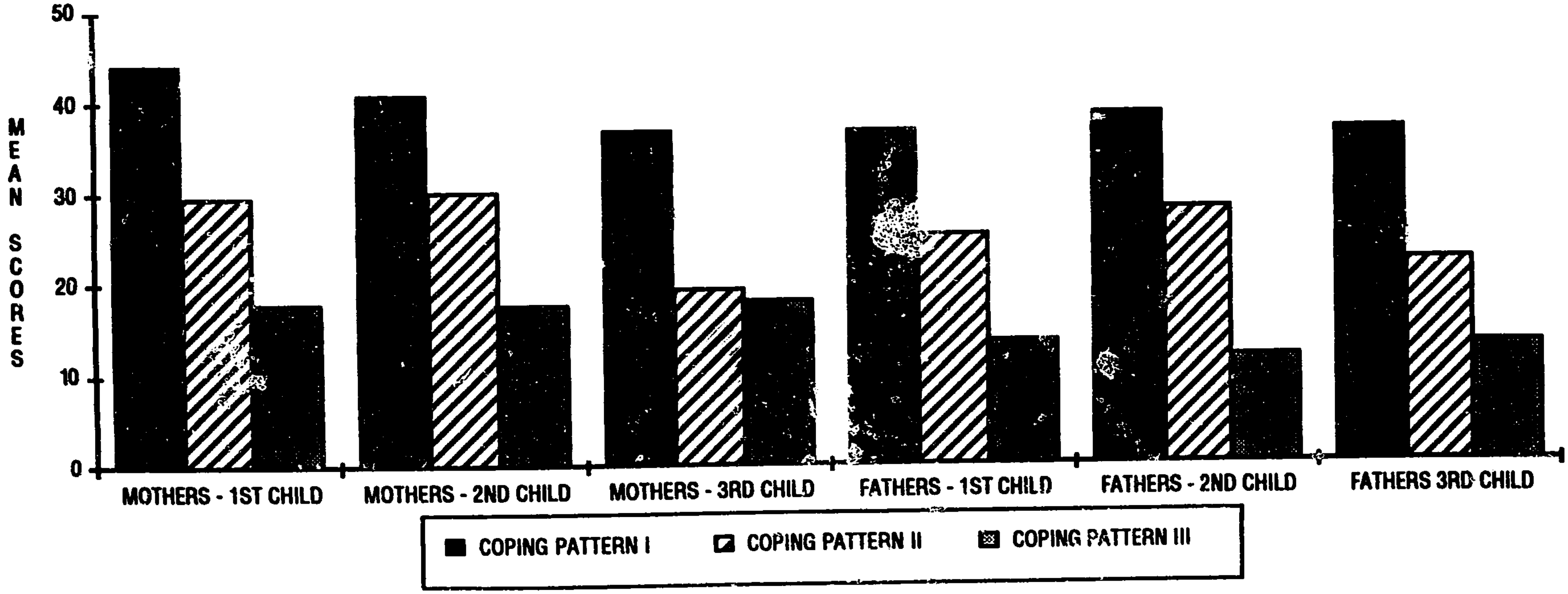


Table 14

Means and Standard Deviations for the CHIP Subscales between Mothers and Fathers with the Birth Order of their Visually Impaired Child

Subscales	Mothers			Fathers		
	1st Child (n = 8)	2nd Child (n = 8)	3rd Child (n = 7)	1st Child (n = 8)	2nd Child (n = 8)	3rd Child (n = 7)
COPING PATTERN I (Integration, Cooperation, Optimism)						
M	44.37	40.87	36.86	36.75	38.75	36.85
SD	5.42	11.41	11.89	7.34	12.44	15.25
COPING PATTERN II (Support, Esteem, and Stability)						
M	29.75	30.25	19.57	25.50	28.25	22.28
SD	6.96	11.84	10.47	8.98	7.92	15.93
COPING PATTERN III (Medical Communication and Consultation)						
M	18.00	17.75	18.28	13.75	11.87	13.14
SD	4.00	2.91	3.30	4.92	6.99	7.24

Figure 8. Means and standard deviations for the CHIP subscales between mothers and fathers with the birth order of their visually impaired child.



Length of Time Since Diagnosis of a Visually Impaired Child

A representation of mothers' and fathers' impact scores versus length of time since the diagnosis of their visually impaired child is presented in Figure 9. Mothers reported moderate impact scores within the first 7 months (38 to 57) since the time of diagnosis and in order, three low impact scores at 8 months which were 25, 28, and 32. In comparison, fathers reported in order, slightly lower impact scores within the first 8 months which were 20, 21, and 25. However, after 8 months through 42 months the majority of mothers and fathers revealed mainly moderate impact scores averaging 45.

[illegible]tion of mothers and fathers CHIP subscale scores versus length of time s[illegible]gnosis of their visually impaired child is presented in Figures 10 through 12. With Coping Patterns I and III, mothers revealed an overall consistent use of these coping behaviors even as the time since diagnosis of their visually impaired child lenghthened. Coping Patterns II with mothers revealed no specific pattern over time. There was variability with Coping Patterns I, II, and III scores for fathers, revealing no definite pattern. Mothers as compared with fathers demonstrated a more consistent use of Coping Patterns I and II.

Figure 9. Mothers and Fathers: Total impact score versus length of time since diagnosis of visually impaired child.

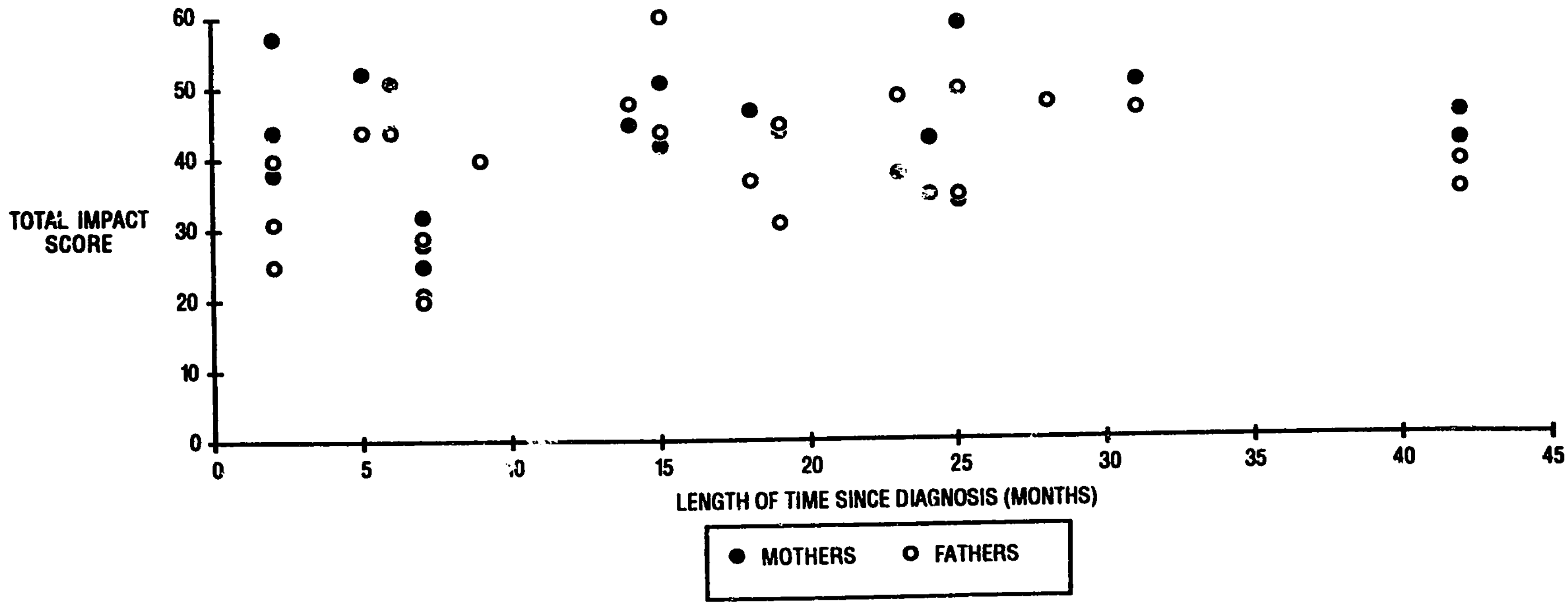


Figure 10. Mothers and Fathers: Coping Pattern I versus length of time since diagnosis of visually impaired child.

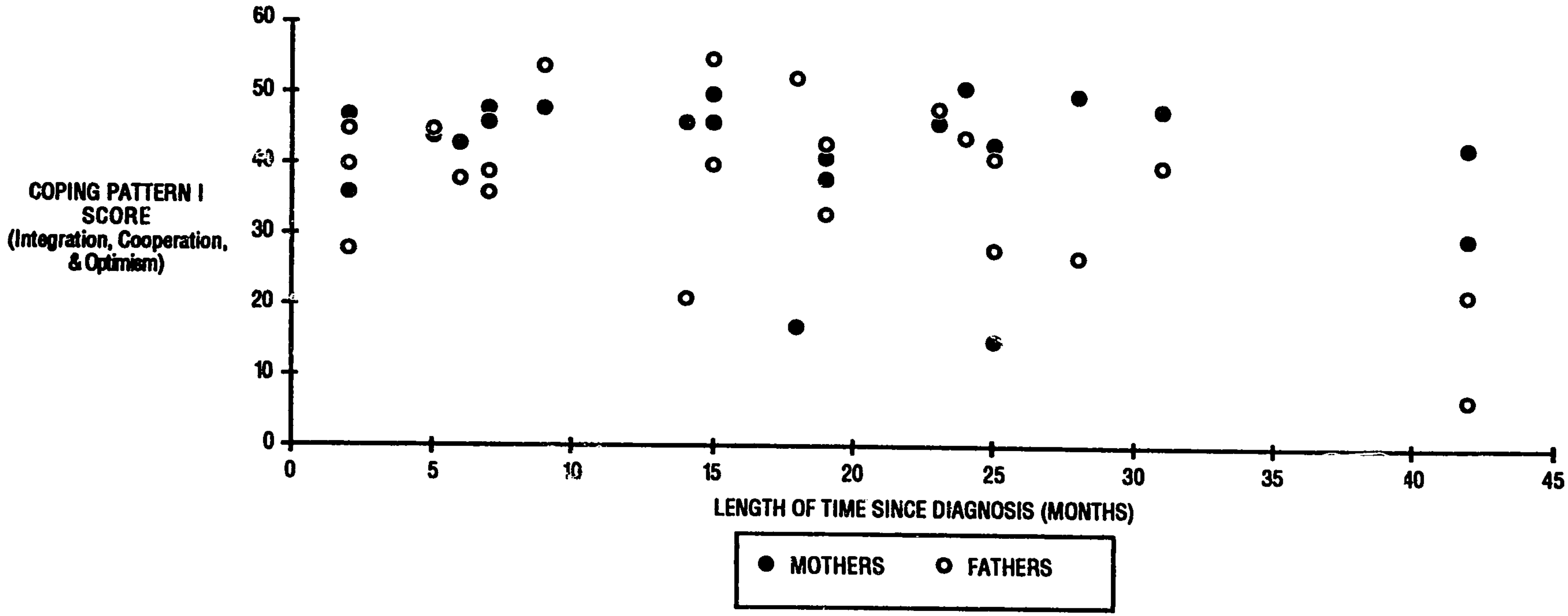


Figure 11. Mothers and Fathers: Coping Pattern II versus length of time since diagnosis of visually impaired child.

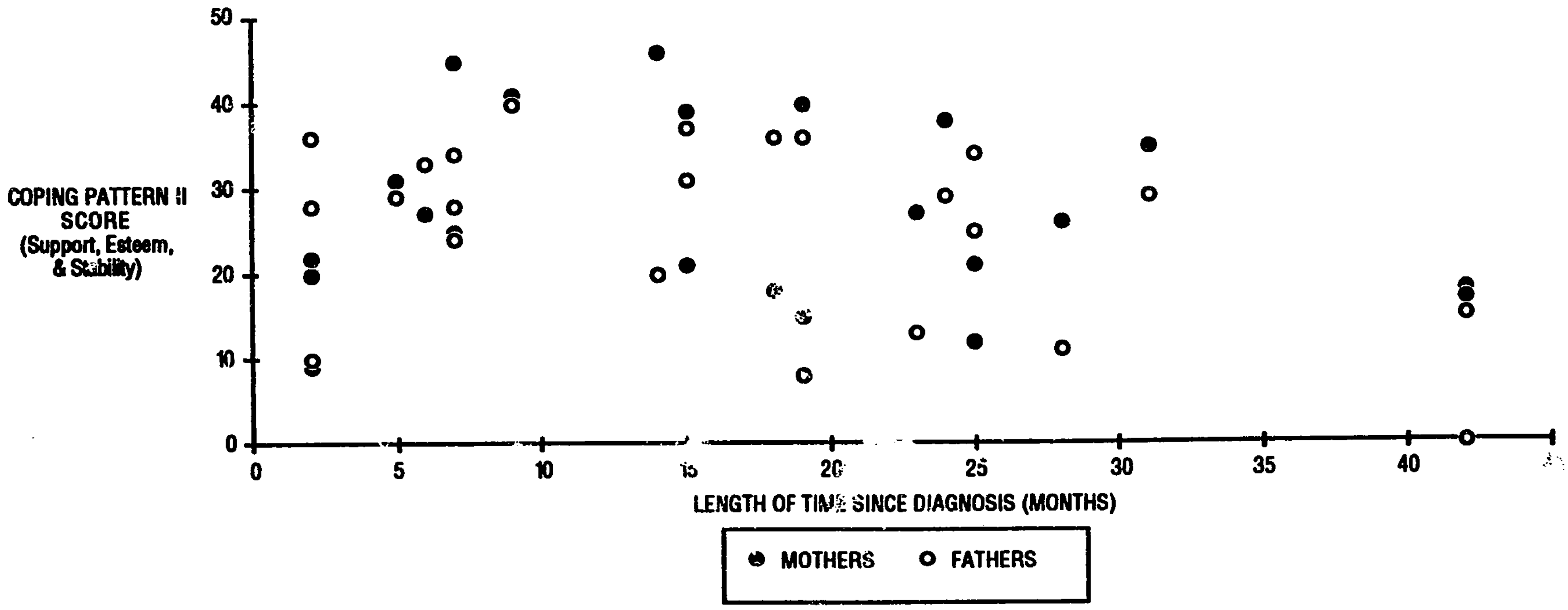
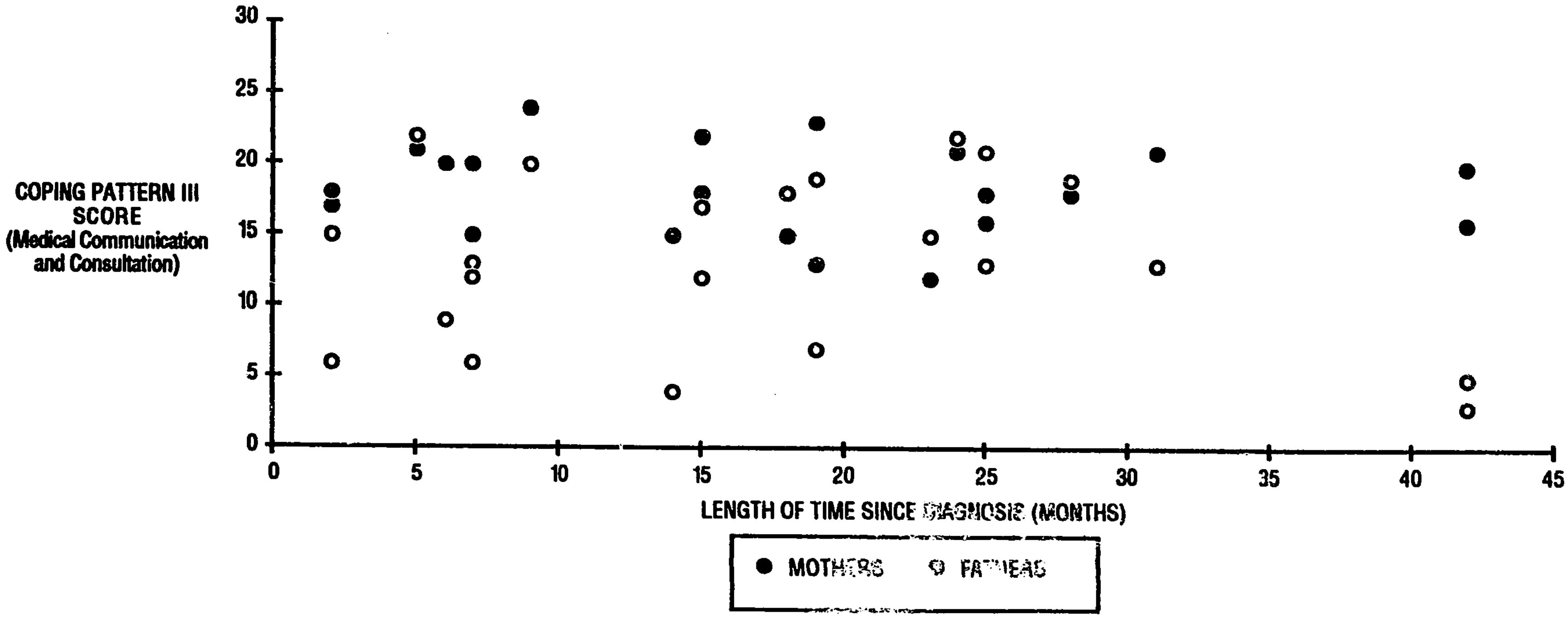


Figure 12. Mothers and Fathers: Coping Pattern III versus length of time since diagnosis of visually impaired child.



Comparison of Impact on Family Subscale Ranges for Mothers and Fathers

To further investigate the question about the differences in the impact between mothers and fathers with a visually impaired child, mothers and fathers were separated into groups based upon the Impact on Family subscale scores, dividing them into high, moderate, and low ranges as presented in Table 15. These ranges were arbitrarily assigned by the researcher to help descriptively analyze the data further. Mothers and fathers reported identical scores for Total Impact, General Negative Impact, Disruption of Social Relations Impact, and Sibling Impact I in the high range category. In the moderate range category, mothers reported slightly higher levels of impact subscale scores as compared with fathers, except for Sibling Impact I where a negligible difference was reported. The ranges for Sibling Impact II were not analyzed in this manner because of a small sample size consisting of only 6 families. There were a negligible differences in ranges between mothers and fathers for Financial Impact. With Coping-Positive Impact ranges, mothers reported 17 scores in the low range category as compared with fathers who had 14 scores, indicating a slightly higher ability to cope better. However, no scores were recorded for either mothers or fathers in the high range.

Next, to further analyze the data for meaningful differences in the impact between mothers and fathers with a visually impaired child, mothers and fathers were divided into high or low range groups for each separate subscale. The ranges for the Impact on Family subscales scores, except for Sibling Impact I and II. were used to place mothers and fathers into these groups. These ranges were arbitrarily divided by the researcher based upon Stein and Jessop's (1985) reported ranges. A comparison of mothers and fathers with the subscale ranges was done to determine whether mothers differed from fathers on the range of subscale scores as presented in Table 16. A Chi-square was computed, comparing the number of mothers and fathers in each category with the number expected. The Chi-square statistic was not calculated for the

Coping-Positive Impact subscale because the expected frequencies in 50% of the cells were less than 5, as the high range category only had one mother and one father, making the validity questionable (Norman & Streiner, 1986). There were no significant differences in the other Impact on Family subscale ranges between mothers and fathers as measured by the Chi-square statistic. This implies that the impact scores between mothers and fathers for the subscale ranges were independent of one another.

Table 15

Contingency Tables of the Impact on Family Subscale Ranges for Mothers and Fathers

A) Total Impact Ranges for Mothers and Fathers

Ranges (19 - 76)	Mothers (n = 23)	Fathers (n = 23)
High - Range = 58 - 76	1	1
Moderate - Range = 38 - 57	17	12
Low - Range = 19 - 37	5	10

B) General Negative Impact Ranges for Mothers and Fathers

Ranges (10 - 40)	Mothers (n = 23)	Fathers (n = 23)
High - Range = 31 - 40	1	1
Moderate - Range = 20 - 30	15	9
Low - Range = 10 - 19	7	13

Table 15 (Continued)

Contingency Tables of the Impact on Family Subscale Ranges for Mothers and Fathers

C) Disruption of Social Relations Impact Ranges for Mothers and Fathers

Ranges (9 - 36)	Mothers (n = 23)	Fathers (n = 23)
High - Range = 28 - 36	0	0
Moderate - Range = 18 - 27	15	12
Low - Range = 9 - 17	8	11

D) Coping-Positive Impact Ranges for Mothers and Fathers

Ranges (4 - 16)	Mothers (n = 23)	Fathers (n = 23)
High - Range = 12 - 16	0	0
Moderate - Range = 8 - 12	6	9
Low - Range = 4 - 7	17	14

Table 15 (Continued)

Contingency Tables of the Impact on Family Subscale Ranges for Mothers and Fathers

E) Financial Impact Ranges for Mothers and Fathers

Ranges (3 - 12)	Mothers (n = 23)	Fathers (n = 23)
High - Range = 10 - 12	1	1
Moderate - Range = 6 - 9	11	12
Low - Range = 3 - 5	11	10

F) Sibling Impact I Ranges for Mothers and Fathers

Ranges (6 - 24)	Mothers (n = 12)	Fathers (n = 12)
High - Range = 19 - 24	1	1
Moderate - Range = 12 - 18	7	6
Low - Range = 6 - 11	4	5

Table 16

Frequencies and Chi-Square Analysis of the Impact on Family Subscale Ranges by Mothers and Fathers

A) Total Impact Ranges by Mothers and Fathers

Ranges (19 - 76)	Mothers (n = 23)	Fathers (n = 23)
High Range = 48 - 76	7	5
Low Range = 19 - 47	16	18
	Chi-square = 0.45	

* p < .05, two-tailed.

B) General Negative Impact Ranges by Mothers and Fathers

Ranges (10 - 40)	Mothers (n = 23)	Fathers (n = 23)
High Range = 26 - 40	4	3
Low Range = 10 - 25	19	20
	Chi-square = 0.17	

* p < .05, two-tailed.

Table 16 (Continued)

Frequencies and Chi-Square Analysis of the Impact on Family Subscale Ranges by Mothers and Fathers

C) Disruption of Social Relations Impact Ranges by Mothers and Fathers

Ranges (9 - 36)	Mothers (n = 23)	Fathers (n = 23)
High Range = 23 - 36	5	4
Low Range = 9 - 22	18	19
	Chi-square = 0.01	

* p < .05, two-tailed.

D) Coping-Positive Impact Ranges by Mothers and Fathers

Ranges (4 - 16)	Mothers (n = 23)	Fathers (n = 23)
High Range = 11 - 16	1	1
Low Range = 4 - 10	22	22

Table 16 (Continued)

Frequencies and Chi-Square Analysis of the Impact on Family Subscale Ranges by Mothers and Fathers

E) Financial Impact Ranges by Mothers and Fathers

Ranges (3 - 12)	Mothers (n = 23)	Fathers (n = 23)
High Range = 8 - 12	4	5
Low Range = 3 - 7	19	18
	Chi-square = 0.01	

* $p < .05$, two-tailed.

CHIP subscale Normative Ranges for Mothers and Fathers

To further investigate the question about the coping behaviors both parents use, mothers and fathers were separated into groups based upon the CHIP subscale normative ranges, dividing them above and below the normative ranges as presented in Table 17. No mothers or fathers had scores above the normative range in the three coping patterns. However, in Coping Patterns I and II there were scores for both mothers and fathers reported in the below range category, with a negligible difference between the two (one more case was reported for mothers). With Coping Pattern III, no mothers were in the below range category, and there was one case reported for fathers.

To analyze the data further for meaningful differences in the coping behaviors parents use with a visually impaired child, mothers and fathers were grouped as being above or below the normative mean for each separate subscale as presented in Table 18. A comparison of mothers and fathers with the subscale means was done with a 2 x 2 Chi-square to determine whether mothers differ from fathers in their coping pattern scores. A Chi-square was computed comparing the numbers of mothers and fathers in each category with the number expected. There were no significant differences in the CHIP subscale normative means between mothers and fathers as measured by the Chi-square statistic. This implies that the coping scores between mothers and fathers for the normative subscale ranges were independent of one another.

Table 17

Contingency Tables of the CHIP Coping Patterns Normative Ranges for Mothers and Fathers

A) Coping Pattern I Normative Ranges for Mothers and Fathers

Normative Ranges	Mothers (n = 23)	Fathers (n = 23)
Above Range		
Mothers Range > 55 Fathers Range > 56	0	0
Below Range		
Mothers Range < 25 Fathers Range < 16	2	1

B) Coping Pattern II Normative Ranges for Mothers and Fathers

Normative Ranges	Mothers (n = 23)	Fathers (n = 23)
Above Range		
Mothers Range > 40 Fathers Range > 41	0	0
Below Range		
Mothers Range < 16 Fathers Range < 10	3	2

Table 17 (Continued)

Contingency Tables of the CHIP Coping Patterns Normative Ranges for Mothers and Fathers

C) Coping Pattern III Normative Ranges for Mothers and Fathers

Normative Ranges	Mothers (n = 23)	Fathers (n = 23)
Above Range		
Mothers Range > 22 Fathers Range > 19	0	0
Below Range		
Mothers Range < 8 Fathers Range < 4	0	1

Table 18

Frequencies and Chi-Square Analysis of the CHIP Coping Patterns Normative Means by Mothers and Fathers

A) Coping Pattern I Normative Means by Mothers and Fathers

Normative Means	Mothers (n = 23)	Fathers (n = 21)a
Above Mean		
Mothers M > 40 Fathers M > 36	16	14
Below Mean	7	7
	Chi-square = 0.04	

a Scores directly on the M.

* p < .05, two-tailed.

B) Coping Pattern II Normative Means by Mothers and Fathers

Normative Means	Mothers (n = 23)	Fathers (n = 22)a
Above Mean		
Mothers M > 28 Fathers M > 25	8	14
Below Mean	15	8
	Chi-square = 3.75	

a Scores directly on the M.

* p < .05, two-tailed.

Table 18 (Continued)

Frequencies and Chi-Square Analysis of the CHIP Coping Patterns Normative Means by Mothers and Fathers

C) Coping Pattern III Normative Means by Mothers and Fathers

Normative Means	Mothers (n = 20)a	Fathers (n = 21)a
Above Mean		
Mothers M > 15 Fathers M > 12	17	13
Below Mean	3	8
	Chi-square = 2.78	

a Scores directly on the M.

* p < .05, two-tailed.

Relationships between Impact and Coping with Mothers and Fathers

Pearson correlation coefficients were used to determine whether relationships existed between the Impact on Family subscale scores and the CHIP Coping Pattern subscale scores. Intercorrelations between the Impact on Family and CHIP subscale scores for mothers and fathers are presented in Tables 19 and 20. With mothers there was a significant, but low correlation between Coping Pattern III and the Total Impact ($r = .41$, p .049), and a moderate correlation with the Financial Impact ($r = .57$, $p = .004$). Ten other significant strong correlations existed between the Impact subscale scores for mothers. For example, Total Impact strongly correlated with General Negative Impact ($r =.96$, $p = .000$), Disruption of Social Relations ($r = .90$, $p = .000$), Financial Impact I ($r = .84$, $p = .000$), and Sibling Impact I ($r = .84$, $p = .001$). In addition, other Impact subscales correlated highly with General Negative Impact, Disruption of Social Relations, and Financial Impact.

For fathers, there was one low but significant inverse relationship between Coping Pattern III and Coping-Positive Impact ($r = -.49$, $p = .016$). It is important to note that a scoring irregularity is inherent with the Coping-Positive Impact score and that this negative correlation actually implies a positive relationship which will be discussed in the next chapter. As with the mothers, 11 other significant strong correlations existed for fathers between the Impact subscale scores, and two significant moderate correlations with the CHIP subscale scores. The Total Impact score correlated highly with General Negative Impact ($r = .91$, $p = .000$), Disruption of Social Relations ($r = .89$, $p =.000$), Financial Impact ($r = .86$, $p = .000$), Sibling Impact II ($r = .95$, $p = .004$), and moderately with Sibling Impact I ($r = .59$, p .04). In addition other Impact subscale scores correlated moderately to highly with General Negative Impact, and with Disruption of Social Relations. With the Chip subscale scores, Coping Pattern I correlated moderately with Coping Pattern II ($r = .65$, $p = .001$) and Coping Pattern III ($r = .67$, $p = .000$).

Table 19

Intercorrelations Between CHIP and Impact on Family Subscales for Mothers

	Subscale	1	2	3	4	5	6	7	8	9a	10b
						Mothers (n = 23)					
CHIP	1. Coping Pattern I	- -	.58*	.27	-.16	-.31	-.05	-.24	-.09	-.46	.61
	2. Coping Pattern II		- -	.39	-.08	-.16	-.09	-.06	.01	-.28	-.28
	3. Coping Pattern III			- -	.41*	.39	.39	-.05	.57*	-.08	.60
IMPACT	4. Total Impact				- -	.96*	.90*	.21	.84*	.84*	.78
	5. General Negative Impact I					- -	.80*	.28	.82*	.84*	.73
	6. Disruption of Social Relations II						- -	.04	.78*	.78*	.70
	7. Coping III							- -	.18	.03	-.05
	8. Financial Impact IV								- -	.71*	.53
	9. Sibling Impact I									- -	- -
	10. Sibling Impact II										- -

a The Sibling Impact I subscale refers to 12 cases in each group of mothers out of 23 cases who had other children older than 4 years of age.

b The Sibling Impact II subscale refers to 6 cases in each group of mothers out of 23 cases who had other children younger than 4 years of age.

* $p < .05$, two-tailed.

Table 20

Intercorrelations Between CHIP and Impact on Family Subscales for Fathers

	Subscale	1	2	3	4	5	6	7	8	9a	10b
					Fathers (n = 23)						
CHIP	1. Coping Pattern I	--	.65*	.67*	.20	.21	.03	-.32	.40	-.22	.11
	2. Coping Pattern II		--	.28	.15	.15	-.05	.00	.26	.12	-.32
	3. Coping Pattern III			--	.23	.30	.16	-.49*	.29	-.01	.47
IMPACT	4. Total Impact				--	.91*	.89*	-.04	.86*	.59*	.95*
	5. General Negative Impact I					--	.77*	.08	.75*	.50	.88*
	6. Disruption of Social Relations II						--	-.08	.68*	.69*	.95*
	7. Coping III							--	-.21	.13	.31
	8. Financial Impact IV								--	.26	.75
	9. Sibling Impact I									--	--
	10.Sibling Impact II										--

a The Sibling Impact I subscale refers to 12 cases in each group of fathers out of 23 cases who had other children older than 4 years of age.

b The Sibling Impact II subscale refers to 6 cases in each group of fathers out of 23 cases who had other children younger than 4 years of age.

* $p < .05$, two-tailed.

Relationships between Impact and Characteristics of Mothers and Fathers

Pearson correlation coefficients were used to determine what the relationships were between the Impact on Family subscale scores and characteristics of mothers and fathers. Intercorrelations between the Impact on Family subscale scores and Background Information for mothers and fathers are presented in Tables 21 through 24. Mothers reported a low significant correlation with General-Negative Impact and affected eye(s) ($r = .46$, $p = .026$). No other significant correlations were reported with the Impact subscale scores including Sibling Impact I and II, and the background information variables for mothers. With fathers, moderate significant correlations were reported with Total Impact ($r = .52$, $p = .01$), Disruption of Social Relations ($r = .47$, $p = .023$), and Financial Impact ($r = .81$, $p = .048$) with Education. In addition, there was a strong correlation with Education and the Sibling Impact II subscale scores. No other significant correlations were reported with the Impact subscale scores including Sibling Impact I and II, and the background information variables for fathers.

Table 21

Intercorrelations Between Impact on Family Subscales and Background Information for Mothers

		Impact Subscales			
Variables	Total	General - Negative	Disruption of Social Relations	Coping - Positive	Financial
			Mothers (n = 23)		
Education	-.08	-.19	.07	-.33	-.14
Employment	.09	.04	.16	.23	-.06
Income	-.02	-.01	.06	-.30	-.25
Religion-Support	.03	.10	-.09	.21	.04
Number of Children	.18	.24	.20	.34	.29
Birth order of Visually Impaired Child	.12	.20	.16	.31	.08
Other Children with Problems	-.29	-.37	-.31	.15	-.38
Gender of Visually Impaired Child	.05	.00	.05	.01	-.15
Visually Impaired Child with other Problems	-.36	-.31	-.25	-.16	-.31
Diagnosis Age of Visually Impaired Child	.05	.06	.12	-.15	.22
Eye Problem	-.02	.04	-.03	.23	-.05
Mothers Age	.15	.12	.18	.02	-.00
Affected Eye(s)	.40	.46*	.18	.09	.23

*p < .05, two-tailed.

Table 22

Intercorrelations Between Impact on Family Subscales and Background Information For Fathers

Variables	Total	Impact Subscales			
		General - Negative	Disruption of Social Relations	Coping - Positive	Financial
			Fathers (n = 23)		
Education	.52*	.27	.47*	-.15	.57*
Employment	- -	- -	- -	- -	- -
Income	-.13	-.06	.07	-.08	-.28
Religion-Support	.14	.06	.19	.28	.10
Number of Children	-.13	-.01	-.23	.18	-.13
Birth order of Visually Impaired Child	-.18	-.00	-.22	.22	-.22
Other Children with Problems	-.18	-.30	-.12	.28	-.21
Gender of Visually Impaired Child	.33	.29	.27	-.06	.15
Visually Impaired Child with other Problems	-.25	-.23	-.13	-.08	-.28
Diagnosis Age of Visually Impaired Child	-.16	-.07	-.14	-.05	.00
Eye Problem	-.38	-.32	-.39	.32	-.28
Fathers Age	-.07	.00	.01	.19	-.22
Affected Eye(s)	.30	.22	.27	.27	.07

*p < .05, two-tailed.

Table 23

Intercorrelations Between Sibling Impact I, II and Background Information for Mothers

Variables	Sibling Impact I	Sibling Impact II
	Mothers ($n = 12$)	Mothers ($n = 6$)
Education	-.12	-.73
Employment	.10	-.12
Income	.90	-.01
Religion-Support	-.37	.12
Number of Children	-.05	- -
Birth order of Visually Impaired Child	-.05	-.12
Other Children with Problems	-.44	- -
Gender of Visually Impaired Child	.10	.61
Visually Impaired Child with other problems	-.09	-.12
Diagnosis Age of Visually Impaired Child	.39	-.39
Eye Problem	.11	-.78
Mothers Age	-.24	.37
Affected Eye(s)	.40	-.38

*$p < .05$, two-tailed.

Table 24

Intercorrelations Between Sibling Impact I, II and Background Information for Fathers

Variables	Sibling Impact I	Sibling Impact II
	Fathers (n = 12)	Fathers (n =6)
Education	-.06	.81*
Employment	- -	- -
Income	-.26	.45
Religion-Support	.64	-.31
Number of Children	- -	-.27
Birth order of Visually Impaired Child	-.24	-.27
Other Children with Problems	- -	-.10
Gender of Visually Impaired Child	.68	.33
Visually Impaired Child with other problems	-.48	.48
Diagnosis Age of Visually Impaired Child	-.77	.04
Eye Problem	-.44	-.53
Fathers Age	.31	.21
Affected Eye(s)	.21	.42

*$p < .05$, two-tailed.

Relationships between Coping and Characteristics of Mothers and Fathers

Pearson correlation coefficients were used to determine what the relationships were between the CHIP subscale scores and characteristics of mothers and fathers. Tables 25 and 26 report the intercorrelations among the three Coping Patterns from the CHIP instrument and the background information variables. With mothers, there was one moderate, but significant relationship between Coping Pattern I and the variable, reporting other children with problems ($r = .54$, $p = .007$). There were no other significant relationships identified. With fathers, there were low, but significant inverse relationships between Coping Patterns I and III with the variable, affected eye(s) ($r = .-44$, $p = .036$, and $r = -.52$, $p = .01$). In addition, there were five other low to moderate inverse correlations between Coping Pattern I and the variable income, Coping Pattern II and the two variables, income and the father's age, and between Coping Pattern III and the two variables, religion as a support and the child's eye problem. No other correlations indicated significant relationships for fathers.

Table 25

Intercorrelations Between CHIP Subscales and Background Information for Mothers

Variables	Coping Patterns I	 II	 III
	Mothers ($n = 23$)		
Education	.17	-.05	-.11
Employment	-.03	-.15	.08
Income	-.02	-.17	-.37
Religion-Support	.04	.01	.20
Number of Children	-.24	-.29	.18
Birth Order of Visually Impaired Child	-.31	-.38	.03
Other Children With Problems	.54*	.36	.09
Gender of Visually Impaired Child	.01	-.27	-.18
Visually Impaired Child With Other Problems	-.21	-.12	-.32
Diagnosis Age of Visually Impaired Child	-.02	.14	.02
Eye Problem	-.21	-.09	-.21
Mothers Age	-.17	-.30	-.06
Affected Eye(s)	-.21	-.24	.05

*$p < .05$, two-tailed.

Table 26

Intercorrelations Between CHIP Subscales and Background Information for Fathers

Variables	Coping Patterns I	II	III
	Fathers (n = 23)		
Education	.20	.10	.01
Employment	- -	- -	- -
Income	-.42*	-.56*	-.10
Religion-Support	-.15	-.21	-.46*
Number of Children	-.03	-.12	.04
Birth Order of Visually Impaired Child	.00	-.11	-.04
Other Children With Problems	-.09	-.05	-.34
Gender of Visually Impaired Child	.00	-.27	.15
Visually Impaired Child With Other Problems	-.06	-.19	.23
Diagnosis Age of Visually Impaired Child	.09	.15	.22
Eye Problem	-.13	.14	-.51*
Fathers Age	-.30	-.50*	-.08
Affected Eye(s)	-.44*	-.02	-.52*

*$p < .05$, two-tailed.

Predictors of Impact and Parental Coping Behaviors

Multiple Regression Analysis of Mothers and Fathers Separately on the Impact on Family Subscale Scores

To determine the predictor variables of impact , as measured by the Impact on Family scale, and coping behaviors, as measured by the CHIP scale for mothers and fathers, multiple regression analysis was conducted. Table 27 presents the multiple regression findings for mothers and fathers separately, concerning the Impact on Family subscale scores as dependent variables. The Sibling Impact subscale was not included in this analysis because of a small sample size. The following variables were entered for the Impact on Family subscales: Coping Patterns I, II, and III, education, employment, income, religion-support, number of children, birth order of visually impaired child, other children with problems, gender of visually impaired child, diagnosis, age of visually impaired child, eye problem, gender of parents, parents age, and affected eye(s). Gender of parents was not entered in the analysis for mothers and gender of parents and employment was not entered for fathers.

The independent variable Coping Pattern III accounted for 17% of the variance for the Total Impact subscale score for mothers. No other independent variables were statistically significant. Whereas for fathers, Education correlated with Total Impact and accounted for 27% of the variance. Subsequently, the five other independent variables, which were, Eye Problem, Other Children with Problems, Religion-support, Affected eye(s), and Coping Pattern II accounted for 79% of the variance.

For the dependent variable, General-Negative Impact score for mothers, the independent variable, Affected Eye(s), accounted for 21% of the variance. No other independent variables were statistically significant. For fathers, no independent variables were statistically significant.

The dependent variables, Disruption of Social Relations Impact and

Coping-Positive Impact revealed no independent variables as statistically significant for mothers. However, for fathers there were two independent variables, Education and Eye Problem that accounted for 37% of the variance for Disruption of Social Relations Impact. With the dependent variable, Coping-Positive Impact, the independent variable, Coping Pattern III, accounted for 24% of the variance.

The two independent variables, Coping Pattern III and Other Children with Problems, explained 53% of the variance for the dependent variable, Financial Impact. With fathers, Education and Other Children with Problems accounted for 47% of the variance for Financial Impact.

Multiple Regression Analysis of Mothers and Fathers Separately on the CHIP Subscale Scores

The multiple regression results for mothers and fathers analyzed separately, concerning CHIP subscales as dependent variables, are presented in Table 28. The following variables were entered for the CHIP subscales: Total Impact, General-Negative Impact, Disruption of Social Relation, Coping-Positive Impact, Financial Impact, education, employment, income religion-support, number of children, birth order of visually impaired child, other children with problems, gender of visually impared child, diagnosis age of visually impaired child, eye problem, gender of parents, parents age, and affected eye(s). Gender of parents was not entered in the analysis for mothers, and gender of parents and employment was not entered for fathers.

With Coping Pattern I, the independent variable Other Children with Problems, explained 30% of the variance for mothers and the two independent variables, Affected Eye(s) and Financial Impact, accounted for 38% of the variance for fathers.

Coping Pattern II did not have any independent variables statistically significant for mothers. Income accounted for 31% of the explained variance for fathers.

The independent variables of Financial Impact and Other Children with Problems accounted for 45% of the variance for the dependent variable of Coping Pattern III for mothers. With fathers, the four independent variables of Involved Eye(s), General-Negative Impact, Religion-Support, and Coping-Positive Impact accounted for 71% of the variance with Coping Pattern III.

Table 27

Multiple Regression Results of Mothers and Fathers Separately: CHIP Subscales and Background Information on Impact on Family Subscales

Variable Entered	Dependent Variable - Total Impact Mothers ($n = 23$)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	.415268	.41527	8.27337	F1,21	4.37603	.0488*

*$p < .05$, two-tailed.

Variable Entered	Dependent Variable - Total Impact Fathers ($n = 23$)					
	Beta	Multiple R	Standard Error	DF	F	P
Education	.523755	.52376	8.64353	F1,21	7.93836	.0103*
Eye Problem	-.379012	.64650	7.9314	F2,20	7.18085	.0045*
Other Children with Problems	-.369476	.73745	7.20468	F3,19	7.55037	.0016*
Religion-Support	.383090	.79942	6.58424	F4,18	7.96765	.0007*
Affected Eye(s)	.290405	.84681	5.99840	F5,17	8.61754	.0003*
Coping Pattern II	.317200	.89428	5.20187	F6,16	10.64969	.0001*

*$p < .05$, two-tailed.

Table 27 (Continued)

Multiple Regression Results of Mothers and Fathers Separately: CHIP Subscales and Background Information on Impact on Family Subscales

Variable Entered	Dependent Variable - General-Negative Impact Mothers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Affected Eye(s)	.463070	.46307	4.80195	F1,21	5.7321	.0261*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - Disruption of Social Relation Impact Fathers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Education	.470436	.47043	4.03844	F1,21	5.96833	.0236*
Eye Problem	-.393362	.61321	3.70432	F2,20	6.02636	.0089*

*p < .05, two-tailed.

Table 27 (Continued)

Multiple Regression Results of Mothers and Fathers Separately: CHIP Subscales and Background Information on Impact on Family Subscales

Variable Entered	Dependent Variable - Coping-Positive Impact Fathers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	-.497709	.49771	1.65943	F1,21	1.65943	.0157*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - Financial Impact Mothers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	.577675	.57768	1.61896	F1,21	10.51774	.0039*
Other Children with Problems	-.448372	.72990	1.38922	F2,20	11.40205	.0005*

*p < .05, two-tailed.

Table 27 (Continued)

Multiple Regression Results of Mothers and Fathers Separately: CHIP Subscales and Background Information on Impact on Family Subscales

Variable Entered	Dependent Variable - Financial Impact Fathers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Education	.571957	.57196	1.72501	F1,21	10.20980	.0044*
Other Children with Problems	-.403381	.69095	1.55776	F2,20	9.13553	.0015*

*p < .05, two-tailed.

Table 28

Multiple Regression Results of Mothers and Fathers Separately: Impact on Family Subscales and Background Information on CHIP Subscales

Variable Entered	Dependent Variable - Coping Pattern I Mothers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Other Children with Problems	.548991	.54899	8.48980	F1,21	9.05974	.0067*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - Coping Pattern I Fathers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Affected Eye(s)	-.442271	.44227	10.49543	F1,21	5.10654	.0346*
Financial Impact	.434872	.61949	9.41313	F2,20	6.22749	.0079*

*p< .05, two-tailed.

Table 28 (Continued)

Multiple Regression Results of Mothers and Fathers Separately: Impact on Family Subscales and Background Information on CHIP Subscales

Variable Entered	Dependent Variable - Coping Pattern II Fathers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Income	-.564607	.56461	9.28866	F1,21	9.82711	.0050*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - Coping Pattern III Mothers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Financial Impact	.577675	.57768	2.74796	F1,21	10.51774	.0039*
Other Children	.379414	.67540	2.54394	F2,20	8.38793	.0023*

*p < .05, two-tailed.

Table 28 (Continued)

Multiple Regression Results of Mothers and Fathers Separately: Impact on Family Subscales and Background Information on CHIP Subscales

Variable Entered	Dependent Variable - Coping Pattern III Fathers (n = 23)					
	Beta	Multiple R	Standard Error	DF	F	P
Affected Eyes	-.5233525	.52352	5.39444	F1,21	7.92873	.0104*
General-Negative Impact	.446660	.68061	4.75326	F2,20	8.62987	.0020*
Religion-Support	-.418904	.79705	4.01981	F3,19	11.03227	.0002*
Coping-Positive Impact	-.304268	.84565	3.65012	F4,18	11.29606	.0001*

*$p < .05$, two-tailed.

Multiple Regression Analysis of Mothers and Fathers as a Total Group for Impact on Family and CHIP Subscale Scores

The multiple regression results for the Impact on Family and CHIP subscales are presented in Tables 29 and 30. The following variables were entered for the Impact on Family subscales: Coping Patterns I, II, and III, education, employment, income, religion-support, number of children, birth order of visually impaired child, other children with problems, gender of visually impaired child, diagnosis, age of visually impaired child, eye problem, gender of parents, parents age, and affected eye(s). With the analysis of the CHIP subscales as dependent variables, the Impact on Family subscales of Total Impact, General-Negative Impact, Disruption of Social Relation, Coping-Positive Impact, Financial Impact, were entered with the other independent variables previously mentioned.

With the dependent variable Total Impact, the two independent variables of Coping Pattern III and Involved Eye(s)s accounted for 32% of the variance. Coping Pattern III and Affected Eye(s) accounted for 34% of the variance for the dependent variable of Total Impact. No independent variables were statistically significant for the dependent variable of Disruption of Social Relations. The independent variables of Coping Pattern III, Number of Children, Other Children with Problems, Education, and Income accounted for 44% of the variance for the dependent variable of Coping-Positive Impact. The last dependent variable examined with the Impact on Family subscales was Financial Impact, revealing the independent variables of Coping Pattern III, Visually Impaired Child with Other Problems, and Other children with Problems accounting for 30% of the variance.

With the CHIP subscales, the first independent variable analyzed was Coping Pattern I which revealed that the two independent variables of Affected Eye(s) and Visually Impaired Child with Other Problems accounted for 18% of the variance. The independent variable of Parent's Age accounted for 17% of the variance with the dependent variable of Coping Pattern II. The last dependent variable analyzed was Coping Pattern III, with the independent variables of Parent's Gender, Eye Problem, Financial Impact, and Affected Eye(s) accounting for 48% of the variance.

Table 29

Multiple Regression Results of Mothers and Fathers as a Total Group: CHIP and Background Information on Impact on Family Subscales

Variable Entered	Dependent Variable - Total Impact Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	.345293	.34529	9.03611	F1,44	5.95613	.0188*
Affected Eye(s)	.471711	.57025	8.00079	F2,43	10.36076	.0002*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - General - Negative Impact Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	.364662	.36466	4.68739	F1,44	6.74845	.0127*
Affected Eye(s)	.481941	.58989	4.11190	F2,43	11.47398	.0001*

*p < .05, two-tailed.

Table 29 (Continued)

Multiple Regression Results of Mothers and Fathers as a Total Group: CHIP and Background Information on Impact on Family Subscales

Variable Entered	Dependent Variable - Coping - Positive Impact Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	-.317392	.31739	1.84974	F1,44	4.92898	.0316*
Number of Children	.294133	.43211	1.77943	F2,43	4.93609	.0118*
Other Children with Problems	.307702	.51820	1.70753	F3,42	5.13948	.0041*
Education	-.321845	.60585	1.60763	F4,41	5.94415	.0007*
Income	-.300447	.67001	1.51871	F5,40	6.51667	.0002*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - Financial Impact Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Coping Pattern III	.354719	.35472	1.86902	F1,44	6.33319	.0156*
Visually Impaired Child with other Problems	-.313776	.47346	1.78112	F2,43	6.21206	.0043*
Other Children with Problems	-.297233	.55554	1.70127	F3,42	6.24946	.0013*

*p < .05, two-tailed.

Table 30

Multiple Regression Results of Mothers and Fathers as a Total Group: Impact on Family Subscales and Background Information on CHIP Subscales

Variable Entered	Dependent Variable - Coping Pattern I Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Affected Eye(s)	-.332303	.33230	10.22830	F1,44	5.46185	.0241*
Visually Impaired Child with other Problems	-.303339	.43452	9.88021	F2,43	5.00421	.0111*

*p < .05, two-tailed.

Variable Entered	Dependent Variable - Coping Pattern II Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Parent's Age	-.421726	.42173	9.84758	F1,44	9.51838	.0035*

*p < .05, two-tailed.

Table 30 (Continued)

Multiple Regression Results of Mothers and Fathers as a Total Group: Impact on Family Subscales and Background Information on CHIP Subscales

Variable Entered	Dependent Variable - Coping Pattern III Mother and Fathers (n = 46)					
	Beta	Multiple R	Standard Error	DF	F	P
Parent's Gender	.464809	.46481	4.95394	F1,44	12.12587	.0011*
Eye Problem	-.347426	.58030	4.60931	F2,43	10.91626	.0001*
Financial Impact	.282575	.64344	4.38382	F3,42	9.89123	.0000*
Affected Eye(s)	-.274953	.69526	4.16604	F4,41	9.59068	.0000*

*p < .05, two-tailed.

Reliability of the Impact on Family and CHIP Scales

Internal consistency reliability of the Impact on Family and CHIP subscales was determined by using the Cronbach's alpha coefficient. The number of items and reliabilities for these subscales are listed in Tables 31 and 32. The Cronbach's alpha for the Impact on Family subscales ranged from .65 to .89, demonstrating a reasonable to high degree of internal consistency (Larochelle, 1989). The Cronbach's Alpha for the CHIP subscales revealed a high degree of internal consistency, ranging from .77 to .86.

Table 31

Reliability Coefficients of the Impact on Family Scale

Scale	# of Items	Cronbach Alpha
Total Impact	19	.86
General Negative (I)	10	.76
Disruption of Social Relations (II)	9	.69
Coping (III)	4	.65
Financial Impact (IV)	3	.68
Sibling Impact	6	.89

Table 32

Reliability Coefficients of the CHIP Scale

Scale	# of Items	Cronbach Alpha
Coping Pattern I	19	.86
Coping Pattern II	18	.85
Coping Pattern III	8	.77

Validity of Impact on Family and CHIP Scales for Mothers and Fathers

To further validate the constructs of impact and coping, the mean scores of the Impact on Family and CHIP subscales for mothers and fathers with children having one or two affected eyes, and children having medical problems and/or visual impairments were compared, as presented in Tables 9 through 12. The findings revealed that both mothers and fathers had higher impact scores with children having two eyes affected, and with children having medical problems and visual impairments, as compared to mothers and fathers having children with only one affected eye, or children having a visual impairment only. These findings are consistent with the theoretical understanding of the impact measure, in that the more a child's condition affects the lives of those caring for them, the higher the impact.

With the CHIP Coping Patterns, the findings revealed that mothers and fathers with children having two affected eyes actually had lower mean scores for Coping Patterns I and II, and fathers for Coping Pattern III as compared with both mothers and fathers with children having one affected eye, where the scores were universally higher for all three Coping Patterns. However, mothers with children having two affected eyes did have a slightly higher mean score on Coping Pattern III as compared with mothers and fathers with children having one affected eye. Differences were found when examining the three mean coping scores for mothers and fathers with children having medical problems and/or visual impairments. It was revealed that both mothers and fathers with children having medical problems and a visual impairment had higher mean coping scores on all three Coping Patterns, as would be expected, with the exception of Coping Pattern III for fathers, which was lower, as compared with mothers and fathers with children having a visual impairment only. These findings are consistent with the theoretical understanding of coping, in which coping behaviors are developed in response to more stressful situations. Therefore, one would expect that more coping behaviors would be employed when caring for a visually impaired child with additional medical problems and one with both eyes affected. However, this was not revealed in this study for mothers and fathers having children with two affected eyes for Coping Patterns I and II. There are various reasons that may explain this finding, such as, the Coping-Positive Impact score on the impact on Family scale revealed that these families are coping fairly well and as a result the coping behaviors on the CHIP tool may not be the behaviors they find helpful or useful. Conversely, the coping scores may indicate that they are not coping as well, however, because of the small sample size and variability in the types of visual impairments they may better be assessed individually. As outlined, even with this aberration in the coping value differences, overall the Impact on Family and CHIP subscales are valid in measuring impact and coping for this study.

Concurrent validity was examined for the Impact on Family subscales with the CHIP subscales as presented in Tables 19 and 20. It was speculated from the beginning of this study that the greater the impact on parents the more coping behaviors that would be used by them to deal with their stressful situation. In Table 19 it was revealed that Coping Pattern III for mothers from the Chip subscale significantly correlated with both the Total Impact score and Financial Impact from the Impact on Family scale, implying a relationship between the two scales. These two significant positive relationships imply that the greater the impact on the mothers, the more coping behaviors will be employed, indicating that these two scales are measuring what they intended to measure.

In Table 20 there was one significant negative inverse correlation with Coping Pattern III and Coping-Positive Impact for fathers. This inverse relationship is actually a positive association, however, because the Coping-Positive Impact score when calculated has been recoded in the opposite direction and this indicates a positive result in comparison with the other scores on the Impact on Family scale. As a result, this relationship is actually a positive association, with fathers using Coping Pattern III and Coping-Positive Impact despite the negative sign.

Table 33 represents a comparison of mothers and fathers between the Impact on Family and CHIP subscales as a group. No significant associations were revealed between the Impact subscales and the Coping Patterns, or within Coping Pattern themselves. However, the impact scores between mothers and fathers revealed positive associations on all of the subscales, implying that the Impact on Family scale is measuring to a moderate degree the construct, impact. Again, the overall validity of the scales is demonstrated.

Table 33

Intercorrelations Between CHIP and Impact on Family Subscales for Mothers and Fathers

					Mothers					
Subscale	1	2	3	4	5	6	7	8	9a	10b
Fathers										
1. Coping Pattern I	-.07	.06	.15	.02	.02	-.01	-.08	.07	-.23	.11
2. Coping Pattern II	-.20	.23	.40	.07	.13	-.00	-.03	.14	.13	-.33
3. Coping Pattern III	.00	.04	.18	.14	.06	.24	-.21	.29	-.02	.45
4. Total Impact	.01	.11	.35	.58*	.52*	.51*	-.15	.52*	.68	.69
5. General Negative I	-.04	.05	.27	.62*	.57*	.56*	-.01	.52*	.78*	.77*
6. Disruption of Social Relations II	.10	.14	.29	.52*	.44*	.51*	-.21	.42	.42	.57
7. Coping III	-.10	.17	.05	.04	.11	-.09	.66*	-.04	.06	-.21
8. Financial Impact IV	.07	.12	.36	.48*	.42*	.44*	-.25	.52*	.65	.79
9.a Sibling Impact I	-.38	-.02	.20	.20	.25	.13	-.23	.01	.34	- -
10.b Sibling Impact II	.12	-.04	.57	.95*	.86*	.82*	.50	.78	- -	.60

a The Sibling Impact I subscale refers to 12 cases in each group of fathers out of 23 cases who had other children older than 4 years of age.

b The Sibling Impact II subscale refers to 6 cases in each group of fathers out of 23 cases who had other children younger than 4 years of age.

* $p < .05$, two-tailed.

CHAPTER V

Discussion

In this study over a four month period, 23 sets of parents (both mothers and fathers) having a child three years of age or younger who was visually impaired, were examinined. The ultimate goal of this study was to obtain a better understanding of these parents and their particular situation in dealing with a child who was visually impaired. The chapter will begin by summarizing the main findings from this study. Second, the similarities and differences found with these parents will be discussed and compared with others parents having children with chronic conditions. Third, the relationships between the impact of having a visually impaired child and parental coping behaviors will be explored. Fourth, implications for nursing as ascertained from the findings of this study will be outlined. Fifth, limitations of this study will be stated and discussed. Sixth, recommendations for further nursing research in the area of parents with children who are visually impaired will be suggested.

Summary of Findings

In this study, the primary purpose was to determine what the relationship was between the impact of having a child who is visually impaired and parental coping behaviors among the parents of these visually impaired children. In addition, factors suggested in the literature (socioeconomic status, education level, and religious beliefs) that may influence the impact of having a child with a chronic condition, and the parental coping behaviors employed, were examined. The findings revealed that there were major trends in the impact among parents and coping with having a visually impaired child. The Total Impact, as measured by the Impact on Family Scale, was higher for mothers than for fathers, implying a greater perceived stress by the mothers. Although coping behaviors, as measured by the CHIP, were similar for both mothers and fathers, mothers were found to use more coping behaviors dealing with communicating with other parents and consulting with health care personnel, as compared with both scale normative data and with fathers. With both mothers and fathers, positive relationships were identified between the impact of having a visually impaired child and parental coping behaviors. In addition, explanations for these positive associations were identified, such as, Coping Pattern III (medical communication and consultation) was the best predictor for mothers' Total Impact, and education the best for fathers' Total Impact. Financial Impact and Children with Other Problems best explained the increase in Coping Pattern III for mothers. General-Negative impact was the best predictor for Coping Pattern III for fathers. With mothers and fathers, grouped together, Coping Pattern III best explained the increase in Total Impact, and Financial Impact was the best predictor for Coping Pattern III. To further explain the findings mentioned above, a more detailed description will be discussed and outlined in the rest of this chapter.

Impact upon Parents having a Visually Impaired Child: Similarities and Differences

The overall results of this study indicated that although an impact among parents having a child who is visually impaired was evident, the impact was lower when compared with the impact values obtained with a Non-Hispanic English speaking group, as reported in Stein and Jessop's (1985) discussion of the psychometric properties of the Impact on Family scale. There may be various reasons for this difference, such as the chronic condition, visual impairment, may be less demanding because of its nonfatal nature. For example, in this study no subjects had a retinoblastoma (a primary intraocular malignancy of childhood) which can be potentially fatal, and could have produced different results in the degree of parental impact. In addition, the number of medical treatments and additional caregiving demands that would be performed by parents for their visually impaired child was lower in this sample.

The only significant difference noted between mothers and fathers on the Impact on Family scale was with the Total Impact score. Mothers were found to have greater overall impact as compared with fathers. This finding may be related to the fact that mothers in this study assumed the majority of the caregiving demands for their visually impaired child. Mothers reported that they had decreased their hours of work to care for their visually impaired child, while others had stopped working because of their child's condition. Whereas, none of the fathers had stopped working because of their child's visual impairment. In addition, more mothers than fathers reported thinking about not having additional children because of the possibility of having another child with a visual impairment as opposed to a normal child. This finding suggests that these mothers were already experiencing greater stress with their present situation and would feel even more stress if they had a second visually impaired child to care for. Mothers also reported higher Total Impact scores as compared to fathers in cases of children with two affected eyes, and with children having medical problems plus a visual impairment. Again, such findings may be attributed to caregiving demands being the primary responsibility of mothers.

This sample was comprised of mothers and fathers with incomes in the middle to upper bracket and who were well educated, having graduated from High School, or having additional schooling in College or University. These parents reported that finances were not a major concern for this group, resulting in less total impact. However, there were some families in this sample that did have lower income levels with accompanying higher impact scores indicating that finances were more of a concern for them. This supports the work of Atheya and McCormick (1987) who reported that low family income was a predictor for increased family impact, and Stein and Jessop (1985) who reported that both low family income and low education were associated with higher impact scores.

There was strong agreement between both mothers and fathers that the overall financial impact of having a visually impaired child was moderate to low. This finding suggests that caring for a visually impaired child does not appear to cause major financial problems for these parents. Despite mothers reporting that they either had to stop working or decrease the number of hours worked, both mothers and fathers reported average to above average combined family incomes. Such findings were not supported by Singer and Farkas (1989), who found, in their study with mothers having children with long-term tracheostomies, that both married and single parent households with both low to high incomes felt the financial stress of caring for their child. The difference that they report can be attributed to the fact that their study was conducted in a country where a two tier health care system operates. Singer and Farkas found that the actual impact of financial stress was less with single parent families because they received subsidized medical care for their children, despite their lower economic status. On the other hand, working or higher income families did not qualify for subsidized medical care, and as a result experienced the financial burden of caring for their child with a chronic condition. In Canada, a comprehensive socialized health care system is operating, and therefore, both single and two parent families having a low to high income are eligible for the same services at a minimal cost. As a result, in this study with parents caring for their visually impaired child, one can speculate that finances may be more of a concern if this study was conducted in a setting without socialized comprehensive health care. In addition, one may speculate that as the visually impaired child gets older, there may be additional expenses, such as, transportation to and from schools, teaching assistants, and specialized school equipment that may present a greater financial impact upon the parents. At the time of this study, the children were 3 years of age and younger and not requiring the additional expenses mentioned above. However, there were some children in this study requiring other visual aids, such as contact lenses, glasses, or medications, and preschool classes that are not covered under the Canadian Medical Plan. This may account for the responses given by under one-third of the mothers and fathers in this study that additional income was needed to cover other medical expenses.

The impact score for Coping, the positive subscale for the Impact on Family scale, indicated that both mothers and fathers overall were coping positively with the experience of having a visually impaired child. This finding suggests that parents had a personal feeling of mastery in managing their child's condition despite the varying caregiving demands. Such positive coping has been reported in the literature by other authors studying families having children with long-term tracheostomies (Singer & Farkas, 1989), cystic fibrosis (Phillips, et al.; 1985), and leukemia (Schulman, 1983). However, Singer and Farkas suggest that their findings may be biased in the fact that only mothers who were coping well may have completed their questionnaire. Their study may not be reflective of mothers who are coping poorly, resulting in an inaccurate picture of positive coping. Singer and Farkas, also suggest that the mothers may have answered the coping-positive items in a socially desirable manner. In this study with parents having a visually impaired child, similar biases may have existed because there were seven sets of parents who refused to participate, and one may speculate that one of their reasons for not participating was their inability to cope well.

There was great effort by both mothers and fathers to discuss their child's problem together and to treat their child as if he/she were normal. Other authors have acknowledged open communication between spouses (Schulman, 1983) and normality (Anderson, 1981; Schulman, 1983) as characteristics of successful coping. Also, the majority of both mothers and fathers reported that having a child with a visual impairment had made them closer as a family. This finding supports other authors (Barton, 1984; Ende, 1972; Froyd, 1973; Hancock, 1988; Marcy, 1989; Matthews, 1979; Scott et al., 1985; Tuttle, 1986; West, 1981) who report that having a visually impaired child does not necessarily result in ineffectual family functioning and marital disruption, but can result in strengthening the family.

Mothers reported a slightly higher impact score on the Disruption of Social Relations as compared with fathers. Overall having a visually impaired child did not greatly affect the parents' ability to interact with family and friends. Mothers reported that traveling was more of a strain on them, but they were still able to cope with the extra stress reasonably well. Philips et al. (1985), reported that changes in family activities with children having cystic fibrosis were minimal which compares favorably with the findings in this study.

Parents of a visually impaired child reported that relatives were extremely helpful and understanding in caring for their child. This finding may suggest that relatives are an important supportive component when dealing with the stress of having a visually impaired child. Singer and Farkas (1989) found mothers with children having tracheostomies also reported relatives as being helpful.

The impact of visual impairment on siblings in the family as reported by the parents demonstrated similar findings between mothers and fathers. The sample sizes were small in this study, but the impact on other siblings as compared to the normative data, does indicate that siblings were also affected by the extra stress within the family. Phillips et al. (1985), studying children with cystic fibrosis, found that parents reported minor problems with their other childrens' behavior, such as feeling jealous or being over protective of their ill brother or sister.

Differences in the degree of impact were noted when the sample of visually impaired children were divided into those children with one or two affected eyes, and those having medical problems and/or visual impairments. As a total group (including both mothers and fathers), the impact scores were higher among parents having children with two affected eyes, and with children having medical problems plus a visual impairment, as compared to parents having children with only one affected eye, or children with a visual impairment only. The greater impact reported by these parents may suggest that they have additional caregiving demands related to the child's visual impairment and to the other medical problems which are absent with children having only one affected eye and a visual impairment only. This supports the work of Singer and Farkas (1989) who reported that mothers caring for children with long-term tracheostomies with additional medical complications (during their first year of life) and the presence of neurological problems, experienced more stress related to caregiving, and thus greater impact among these mothers. In addition, Athreya and McCormick (1987) noted greater impact among parents caring for children who were unable to perform activities of living by themselves because of their medical condition. McCubbin (1988) studying families of children with myelomeningocele, and Cauble (1988) studying families of children with cerebral palsy also found that the more severe the child's impairment, the greater the demand and impact on the whole family.

Differences were found when comparing the length of time since diagnosing a child as visually impaired and the impact between mothers and fathers. During the first eight months, mothers reported higher total impact as compared with fathers. However, after eight months, both mothers and fathers maintained moderate levels over time. An explanation for this discrepancy between mothers and fathers during the first eight months, may suggest that both mothers and fathers are responding and perceiving their situation differently. Once the diagnosis of their child's visual impairment has been made, these mothers and fathers may proceed through various stages, comparable to the grieving process, before accepting and/or adjusting to their situation, as suggested by several authors (Bristor,1984; Butani, 1974; Drotar et al., 1975; Fortier & Wanlass, 1984; Parks, 1977; Solnit & Stark, 1961; Young, 1977) studying reactions of parents of children with chronic conditions. Over the long term, these findings may suggest that both mothers and fathers may be experiencing "chronic sorrow", meaning the sorrow of their permanent situation is always present, with the intensity varying over time. Wilker et al., (1981) reported that differences existed in the frequency of chronic sorrow between mothers and fathers as their retarded child grew older. Conversely, Damrosh and Perry (1989), examining mothers and fathers of children with Down Syndrome, reported that the frequency of chronic sorrow decreased as the age of the child increased. However, Damrosh and Perry note that their data should not be viewed as contradicting other researchers work in this area because of the small sample size they used.

There were differences in impact among mothers and fathers with the birth order of their visually impaired child. Mothers reported an overall increase in impact when the visually impaired child was the second or third child. Conversely, fathers reported about the same overall impact when the visually impaired child was the first or second child. However, with fathers, when the visually impaired child was the third, there was a decrease in the overall impact. With mothers, an explanation for the increasing impact may be due to the fact that each additional child may result in more caregiving demands and thus increased stress placed on the mother. Fathers in this study were employed full-time and therefore may not be as involved on a continual basis in caring for the demands of the children, resulting in lower impact.

Parental Coping with a Visually Impaired Child: Similarities and Differences

The findings in this study suggest that parents used coping behaviors from all three Coping Patterns on the CHIP scale to help them deal with managing their visually impaired child. These findings were compared with the CHIP normative data obtained from a sample of 308 parents having a chronically ill child (McCubbin, 1987), revealing comparable results, with the exception that mothers in this study used slightly less coping behaviors in Coping Pattern II and slightly more coping behaviors in Coping Pattern III. Overall, the impact among mothers having a visually impaired child was greater than fathers, and may suggest that mothers found other coping behaviors more helpful as compared to fathers.

The only significant difference found between mothers' and fathers' coping behaviors on the CHIP scale was with Coping Pattern III, which is comprised of coping behaviors dealing with parents' relationships with other parents having children with chronic conditions, and with health care professionals. Mothers used more of these coping behaviors as compared to fathers. Although there was strong agreement between both mothers and fathers in discussing concerns about their child's visual impairment with a variety of medical personnel, such as nurses, doctors, and social workers, mothers also reported that coping behaviors such as talking with other parents in the same situation, discussing their child's condition with friends and neighbors to help them understand, and reading about their child's condition was helpful. The explanation for mothers using more of these coping behaviors may be due to the fact that they are more involved in performing the majority of prescribed medical treatments and other caregiving demands for their children because they are at home. Another reason may be that the mothers are more likely to accompany their child to office appointments rather than fathers, who are usually working during the day. As a result, mothers may be more interested in receiving information about their child's condition at these appointments. In addition, mothers in this study reported greater impact than fathers in caring for their visually impaired child, and therefore one would expect the use of more coping behaviors in response to a stressful situation. Other authors Damrosch and Perry (1989), Gibson (1986) and Schilling et al., (1985) also found differences in coping behaviors used by mothers and fathers. Schilling et al., reported that the differences in mothers and fathers responses to a stressful situation may be attributed to sex-differentiated role socialization, whereby the mother remains the traditional caregiver. As a result, both mothers' and fathers' interpretation of the same situation may be different. Gibson, reported that parents of children with cystic fibrosis, used different coping behaviors which may be due to mothers' and fathers' differing perceptions of coping resulting in the use of different coping behaviors.

The helpfulness of the coping behaviors dealing with mothers sharing their experiences of having a visually impaired child with other individuals, is supported by Hancock (1988) in her study of mothers with visually impaired children, and in Miller's (1989) autobiographical account of parents of children with cataracts. In addition, other studies examining parents of children with other chronic conditions found that sharing the experience with others was also helpful (Gibson, 1986; Van Cleve, 1989; Venters, 1981). Hancock in studying mothers having a child 5 to 17 years of age with a visual impairment reported that various types of support, such as agencies for the visually impaired, parent support groups, friends and extended family members, and other professionals in the field of visual impairment, appeared to facilitate mothers' ability to cope. In addition, Venters (1981), in a study of children with cystic fibrosis, reported that sharing the burden of their childs' condition with others was associated with strengthening long-term functioning. In other studies of children with spina bifida and cerebral palsy, Gibson (1986) and Van Cleve (1989) also reported that attending parent support groups was helpful.

Medical information about their child's visual impairment was a coping behavior more helpful to mothers than to fathers. This finding is supported by Gibson (1986) with mothers of children with cystic fibrosis, diagnosed at a younger age. However, Cauble (1988) reported that with mothers and fathers of children with cerebral palsy, fathers found medical information to be more helpful than mothers. The children in Cauble's study ranged in age from 2 to 26 years, suggesting the possibility that as children with chronic conditions get older, fathers demonstrate an increased interest in reading medical information concerning the condition.

No significant differences were found between mothers and fathers concerning Coping Patterns I and II. However, there was a higher percentage of agreement between both mothers and fathers using coping behaviors found in Coping Pattern I which focuses upon maintaining family integration and parents' optimistic outlook on life with a child with a chronic condition, as compared with Coping Pattern II which focuses upon parents' efforts to develop themselves, participate in activities to manage psychological pressures, and develop relationships with other friends. However, some specific differences and similarities were noted when examining individual responses between mothers and fathers with Coping Patterns I and II.

In Coping Pattern I there was strong agreement between both mothers and fathers that coping behaviors concerning support from one's spouse and children, and sharing concerns with one's spouse were helpful. Other researchers support these findings. Hancock (1988), reported that family support was also found to be extremely helpful for mothers in their adjustment to their child's visual impairment, and in Gibson's (1986) and McCubbin's (1984) studies with parents of children with cystic fibrosis the same was found. In addition, Van Cleve (1989) noted in her study of parents of children with spina bifida that marital satisfaction and the quality of the relationship between husband and wife were significantly related to positive coping. As well, Schulman (1983) reported that strong family and marital relationships, plus open communication were characteristics of successful coping.

More mothers than fathers reported that believing in God was helpful in dealing with their situation. This result was congruent with the findings from the question on the background information form asking mothers and fathers whether their religion had been a support to them. Hancock (1988) reported that religion assisted some mothers in their ability to cope with their visually impaired children. Whereas in Van Cleve's (1989) study with parents of children with spina bifida, no relationship was found between their belief, religious preference or church attendance and coping. Van Cleve states that the lack of association may be due to problems with the particular instrument used to measure attitudes and beliefs. Conversely, Venters (1981) found in a study with parents who had been managing their child with cystic fibrosis for several years, endowing the illness situation with meaning either scientifically or religiously, or focusing on the positive rather than the negative aspects of the situation was a useful coping strategy. In addition, Schulman (1983), reported that religious faith contributed to coping well.

Both mothers and fathers shared an overall positive outlook about their situation despite choosing different coping behaviors in Coping Pattern I which dealt with having an optimistic view. Mothers' belief that their visually impaired child was receiving quality medical care was a coping behavior in Coping Pattern I rated most highly by all of the mothers. This finding is supported by Schulman (1983) as one of the characteristics of successful coping. On the other hand, fathers rated the coping behavior, believing things will always work out from Coping Pattern I, as being most useful to them.

The coping behaviors in Coping Pattern I dealing with the care of their children's medical supplies at home, was more helpful to mothers as compared to fathers, although the usefulness of this coping behavior for mothers wasn't as high as might be expected. An explanation for this may be due to the fact that for many of the families in this study there were no medical supplies associated with their child's visual impairment. However, for those parents that did have visual aids, such as contact lenses, eye prostheses, and glasses to care for, these became the primary responsibility of the mother. Again this may be attributed to the fact that all the fathers in this study were employed full-time and more than half of the mothers were at home. As a result, the major caregiving tasks became the mothers' responsibility.

In Coping Pattern II, the coping behavior of talking with other individuals (excluding medical personnel or professional counselors) about their feelings of having a visually impaired child, was more helpful for mothers than fathers. Similar findings were reported in a study of parents with children having Down Syndrome where mothers more than fathers found it useful to share their feelings with other mothers of children with Down Syndrome (Damrosch &Perry, 1989). This finding suggests that men appear to prefer to discuss their intimate concerns about their child's visual impairment with their spouse or close family members, a coping behavior in Coping Pattern I that both parents reported useful. At the completion of one of the interviews, a statement made by one of the fathers seemed to support this finding. He stated that "When people at work ask me how my child is, I just tell them everything is okay, I don't tell them he has a problem".

There were differences between both mothers and fathers in coping behaviors used when dealing with a child with one eye affected as compared with two eyes affected. Both mothers and fathers reported using less of both Coping Patterns I and II with a child with two eyes affected. However, mothers as compared with fathers, used more coping behaviors in Coping Pattern III with a child with two eyes affected than with children having only one eye affected. It may be that for fathers, the finality of the situation with a child having two affected eyes is less stressful than caring for a child with only one affected eye. However, for fathers having a child with only one affected eye, the uncertainty of the future vision in the seeing eye may cause them to be more concerned and therefore use more coping behaviors in this situation. On the other hand, for mothers, the continued need for information from medical personnel and other parents in a similar situation exist and therefore they continue to find the coping behaviors in Coping Pattern III helpful to them.

Differences were found between mothers and fathers of children having a visual impairment only, with mothers using slightly more of all three Coping Patterns than fathers. With children having a visual impairment plus a medical problem, both mothers and fathers used all three Coping Patterns similarly. However there was one exception, fathers reported using less coping behaviors with Coping Pattern III with children having a visual impairment plus a medical problem, as compared with mothers and fathers of children having a visual impairment only. This suggests that both mothers and fathers find caring for a visually impaired child who has additional medical problems more stressful, and as a result they use more of the coping behaviors. However, mothers more than fathers require more medical information about the condition that concerns them and find it important to keep communicating with other parents and the health care team.

Differences were found when comparing the length of time since diagnosing a child as visually impaired and the coping behaviors used by mothers and fathers. Fathers coping behaviors revealed no definite pattern over time with no consistent use of one pattern more than another. In contrast, mothers reported a more consistent use of Coping Patterns I (integration, cooperation, and optimism) and Coping Pattern III (medical communication and consultation) over time. This finding may suggest that even as their visually impaired child grows older, mothers find it important to not only maintain good relationships with her spouse and family, but to maintain ongoing communication with the health professionals caring for her child.

There were differences in coping behaviors used among mothers and fathers with the birth order of their visually impaired child. Overall, mothers reported consistent usefulness of Coping Pattern III (medical communication and consultation) whether the visually impaired child was their first, second, or third child, as compared with fathers. This finding may suggest that because most mothers are the primary caregiver, they are intently interested in knowing how they can better care for their child on a continual basis. With both mothers and fathers, the use of coping behaviors in Coping Pattern II (support, esteem and stability) were helpful when their visually impaired child was their first or second child. However, there was a major decrease in helpfulness of Coping Pattern II with both mothers and fathers when their third child was visually impaired. An explanation for this major difference may have been due to the increased demands of caring for this third child when these parents already had two other children to care for. In addition, an increased level of severity of the child's visual impairment when both eyes were affected, or having a visually impaired child with additional medical problems, may have contributed to a decrease in the usefulness of Coping Pattern II behaviors. As a result, both mothers and fathers chose to concentrate less on efforts concerning their own personal activities and development of outside non professional relationships and more on obtaining the necessary medical information to care for their child. This need for information is noted by a slight increase with both mothers and fathers when their visually impaired child was their third child.

Relationship between the Impact of having a Visually Impaired Child and Parental Coping Behaviors

In this study, mothers reported a positive relationship between the impact of having a visually impaired child and the use of coping behaviors in Coping Pattern III. This positive relationship may suggest that external resources, such as understanding their child's condition, talking with other parents of children with a visual impairment and health care professionals are useful in helping mothers deal with the impact of their stressful situation. In addition, with mothers there was a positive relationship between financial impact and Coping Pattern III. However, this particular relationship seems unclear because finances did not have an overall major impact for the majority of the families in this study.

For fathers there was an inverse relationship between Coping Pattern III, the positive dimension on the Impact on Family scale, and Coping Pattern III on the CHIP scale. Because the Coping-Positive items are recoded in the opposite direction for scoring purposes on the Impact on Family scale, this relationship is actually positive. This relationship suggests that fathers deal positively with the impact of having a visually impaired child by employing coping behaviors dealing with understanding more about their child's condition, talking with other heath care professionals and parents in a similar situation.

Background Information that may Influence the Impact of having a Visually Impaired Child and Parental Coping Behaviors

There was a positive relationship for mothers between the General-Negative subscale of the Impact on Family scale and the variable, affected eyes. This positive association may be explained by examining the actual General-Negative scores for mothers having a child with one affected eye as opposed to having two affected eyes, where the scores are higher with two affected eyes. This suggests that the impact on mothers in caring for a child with two affected eyes is greater.

Fathers reported positive relationships between the Total Impact scale and education, Disruption of Social Relations and education, Financial Impact and education, and Sibling Impact II and education. In this study, these positive associations suggest that the educated fathers may have more insight into their childs' situation, thus the greater the total impact on fathers because of this educational background. However, this finding differs from Jessop and Stein's (1985) finding on the Impact on Family tool, whereby individuals with low education and low family income were indicative of increasing impact. In addition, an educated father is also more likely to have a better socioeconomic situation and be willing to invest more time and money in helping his visually impaired child. For example, an educated father may perceive a need for visual aids to broaden the child's development and be able to provide them, a situation less likely with a poorly educated father. This is not to imply that the overall impact is high because, as discussed earlier, the impact scores for fathers were generally lower as compared with values obtained from a Non Hispanic English speaking group. However, these positive associations imply that relationships exist.

Mothers reported a positive relationship between Coping Pattern I and visually impaired children having additional medical problems. This positive association suggests that the more problems a visually impaired child possesses, the more coping behaviors mothers use to assist them with maintaining and strengthening the relationships among her spouse and other family members.

Other negative associations were reported with fathers among the CHIP scales and the background information variables. There was a negative relationship between the number of affected eyes of their visually impaired child and Coping Pattern I, which focuses on maintaining family integration and a positive outlook on the situation. This negative association implies that less coping behaviors are used by fathers when more than one eye is affected. An examination of the mean differences between fathers having a child with one affected eye as opposed to two affected eyes, reveals that the coping behaviors with Coping Pattern I decreases with a child with two affected eyes. One may not expect to find this kind of result and expect that with two affected eyes more coping behaviors would be employed to care for their child. However, fathers may use more coping behaviors when dealing with a child with one affected eye because there may be a perceived threat of possible loss of the other eye, resulting in blindness. It may be with fathers caring for a child having two affected eyes, the certainty of the situation is more final and therefore they use less coping behaviors that comprise Coping Pattern I. However, this is not to suggest that fathers were not using other coping behaviors which are not on the CHIP scale or were coping poorly when dealing with a child with two affected eyes.

Fathers also had negative relationships between Coping Pattern I (integration, cooperation, and optimism), and income, and Coping Pattern II (maintaining social support, self esteem and psychological stability). These negative associations may suggest that the lower the income, the increased use of coping behaviors in Coping Patterns I and II. A negative relationship existed between Coping Pattern II and fathers' age. This negative association may imply that the older the father the less coping behaviors used in Coping Pattern II. As fathers' age increases, their maturity and other life experiences may help them deal with their child's visual impairment better.

In addition, two more negative relationships were discovered for Coping Pattern III (medical communication and consultation) with religion as a support, and Coping Pattern III with the child's eye problem. The first negative association may suggest that the more religion is viewed as a support, the less the need to use coping behaviors in Coping Pattern III. As discussed earlier in this chapter, some authors report that religion supports positive coping (Schulman, 1983). The second negative association concerning the child's eye problem is difficult to intepret because of the variety of types of visual impairments grouped into this one variable. It may be that there are specific types of visual impairments that may require more use of coping behaviors in Coping Pattern III, however this is difficult to ascertain from this particular negative association.

Predictors of Impact for Mothers and Fathers

Coping Pattern III (medical communication and consultation) acted to increase mothers' Total Impact and Financial Impact. In addition, the variable, affected eye(s) helped to explain the increase in mothers' General-Negative Impact. Education was the most important variable that helped explain an increase in fathers' Total Impact, Disruption of Social Relations Impact, and Financial Impact. In addition, the other variables, religion viewed as being supportive, affected eye(s), and Coping Pattern II acted to increase fathers' Total Impact. These findings suggest that fathers in this sample with higher education levels may be more susceptible to having increased impact. Also, Coping Pattern III (medical communication and consultation) was a predictor for fathers' Coping-Positive Impact.

Predictors of Parental Coping for Mothers and Fathers

Financial Impact, followed by the variable, having other children with problems, acted to increase mothers' use of Coping Pattern III (medical communication and consultation). Also, having children with other problems was the best predictor for mothers' Coping Pattern I (integration, cooperation, and optimism). With fathers, the variable, affected eye(s) negatively correlated with Coping Pattern I (integration, cooperation, and optimism). However, this was followed by Financial Impact which helped explain the increase in Coping Pattern I for fathers. Finally, the variable, General-Negative Impact was the best predictor to explain the increase in Coping Pattern III (medical communication and consultation).

Predictors for Mothers and Fathers, as a Group, on their Impact and Parental Coping

With mothers and fathers, as a total group, Coping Pattern III (medical communication and consultation) was the best predictor to explain the increase in their Total Impact, and General-Negative Impact, Coping-Positive Impact, and Financial Impact. In terms of mothers and fathers coping as a group, Financial Impact was the best predictor to explain an increase in Coping Pattern III (medical communication and consultation).

Implications for Nursing

In this study, it was found that the impact on parents having children who are visually impaired was apparent, and was greater when the child's level of impairment was more severe. The level of impact was greater among parents of visually impaired children with both eyes affected, and with children having a visual impairment plus additional medical problems. There were also differences in the level of impact between mothers and fathers, with mothers reporting greater total impact as compared with fathers. It is important for nurses to recognize that when assessing parents of children who are visually impaired, that differences in the level of impact may be present, especially when the child's impairment is more severe. In addition, there may be individual differences between mothers and fathers in their perception of their child's situation, resulting in varying degrees of impact. These differences may be the result of additional caregiving demands by the mothers, and therefore some mothers may benefit from having additional assistance in order to provide them some relief from their situation.

Finances were not a major concern for parents in this study in caring for their visually impaired child. All of these families were covered by a socialized health care plan, with the majority of them having average to high incomes, which may have contributed to their moderate to low impact scores concerning finances. However, for some families, the extra supplies and treatments, such as contact lenses and medications that are not covered under a socialized health care plan, may be a financial concern especially for families in a lower income bracket. Also, visually impaired children with other medical problems may have other needs, that may increase the financial hardship for some families. In addition, single parent families (which were not examined in this study) may be at risk for having financial concerns because of a lower income (Schilling et al., 1986). As these visually impaired children grow older, there may be additional financial demands, such as, teacher assistants and other visual aids which may not be anticipated by these parents who are presently caring for younger children. As a result, nurses may assist parents by recognizing those lower income families (both one parent and two parent households) requiring financial assistance in providing care for their visually impaired child, and also by providing counselling about future financial needs.

There were a variety of internal and external social supports that parents of visually impaired children found helpful in coping. Spouses, their immediate family members, relatives, and conversing with medical personnel assisted them in coping with their situation. Mothers more than fathers found speaking with other parents in the same situation was also helpful. It is important for nurses to recognize that when caring for one parent families, and two parent families without a satisfying relationship, they may require additional social support in coping as opposed with two parent families with a satisfying relationship. The primary contact with medical personnel for many of these parents is in a doctor's office, community clinic, or agency setting, and to a lesser degree, a hospital setting. Therefore, nurses must recognize their important role in supporting these families by being available to answer parent's concerns and questions about them and their child(ren). Parent meeting groups may be a supportive medium, whereby nurses could be involved with assisting these parents with their perceived needs (Van Cleve, 1989). In addition, for those parents expressing a desire to talk to families in a similar situation to them, nurses may assist them in making the appropriate arrangements for such a meeting.

Mothers more than fathers reported that reading about their child's visual impairment was extremely helpful in coping with their situation. Medical information needs were particularly important for mothers coping with young visually impaired children. Nurses may be able to assist these families with their information needs by individually consulting with them, or providing classes for these parents on topics of particular interest to them concerning caring for and raising their visually impaired child.

Although the majority of the parents in this study were coping fairly well, some differences between the level of impact among mothers and fathers, and the usefulness of particular coping behaviors were found. For nurses' assessment of both mothers and fathers, it is important to consider the individual parent's prior coping abilities, and their appraisal of the situation which may differ greatly from their spouse's perception and the nurse's perception. As a result, with a better understanding of their perceptions and the characteristics indicative of positive coping with these parents of visually impaired children, nurses can better assess the family and individual members in order to meet their needs and intervene when appropriate.

Limitations

The following is a list of the limitations of this present study:

1. This study employed convenience sampling consisting of parents (both mothers and fathers) who were the legal caretakers of a child who is visually impaired in a designated area in Western Canada. Sampling bias may have occurred in that only parents who were coping well participated, and as a result their responses may not be reflective of the general population. Therefore, the findings from this study are not generalizable beyond this sample.

2. The self-report questionnaires were coded to ensure anonymity, however the presence of the researcher in the study subjects' homes while they were completing the questionnaires may have biased their responses somewhat by not expressing their true feelings.

3. There are many definitions for the term, visual impairment. The definition devised was specifically designed for this study and included a variety of types of visual impairments with varying degrees of vision. However, in this study only some of the types of childhood visual impairments were included and therefore the results cannot be generalized beyond this sample.

4. Both the Impact on Family and the CHIP scales, contained items that created confusion for some parents. For example, on the Impact on Family scale, the statement "We have little desire to go out because of my child's illness", implies that the individual parent must make a choice based on a joint decision rather than an individual one, which may influence the findings for that statement. On the CHIP scale, statements such as, "Doing things with my children" and "Investing myself in my child(ren)", were coping behaviors that some parents stated they would use regardless of their child's visual impairment. Just because an individual does not use those particular behaviors does not necessarily imply that they are not coping well, but that

they may be using other coping behaviors not found on this instrument. Revisions to enhance content validity may increase the accuracy of measurement.

Recommendations For Further Research

Based upon the findings of this study, the following recommendations for further research in this area have been derived:

1. Include other family types such as single parent families, step families and their siblings, and compare their responses with two parent families and their siblings concerning the impact of having a child who is visually impaired and the parental coping behaviors they employ.

2. Conduct a longitudinal study examining the impact among families at the time of diagnosis and systematically follow these families to adulthood to better understand the processes and factors which influence these families and their ability to cope long-term.

3. Classify the chronic condition, visual impairment into specifically defined groups, such as (a) mild, moderate, and severely impaired according to functional limitations as related to the child's level of vision; (b) visually impaired groups with one affected eye as opposed to two affected eyes; and (c) children having a visual impairment only with children having a visual impairment plus a medical problem, whereby medical problems may be catergorized into neurological, physical, or mental impairment(s), in order to examine the similarities and differences in impact among parents and the coping behaviors used.

4. Employ a qualitative research method to examine the impact among parents having a child who is visually impaired during a specified time period, for example, from the time of diagnosis to the end of the first year.

5. Compare the chronic condition, visual impairment with other types of chronic conditions and categorize them into specific groups, such as those that are physically visible or non visible, and compare the similarities and differences in impact

among mothers and fathers and the various coping behaviors used to manage their particular situation.

Summary

It is hoped that studies such as this one will assist nurses with a beginning understanding of some of the factor[illegible]fluence the impact of having a child who is visually impaired and coping [illegible] that parents use in such a situation. In addition, findings from studies such as [illegible] will contribute to the continuing body of knowledge concerning how parents deal with children having a variety of chronic conditions. Ultimately, it is the goal to have nurses possess the knowledge necessary to assess family functioning with parents having children with chronic conditions. Thus, more appropriate intervention strategies can be implemented to promote better overall long-term care for these families.

References

Akeson, N. N. (1983). After the diagnosis-care of blind children in the United States. In K. Wybar & D. Taylor (Eds.), Pediatric ophthalmology: Current aspects (pp. 137-140). New York: Marcell Dekker.

Anderson, J. M. (1981). The social construction of illness experience: Families with a chronically-ill child. Journal of Advanced Nursing, 6, 427-434.

Athreya, B. H., & McCormick, M. C. (1987). Impact of chronic illness on families. Rheumatic Disease Clinics of North America, 13, 123-131.

Austin, J. K. (1990). Assessment of coping mechanisms used by parents and children with chronic illness. Maternal Child Nursing, 15, 98-102.

Barton, D. D. (1984). Uncharted course: Mothering the blind child. Journal of Visual Impairment, 78, 66-69.

Beckman, P. J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 88, 150-156.

Bennett, C. (1986). Parenting a special child: How difficult is it? The Exceptional Parent, 16, 50-52.

Bristor, M. (1984). The birth of a handicapped child: A wholistic model for grieving. Family Relations, 33, 25-32.

Bruhn, J. G. (1977). Effects of chronic illness on the family. The Journal of Family Practice, 4, 1057-1060.

Bryden, W. (1990, February 18). A strong sense of family. Calgary Herald Magazine, pp. 6-8.

Burr, C. K. (1985). Impact on the family of a chronically ill child. In N. Hobbs & J. M. Perrin (Eds.), Issues in care of children with chronic illnesscss (pp. 24-40). San Francisco: Jossey-Bass.

Cauble, A. E. (1988). Parental coping in families of children with cerebral palsy. Dissertation Abstracts International, 49, 1587A.

Cummings, S. T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically ill children. American Journal of Orthopsychiatry, 46, 246-255.

Damrosch, S. P., & Perry L. A. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with down syndrome. Nursing Research, 38, 25-30.

Deatrick, J. A., & Knafl, K. A. (1990). Understanding family response to childhood chronic conditions. Journal of Pediatric Nursing, 5, 2-3.

Doherty, W. J. (1985). Family interventions in health care. Family Relations, 34, 129-137.

Doherty, W. J., & McCubbin, H. I. (1985). Families and health care: An emerging arena of theory, research, and clinical intervention. Family Relations, 34, 5-11.

Drotar, D., Baskiewicz, B. A., Irvin, N., Kennel, J., & Klaus, M. (1975). The adaptation of parents to the birth of an infant with a congenital malformation: A hypothetical model. Pediatrics, 56, 710-717.

Ellison, S. K. (1986). Relationship between parental coping and current health status in school-age children with cystic fibrosis. Masters Abstract International, 25, 87.

Ende, M. (1972). Three congenitally blind infants and their mothers. Maternal-Child Nursing Journal, 1, 55-65.

Fortier, L. M., & Wanlass, R. L. (1984). Family crisis following the diagnosis of a handicapped child. Family Relations, 33, 13-24.

Friendly, D. S. (1989). Visual acuity assessment of the preverbal patient. In S. J. Isenberg (Ed.), The eye in infancy (pp. 48-56). Chicago: Year Book Medical.

Froyd, H. E. (1973). Counseling families of severely visually handicapped children. The New Outlook, 67, 251-257.

Gallagher, J. J., Beckman, P., & Cross, A. H. (1983). Families of handicapped children: Sources of stress and amelioration. Exceptional Children, 50, 10-19.

Gibson, C. (1984). Relationships between family-related factors, parent's appraisal of coping, parental coping behaviors, and the impact on the family of a child with cystic fibrosis. Unpublished master's thesis, University of Toronto, Toronto, ON.

Gibson, C. (1986). How parents cope with a child with cystic fibrosis. Nursing Papers, 18, 31-45.

Gibson, C. (1988). Perspective in parental coping with a chronically ill child: The case of cystic fibrosis. Issues in Comprehensive Pediatric Nursing, 11, 33-41.

Gortmaker, S. L., & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. Pediatric Clinics of North America, 31, 3-18.

Gottesfeld, I. B. (1979). The family of the child with congenital heart disease. MCN: The American Journal of Maternal Child Nursing, 4, 101-104.

Hancock, K. (1988). Parenting a visually impaired child: A mother's perspective. Unpublished master's thesis, University of Alberta, Edmonton.

Hanson, S. H. M. (1987). Family nursing and chronic illness. In L. M. Wright & M. Leahey (Eds.), Families and chronic illness (pp. 2-32). Springhouse, PA: Springhouse.

Hobbs, N., Perrin, J. M., & Ireys, H. T. (1985). Chronically ill children and their families. San Francisco: Jossey-Bass.

Holaday, B. (1984). Challenges of rearing a chronically ill child: Caring and coping. Nursing Clinics of North America, 19, 361-368.

Hymovich, D. P. (1981). Assessing the impact of chronic childhood illness on the family and parent coping. Image, 13, 71-74.

Hymovich, D. P. (1983). The chronicity impact and coping instrument: Parent questionnaire. Nursing Research, 32, 275-281.

Hymovich, D. P. (1984). Development of the chronicity impact and coping instrument: Parent questionnaire (CICI: PQ). Nursing Research, 33, 218-222

Hymovich, D. P., & Baker, C. D. (1985). The needs, concerns and coping of parents of children with cystic fibrosis. *Family Relations, 34*, 91-97.

Isenberg, S. J. (1989). Examination methods. In S. J. Isenberg (Ed.), *The eye in infancy* (pp. 57-68). Chicago: Year Book Medical.

Jan, J. E., Freeman, R. D., & Scott, E. P. (1977). *Visual impairments in children and adolescents*. New York: Grune & Stratton.

Jan, J. E., & Robinson, G. C. (1989). A multidisciplinary program for visually impaired children and youths. *International Ophthalmology Clinics, 29*, 33-36.

Katz, S. (1988, May). *Nursing of families with chronically ill children in Israel*. Paper presented at the meeting of the International Family Nursing Conference, Calgary, AB, Canada.

Kazak, A. E., & Marvin, R. S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33*, 67-77.

Kivlin, J. D. (1984). The infant with poor vision. *International Ophthalmology Clinics, 24*, 1-14.

Kodadek, S. M., & Haylor, M. (1988, May). Parents' perceptions of the experience of caring for a blind child [Summary]. *Proceedings of the International Family Nursing Conference*, (p. 101). Calgary, Alberta, Canada: University of Calgary, Faculty of Nursing.

Larochelle, D. R. (1989). The selection and development of psychosocial instruments. In H. S. Wilson (Ed.), *Research in nursing* (2nd ed.; pp. 333-364). Redwood City, CA: Addison-Wesley.

Longo, D. C., & Bond, L. (1984). Families of the handicapped child: Research and practice. *Family Relations, 33*, 57-65.

Mac Keith, R. (1973). The feeling and behaviors of parents of handicapped children. *Developmental Medicine and Child Neurology, 15*, 524-527.

Marcy, T. G. (1989). The blind child and his family. In S. J. Isenberg (Ed.), The eye in infancy (pp. 492-500). Chicago: Year Book Medical.

Mardiros, M. (1982). Mothers of disabled children: A study of parental stress. Nursing Papers, 14, 47-55.

Masters, J. C., Cerreto, M. C., & Mendlowitz, D. R. (1983). The role of the family in coping with childhood chronic illness. In T. G. Burish & L. A. Bradley (Eds.), Coping with chronic disease (pp. 381-407). New York: Academic Press.

Matthews, G. (1979). Services for young visually handicapped children: A parent's view. In V. Smith & J. Keen (Eds.), Clinics in developmental medicine No 73: Visual handicap in children (pp. 171-172). Philadelphia: J. B. Lippincott.

McCubbin, H. I. (1979). Integrating coping behavior in family stress theory. Journal of Marriage and the Family, 41, 237-244.

McCubbin, H. I., & Boss, P. (1980). Family stress and coping: Targets for theory, research, counseling, and education. Family Relations, 29, 429-430.

McCubbin, H. I., Joy, C. B., Cauble, A. E., Comeau, J. K., Patterson, J. M., & Needle, R. H. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42, 855-871.

McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, A. E., Wilson, L. R., & Warwick, W. (1983). CHIP-coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child. Journal of Marriage and the Family, 45, 359-370.

McCubbin, H. I., & Thompson, A. I. (Eds.). (1987). Family assessment: Inventories for research and practice. Madison, WI: University of Wisconsin.

McCubbin, M. (1984). Nursing assessment of parental coping with cystic fibrosis. Western Journal of Nursing Research, 6, 407-422.

McCubbin, M. (1987). CHIP Coping health inventory for parents. In H. I. McCubbin & A. I. Thompson (Eds.), Family assessment: Inventories for research and practice (pp. 173-192). Madison, WI: University of Wisconsin.

McCubbin, M. A. (1988). Family stress, resources, and family types: Chronic illness in children. Family Relations, 37, 203-210.

McCubbin, M. A., & Huang, S. T. T. (1989). Family strengths in the care of handicapped children: Targets for intervention. Family Relations, 38, 436-443.

Miller, G. (1989). Parents and cataract kids: Supporting the family to treat the child. Journal of Ophthalmic Nursing and Technology, 8, 22-24.

Murphree, A. L., Horn, M., & Chernus-Mansfield. (1990). Parents reactions/professional reactions to the diagnosis of visual impairment in children. American Orthoptic Journal, 40, 2-5.

Norman, G. R., & Streiner, D. L. (1986). PDQ statistics. Toronto: B.C. Decker.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. Social Casework, 43, 190-193.

Parks, R. M. (1977). Parental reactions to the birth of a handicapped child. Health and Social Work, 2, 51-66.

Patterson, J. M. (1988). Chronic illness in children and the impact on families. In C. S. Chilman, E. W. Nunnally, & F. M. Cox (Eds.), Chronic illness and disability: Families in trouble series, Vol 2 (pp. 69-107). Newbury Park: Sage.

Phillips, S., Bohannon, W. E., Gayton, W. R., & Friedman, S. B. (1985). Parent interview findings regarding the impact of cystic fibrosis on families. Developmental and Behavioral Pediatrics, 6, 122-127.

Pless, I., & Pinkerton, P. (1975). Chronic childhood disorder-promoting patterns of adjustment. Chicago: Year Book Medical.

Robinson, G. C., Jan, J. E., & Kinnis, C. (1987). Congenital ocular blindness in children, 1945 to 1984. American Journal of Diseases in Children, 141, 1321-1324.

Rolland, J. S. (1987). Chronic illness and the family: An overview. In L. M. Wright & M. Leahey (Eds.), Families and chronic illness (pp. 33-54). Springhouse, PA: Springhouse.

Rosenbaum, P. L. (1988). Children with chronic handicaps: Implications for care-giving. In R. S. Tonkin & J. R. Wright (Eds.), Redesigning Relationships in Child Health Care: Vol 2 , Poceedings of a Symposium (pp. 134-142). Vancouver, British Columbia, Canada: British Columbia's Children's Hospital.

Sabbeth, B. (1984). Understanding the impact of chronic childhood illness on families. Pediatric Clinics of North America, 31, 47-57.

Sargent, A. J. (1983). The sick child and the family. The Journal of Pediatrics, 102, 982-987.

Scharer, K., & Dixon, D. M. (1989). Managing chronic illness: Parents with a ventilator-dependent child. Journal of Pediatric Nursing, 4, 236-247.

Schilling, R. F., Kirkham, M. A., Snow, W. H., & Schinke, S. P. (1986). Single mothers with handicapped children: Different from their married counterparts? Family Relations, 35, 69-77.

Schilling, R. F., Schinke, S. P., & Kirkham, M. A. (1985). Coping with a handicapped child: Differences between mothers and fathers. Social Science and Medicine, 21, 857-863.

Schlomann, P. (1988). Developmental gaps of children with a chronic condition and thier impact on the family. Journal of Pediatric Nursing, 3, 180-187.

Schulman, J. L. (1983). Coping with major disease: Child, family, pediatrician. The Journal of Pediatrics, 102, 988-991.

Schultz, P. (1980). How does it feel to be blind? Van Nuys, CA: Muse-Ed.

Scott, E. P., Jan, J. E., & Freeman, R. D. (1985). Can't your child see? A guide for parents of visually impaired children (2nd ed.). Austin, TX: Pro-ed.

Searl, S. J. (1978). Stages of parent reaction. The Exceptional Parent, 8, F27-F29.

Shapiro, J. (1983). Family reactions and coping strategies in response to the physically ill or handicapped child: A review. Social Science and Medicine, 17, 913-931.

Singer, L., & Farkas, K. J. (1989). The impact of infant disability on maternal perception of stress. Family Relations, 38, 444-449.

Solnit, A., & Stark, M. (1961). Mourning and the birth of a defective child. The Psycholanalytic Study of the Child, 16, 523-537.

Sonksen, P. M. (1983). Vision and early development. In K. Wybar & D. Taylor (Eds.), Pediatric ophthalmology: Current aspects (pp. 85-94). New York: Marcell Dekker.

Stein, R. E. K. (1989). Introduction. In R. E. K. Stein (Ed.), Caring for children with chronic illness: Issues and stratiegies (pp. xxiii-xxx). New York: Springer.

Stein, R. E., & Jessop, D. (1984). General issues in the care of children with chronic physical conditions. Pediatric Clinics of North America, 31, 189-198.

Stein, R. E., & Jessop, D. (1985). Tables documenting the psychometric properties of a measure of the impact of chronic illness on a family (Pacts Papers). Bronx, NY: Albert Einstein College of Medicine.

Stein, R. E. , & Reissman, C. K. (1980). The development of an impact-on-family scale: Preliminary findings. Medical Care, 18, 465-472.

Taylor, D. (1983). Clinical visual assessment in infancy. In K. Wybar & D. Taylor (Eds.), Pediatric ophthalmology: Current aspects (pp. 5-9). New York: Marcel Dekker.

The Institute for Families of Blind Children (Producers). (1989). Heart to heart [Videotape]. Los Angeles, CA: Author.

Thomas, R. B. (1987a). Introduction and conceptual framework. In M. H. Rose & R. B. Thomas (Eds.), Children with chronic conditions: Nursing in a family and community context (pp. 3-28). Orlando, FL: Grune & Stratton.

Thomas, R. B. (1987b). Family adaptation to a child with a chronic condition. In M. H. Rose & R. B. Thomas (Eds.), Children with chronic conditions: Nursing in a family and community context (pp. 29-54). Orlando, FL: Grune & Stratton.

Tornquist, E. M. (1986). From proposal to publication: An informal guide to writing about nursing research. Menlo Park, CA: Addison-Wesley.

Travis, G. (1976). Chronic illness in children: Its impact on child and family. Stanford, CA: Stanford University Press.

Tuttle, D. W. (1986). Family members responding to a visual impairment. Education of the Visually Handicapped, 18, 107-116.

Urrea, P. T., & Rosenbaum, A. L. (1989). Retinopathy of prematurity: An ophthalmologist's perspective. In S. J. Isenberg (Ed.), The eye in infancy (pp. 428-456). Chicago: Year Book Medical.

Van Cleve, L. (1989). Parental coping in response to their child's spina bifida. Journal of Pediatric Nursing, 4, 172-176.

Velleman, R. A. (1990). Meeting the needs of people with disabilities: A guide for librarians, educators, and other service professional. Phoenix: Oryx Press.

Venters, M. (1981). Familial coping with chronic and severe childhood illness: The case of cystic fibrosis. Social Science and Medicine, 15, 289-297.

Ventura, J. N. (1982). Parent coping behaviors, parent functioning, and infant temperament characteristics. Nursing Research, 31, 269-273.

Ventura, J. N. (1986). Parent coping: A replication. Nursing Research, 35, 77-80.

Warnick, L. (1969). The effect upon a family of a child with a handicap. The New Outlook for the Blind, 63, 299-304.

Weiss, S. (1983). Optical aids for children with subnormal vision. In R. D. Harley (Ed.), Pediatric ophthalmology (2nd ed., Vol. 11, pp. 1349-1385). Philadelphia: W. B. Saunders.

West, E. (1981). My child is blind-thoughts on family life. The Exceptional Child, 11, S9-S12.

Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parents vs. professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatry, 51, 63-70.

Young, R. K. (1977). Chronic sorrow: Parents' response to the birth of a child with a defect. MCN: The American Journal of Maternal Child Nursing, 2, 38-42.

Appendix A

Example of the Impact on Family Instrument

Code Number _____

IMPACT ON FAMILY QUESTIONNAIRE

Directions:

Please read each statement below and circle ONE number which best describes your situation:

1 = Strongly Agree

2 = Agree

3 = Disagree

4 = Strongly Disagree

All answers will remain strictly confidential and will be used only for the purpose of this study. Your name will not appear on this form. You do not have to answer any specific question(s), unless you want to.

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	The illness is causing financial problems for the family	1	2	3	4
2.	Time is lost from work because of hospital appointments	1	2	3	4
3.	I am cutting down the hours I work to care for my child	1	2	3	4
4.	Additional income is needed in order to cover medical expenses	1	2	3	4
5.	I stopped working because of my child's illness	1	2	3	4

		Strongly Agree	Agree	Disagree	Strongly Disagree
6.	Because of the illness, we are not able to travel out of the city	1	2	3	4
7.	People in the neighborhood treat us specially because of my child's illness	1	2	3	4
8.	We have little desire to go out because of my child's illness	1	2	3	4
9.	It is hard to find a reliable person to take care of my child	1	2	3	4
10.	Sometimes we have to change plans about going out at the last minute because of my child's state	1	2	3	4
11.	We see family and friends less because of the illness	1	2	3	4
12.	Because of what we have shared we are a closer family	1	2	3	4
13.	Sometimes I wonder whether my child should be treated "specially" or the same as a normal child	1	2	3	4
14.	My relatives have been understanding and helpful with my child	1	2	3	4
15.	I think about not having more children because of the illness	1	2	3	4

	Strongly Agree	Agree	Disagree	Strongly Disagree
16. My partner and I discuss my child's problems together	1	2	3	4
17. We try to treat my child as if he/she were a normal child	1	2	3	4
18. I don't have much time left over for other family members after caring for my child	1	2	3	4
19. Relatives interfere and think they know what's best for my child	1	2	3	4
20. Our family gives up things because of my child's illness	1	2	3	4
21. Fatigue is a problem for me because of my child's illness	1	2	3	4
22. I live from day to day and don't plan for the future	1	2	3	4
23. Nobody understands the burden I carry	1	2	3	4
24. Traveling to the hospital is a strain for me	1	2	3	4
25. Learning to manage my child's illness has made me feel better about myself	1	2	3	4

		Strongly Agree	Agree	Disagree	Strongly Disagree
26.	I worry about what will happen to my child in the future (when he/she grows up, when I am not around)	1	2	3	4
27.	Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	1	2	3	4

* Answer questions 28 and 29 if there are other children in your household.

28.	It is hard to give much attention to the other children because of the needs of my child	1	2	3	4
29.	Having a child with an illness makes me worry about my other children's health	1	2	3	4

* Answer Questions 30 to 33 if your <u>OTHER</u> children are 4 years of age or older.

30.	There is fighting between the children because of my child's special needs	1	2	3	4
31.	My other children are frightened by his/her illness	1	2	3	4
32.	My other children seem to have more illnesses, aches and pains than most children their age	1	2	3	4

	Strongly Agree	Agree	Disagree	Strongly Disagree
33. The school grades of my other children suffer because of my child's illness	1	2	3	4

Appendix B

Example of the Coping-Health Inventory for Parents (CHIP) Instrument

Code Number ______

FAMILY STRESS COPING AND HEALTH PROJECT
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

CHIP

FORM D
1983
© H. McCubbin

COPING-HEALTH INVENTORY FOR PARENTS

Family Health Program

Hamilton I. McCubbin Marilyn A. McCubbin Robert S. Nevin Elizabeth Cauble

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PURPOSE

CHIP – The Coping-Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period *or* has a medical condition which call for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- For each coping behavior you used, please record how helpful it was.

  HOW HELPFUL was this COPING BEHAVIOR to you and/or your family: Circle ONE number
  3 = *Extremely* Helpful
  2 = *Moderately* Helpful
  1 = *Minimally* Helpful
  0 = *Not* Helpful
- For each Coping Behavior you did *Not* use please record your "Reason."

  Please RECORD this by *Checking* ☑ *one* of the reasons:

  Chose not to use it ☐ or Not Possible ☐

PLEASE BEGIN: Please read and record your decision for EACH and EVERY Coping Behavior listed below.

COMPUTER CODES: IID ☐☐☐☐ GID ☐☐☐ FAMID ☐☐☐☐

COPING BEHAVIORS

		Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because: Chose Not To	I do not cope this way because: Not Possible	For Computer Use Only F	S	M
1	[illegible] maintain family stability	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○		☐
2	[illegible] relationships and friendships which help me to feel important and appreciated	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
3	Trusting my spouse (or former [illegible]) to help support me and my child(ren)	3	2	1	0	☐	☐	○	☐	
4	Sleeping	3	2	1	0	☐	☐		○	☐
5	[illegible] with the medical staff (nurses, social worker, etc.) when we visit [illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		☐	○
6	[illegible] my child(ren) will get better*	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○	☐	
7	Working, outside employment	3	2	1	0	☐	☐	☐	○	
8	Showing that I am strong	3	2	1	0	☐	☐	○		☐
9	[illegible] for myself and/or other family members	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
10	[illegible] other individuals/parents in my same situation	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		☐	○
11	Taking good care of all the medical equipment at home	3	2	1	0	☐	☐	○		☐
12	Eating	3	2	1	0	☐	☐		○	☐
13	[illegible] other members of the family to help with chores and tasks at home	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○	☐	
14	[illegible] by myself	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
15	Talking with the Doctor about my concerns about my child(ren) with the medical condition*	3	2	1	0	☐	☐	☐		○
16	Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0	☐	☐	○	☐	
17	[illegible] close relationships with people	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
18	Believing in God	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○		☐
19	Develop myself as a person	3	2	1	0	☐	☐	☐	○	
20	Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0	☐	☐		☐	○
21	[illegible] together as a family (involving all members of the family)	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○	☐	
22	[illegible] time and energy in my job	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		○	☐
23	Believing that my child is getting the best medical care possible*	3	2	1	0	☐	☐ 34	○		☐
24	Entertaining friends in our home	3	2	1	0	☐	☐	☐	○	
25	[illegible] how other persons in my situation handle things	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		☐	○
26	[illegible] family relatives	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○	☐	
27	Becoming more self reliant and independent	3	2	1	0	☐	☐		○	☐
28	Telling myself that I have many things I should be thankful for	3	2	1	0	☐	☐	○	☐	
29	[illegible] hobbies (art, music, jogging, etc.)	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
30	[illegible] our family situation to friends and neighbors so they will understand [illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		☐	○
31	Encouraging child(ren) with medical condition to be more independent*	3	2	1	0	☐	☐	○	☐	
32	Keeping myself in shape and well groomed	3	2	1	0	☐	☐		○	☐
33	[illegible] social activities (parties, etc.) with friends	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
34	[illegible] with my spouse on a regular basis	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	☐	○	
35	Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0	☐	☐		☐	○
36	Building a closer relationship with my spouse	3	2	1	0	☐	☐	○	☐	
37	Allowing myself to get angry	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		○	☐
38	[illegible] myself in my child(ren)	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○		☐
39	Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0	☐	☐	☐	○	
40	Reading more about the medical problem which concerns me	3	2	1	0	☐	☐		☐	○
41	[illegible] personal feelings and concerns with spouse	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	○	☐	
42	[illegible] away from the home care tasks and responsibilities for [illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		○	☐
43	Having my child with the medical condition seen at the clinic/hospital on a regular basis*	3	2	1	0	☐	☐	○	☐	
44	Believing that things will always work out	3	2	1	0	☐	☐	○	☐	
45	Doing things with my children	3	2	[illegible]	[illegible]	[illegible]	[illegible]	○		☐

PLEASE Check all 45 items to be sure you have either circled a number or checked a box for each one. This is important.

FAM ☐☐58
SUP ☐☐60
MED ☐☐6

Appendix C

Initial Contact Letter for Potential Subjects

Dear Parent(s):

My name is Barbara Astle and I am a nursing student who is taking a master's degree in nursing at the University of Alberta. I am studying the impact that having a child with a visual impairment has on parents and how parents deal with this situation. I would like to talk to you and your spouse about the study to find out if you might be interested in being in this study.

Parents who agree to be a part of this study will be asked to fill out two questionnaires and a background information form that will take about 30 to 45 minutes to finish in their homes.

If you are interested in knowing more about this study, please let your doctor, nurse, orthoptist and/or social worker know and I will phone you. My phoning you to further explain the study does not mean that you agree to be in the study. After I have explained the study to you, I will let you decide if you would like to be a part of this study.

Thank-you for taking the time to consider being a part of this study with your spouse.

Sincerely,

Barbara J. Astle, BScN.,RN.
Master of Nursing Candidate
Faculty of Nursing
University of Alberta

Phone: 424-0890

Appendix D

Informed Consent

Study Title: Relationship between the Impact of having a Visually Impaired Child and Parental Coping Behaviors.

Researcher:	Advisor:
Barbara Astle Master of Nursing Candidate Faculty of Nursing University of Alberta phone: 424-0890	Dr. M. Allen Associate Professor Faculty of Nursing University of Alberta phone: 492-6411

Purpose of the Study

To determine the impact that having a child with a visual impairment has on you as a parent and the various ways that you as a parent may use to deal with this situation.

Procedure

Both mothers and fathers having a child with a visual impairment will be asked to complete two questionnaires and a background information form. Each parent will complete the two questionnaires and the background information form by themselves without help from each other.

The first questionnaire will ask you questions about the impact your child's visual impairment has had on you and your family. The second questionnaire will ask you questions about the various ways that you may use to deal with having a child with a visual impairment. The background information form will ask you questions about you, your husband and/or wife, and your child/children.

The two questionnaires and the background information form will take about 30 to 45 minutes to finish. You do not have to answer questions on the questionnaires or the background information form unless you want to.

Risks

There may be no benefit to you in completing the two questionnaires and the background information form. However, the information gathered from these questionnaires and background information form may help nurses better understand your situation so that other families may be helped.

Voluntary Participation and Confidentiality

You do not have to be in the study unless you want to. If you decide you want to be in the study, you are free to drop out at any time without affecting the care you or your child is getting. Let me know if you wish to drop out of the study.

A number rather than your name will be written at the top of the two questionnaires and the background information form. No one but me will know which number is your number. Your name, address, telephone number, and answers to the two questionnaires and the background information form will be kept in a locked drawer during the study. At the end of the study, your name, address, and telephone number will be destroyed. The two questionnaires and background information form will be kept in a locked drawer for five years and then destroyed. Your name will not be mentioned in any articles or talks given about this study. Any information provided by one parent will not be disclosed to the other parent.

If you have any questions, I will answer them now, or at any time. If you have any questions later, you can call me or Dr. Allen.

I ______________________________, have read this information and agree to be in the study called "Relationship between the Impact of having a Visually Impaired Child and Parental Coping Behaviors". I have been given a copy of this consent form.

______________________________ ______________

(signature of participant) (date)

______________________________ ______________

(signature of researcher) (date)

Appendix E

Verbal Instructions to Parents

Instructions to be given to parents before completing the two questionnaires and background information form.

1. Thank you for agreeing to be a part of this study.

2. In these envelopes are two questionnaires and a background information form that I would like each of you to complete by yourself.

3. It will take you about 30 to 45 minutes to complete the two questionnaires and the background information form.

4. Your name is not to be placed on the two questionnaires or the background information form.

5. Please follow the instructions at the beginning of each questionnaire and the background information form. You do not have to answer any questions unless you want to.

6. Please answer all questions by yourself without talking to your spouse.

7. If you have a question while you are completing the two questionnaires and the background information form, you may ask me about it.

8. Once you have completed the two questionnaires and the background information form, please place them back in the envelope provided, seal it and give it to me before I leave your home.

Appendix F

CODE NUMBER ________

BACKGROUND INFORMATION FORM

Please circle the number which describes your situation or write your response(s) in the space(s) provided.

All answers will remain strictly confidential and will be used only for the purpose of this study. Your name will not appear on this form. You do not have to answer any specific question(s), unless you want to.

What is your highest education level?

1. University or college degree
2. Some university or college education
3. High school graduate
4. Some high school education
5. less than high school education

2. Are you:

1. employed
2. not employed

3. What is your combined family income each year?

1. Under $10,000
2. $10,000 to $19,999
3. $20,000 to $29,999
4. $30,000 to $39,999
5. $40,000 to $49,999
6. $50,000 to $99,999
7. $100,000 or more
8. No response

4. Is your religion a source of support to you?

1. Yes
2. No
3. Not Applicable

5. How many children do you have in your family?

    1. 1 child
    2. 2 children
    3. 3 children
    4. 4 children
    5. 5 children
    6. 6 children or more

6. What is the birth order of your visually impaired child that is 3 years of age or younger?

    1. First child
    2. Second child
    3. Third child
    4. Fourth child
    5. Fifth child
    6. If different than above, please state the order ________________

7. Do you have any other children with

    1. a visual impairment only. How many ? ____________________
    2. a visual and medical problem. How many ? ________________
    3. a medical problem only. How many ? ______________________
    4. None

8. What is the sex of your visually impaired child that is 3 years of age or younger?

    1. Male
    2. Female

9. Does your visually impaired child that is 3 years of age or younger have any other medical problems?

    1. Yes, please state what kind ____________________________
    2. No

10. How old was your child when he/she was diagnosed as being visually impaired?

    ____________/__________
    years / months

11. What was your child's date of diagnosis?

__________/__________
year / month

12. What kind of eye problem does your child have?

____.

13. What is <u>YOUR</u> sex?

1. Male
2. Female

14. What is <u>YOUR</u> present age?

__________ years

Thank you very much for taking the time to answer these questions.

Appendix G

Letter for Permission to Access Subjects for the Study

Date

Address of Setting

Dear Dr. ________:

I am a nursing student who is taking a Master's degree in Nursing at the University of Alberta and I am presently working on my thesis. I am interested in examining the impact parents face in having a child with a visual impairment and the related coping behaviors used to manage this stressful situation. To complete this study, I am requesting written approval from you to access subjects from (name of setting) during the next six months.

It is understood that potential subjects will voluntarily participate in the study. They may decide to withdraw from the study at any time without loss of benefits to them. All personal information will be kept strictly confidential with final results of the study being published without reference to individual subject names or addresses.

If you have questions, please contact me or my thesis supervisor. I would appreciate hearing from you at your earliest convenience.

Sincerely,

Barbara J. Astle, BScN., RN.
Master of Nursing Candidate
Faculty of Nursing
University of Alberta
Phone: 424-0890

Marion Allen, PhD., RN.
Thesis Supervisor
Associate Professor
Faculty of Nursing
University of Alberta
Phone: 492-6411