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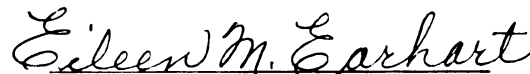
Families with Chronically Ill and Handicapped Children
and Nonaffected Children: Self-Esteem, Stressful Life
Events, Family Role Expectations and Family Relation-
ships

presented by

Linda Diane Lee Bond

has been accepted towards fulfillment
of the requirements for

Ph.D. degree in Family and Child Ecology


Major professor

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FAMILIES WITH CHRONICALLY ILL AND HANDICAPPED CHILDREN
AND NONAFFECTED CHILDREN: SELF-ESTEEM, STRESSFUL LIFE
EVENTS, FAMILY ROLE EXPECTATIONS AND FAMILY RELATIONSHIPS

By

Linda Diane Lee Bond

A DISSERTATION

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ABSTRACT

FAMILIES WITH CHRONICALLY ILL AND HANDICAPPED CHILDREN AND NONAFFECTED CHILDREN: SELF-ESTEEM, STRESSFUL LIFE EVENTS, FAMILY ROLE EXPECTATIONS AND FAMILY RELATIONSHIPS

By

Linda Diane Lee Bond

Data are available to suggest that the proportion of children with some limitation in their activities has dramatically increased over the past few years (Newacheck, Budetti & McManus, 1984). The presencer of a disabled child in a family is a potential stressor, causing families to adapt if they are to meet the needs of all family members. The degree of adaptation called for depends upon the type and severity of the condition and is not the same for all families (Earhart, 1984).

The conceptual framework selected for this study was family ecosystems. Intrafamily concepts were the primary focus of this study and included: ¹ self-esteem, ² stressful life events, ³ family role expectations and ⁴ family relationships.

Data for this study were drawn from a larger study, the Michigan Early Adolescent Survey. One hundred and ninety-seven families of the original 304 families met the criteria for inclusion in this study. The central focus of this study was the family and necessitated data from fathers, mothers and adolescents. Families were divided by

the presence of a chronically ill or handicapped child. Statistical analysis included t tests and repeated measures analysis of variance.

Five major hypotheses were tested in this study. Self-esteem was lower among the members in handicapped families. The most significant differences were among adolescents. Low numbers of stressful life events were reported for both groups of families. The majority of family members were traditional in their family role expectations. The presence of a handicapped child did not significantly influence these role attitudes. Family relationships were positive in all the study families with no significant differences between the two groups. The findings of this study suggest that on the variables measured, families with chronically ill and handicapped children are very similar to families with nonaffected children except in self-esteem.

Dedicated to the memory of our daughter

Kelly Lynn Bond

She taught our family about courage through her death
and about the pain of living with a dreaded disease.

ACKNOWLEDGEMENTS

The course of study leading to this final effort, the dissertation, has been facilitated by many persons. Eileen Earhart has seen me through my entire course of doctoral study as a teacher, academic advisor and most importantly as the chairperson of my dissertation committee. Her expertise in families with handicapped members was invaluable as I explored the literature to formulate my research questions and then proceeded to study these families. The collegial support of the research team from the Michigan Early Adolescent Survey made this all an enjoyable undertaking. Dr. Joanne Keith, Dr. Christine Nelson and Anita Covert provided a collaborative environment which served as a milieu for our growth as researchers and scholars.

One of the most rewarding experiences of my doctoral study was the opportunity to have studied with the late Dr. Beatrice Paolucci. Her scholarly abilities coupled with her humane and unpretentious qualities will continue to serve as ideals for me to emulate. Other members of my dissertation committee are acknowledged for each has offered unique contributions: Dr. Richard Featherstone (College of

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Chapter I

INTRODUCTION TO THE STUDY

The incidence of children with chronic illness or handicapping conditions has been estimated to be as high as 30 to 40 percent of all children if the conditions are broadly defined to include hearing and speech problems along with learning problems and behavior disorders (Mattsson, 1972). The presence of an affected child within a family has the potential to be a constant stress, although the nature and severity of the condition will influence, in part, the impact on the family. The meaning derived from the presence of a chronically ill or handicapped child will be different for each family, and adaptation to the situation will depend upon the family's ability to withstand the crisis of the event and their ability to adapt to meet the needs of all family members (Earhart, 1984).

Advances in medical science over the past few decades have reduced infant mortality through better and more sophisticated methods of prenatal, perinatal and neonatal care; reduced the incidence of childhood deaths due to contagious diseases; and instituted improved methods of treatment to successfully prolong life of persons affected with chronic diseases such as diabetes. In 1930, the infant

mortality rate was 65 per 1,000 live births, but by 1979 that rate had dramatically decreased to 13 per 1,000 live births. Similarly, the death rate for young children was 564 per 100,000 in 1930 while in 1978 that figure was reduced to 69. Accidents are now the leading cause of death among young children (Kovar, 1982). One outcome of aggressive medical interventions that may not have been anticipated, has been to salvage children who might otherwise have died. In some situations, the successes of medical science are not necessarily without some costs to families as well as society as a whole. The number of children who now survive has increased, but ironically, so has the number of children who have some type of long term sequelae that can potentially have a negative impact upon their lives as well as the lives of their families.

Newacheck, Budetti, and McManus (1984) noted:

Data from the National Health Interview Survey ... suggest that the proportion of children with some limitation of activity has doubled over the last two decades. The degree of limitation of activity varies from those who are unable to attend school, to those who must attend special schools, to those who attend regular schools, but are limited in their ability to participate in sports and other recreational activities (p. 232).

In the recent past families were often advised by well-meaning health care providers to institutionalize

children born with handicapping conditions.

Institutionalization of children with mental and/or physical defects, once an option, has now virtually ceased to exist for most families. The movement away from widespread use of custodial care institutions is relatively recent. The numbers of institutions to warehouse the defective and disabled members of society have been significantly lowered. In 1960 Michigan, for example, had 13,000 residents in state developmental centers, whereas in 1984, only 2,600 remain ("M.R. state," 1984).

Deinstitutionalization has led to mainstreaming handicapped individuals back into our communities, a practice not always well accepted. Families are now encouraged to accept responsibility for their children by caring for them in their own homes. This caretaking can potentially be both a positive and a negative force depending upon the family's resources and the nature of the illness or disability.

Regardless of the severity of the chronic illness or the magnitude of the handicapping condition, a major influence on how each individual family is affected is in the way the family members interpret or define their own situation. The onset or occurrence of a potentially disabling condition in a child is the time at which crisis is likely to occur, while the day to day management may account for the long term stress to which the family must adapt.

Family stress study has been greatly influenced by the

writings of Hill (1958). Hill described the occurrence of a stress as follows, "The family's definition of the event reflects partly the value system held by the family, partly its previous experience in meeting crisis, and partly the mechanisms employed in previous definition of events" (1958, p. 145).

Research studies on families affected with chronically ill or handicapped children provide considerable information, but inconsistent findings. The negative outcomes for these families have been reported as: higher than normal stress levels for mothers (Bradshaw & Lawton, 1978; Burden, 1980; Dorner, 1975; Tew & Laurence, 1973); lowered self-esteem for mothers (Cummings, Bailey & Rie, 1966) and fathers (Cummings, 1967); higher than average divorce rates (Tew, Laurence, Payne & Rawnsley, 1977); and maladjustment of the siblings (Cairns, Clark, Smith & Lansky, 1979; Crain, Sussman & Weil, 1966; Gath, 1972, 1973; Tew & Laurence, 1973). Conversely, studies exist where more optimistic results have been reported: adequate family coping (Korn, Chess & Fernandez, 1978); satisfactory marital relationships with divorce rates no higher than national norms (Buchanan, LaBarbera, Roelofs & Olson, 1979; Dorner, 1975; Freeston, 1971; Starr, 1981); relatively well adjusted siblings (Cleveland & Miller, 1977; Gayton, Friedman, Tavormina & Tucker, 1977; Pinyerd, 1983); and successful parenting (Gallagher, Cross & Scharfman, 1980).

Evidence presented in the research regarding the

presence of a chronically ill or handicapped child in the family is far from conclusive. Most of the studies have been carried out using small numbers of subjects drawn from clinical populations. Relatively few studies used control groups for comparisons. In a number of the studies mothers were used as the sole subjects. She was the spokesperson for the entire family, but study results have usually been reported as family data. Larson (1974) suggested that the most apparent weakness in family research is the reliance on the response of one family member. Safilios-Rothschild (1969) concurred with this observation and described family research in sociology as "wives' family" sociology.

When more than one family member is included in a research study, differences begin to emerge. Ferreira (1964) studied family triads on perceptivity and found children to be more perceptive than their parents; parents were more perceptive of same sex children; and the adult partners in the family were about equal in perceptivity. In contrast, Reiss and Oliveri (1983) stated, "we have noted informally in the problem-solving task, and in clinical work, that under tension families of adolescents often split, with father moving closer to an adolescent daughter and mother to an adolescent son" (p. 305).

Larson (1974) noted that it is advantageous to include all family members in a study if possible, as family system perceptions are not congruous. Further, Larson contended that children should be included in any study of

the family as they see family processes quite differently than other family members. Klein (1983) emphatically supported the use of the entire family as the primary unit of analysis in family studies if the results are to be valid and meaningful.

Evidence is emerging in the family research literature to suggest that the use of multiple family members in any study of the family will provide a more valid view of the family. In this study, three family members, the father, the mother and one early adolescent child were included to provide a broad perspective of their family situation. Each subject, responding to similar items, supplied data to provide a comprehensive picture of the family as a group in the selected areas of self-esteem, stressful life events, family role expectations, and family relationships.

Purpose of the Study

The purpose of this study was to determine if differences exist between families with healthy, nonaffected children and families with chronically ill and handicapped children in the areas of self-esteem, stressful life-events family role expectations, and family relationships. In view of the diversity of existing research, individual responses on the selected variables provided the basis to determine if there were differences between the two family types on the identified variables.

Research Questions

1. Do individual family members (i.e. fathers, mothers and adolescents) and families as a whole with chronically ill or handicapped children differ in self-esteem from individual family members and families with nonaffected children?
2. Do families with chronically ill or handicapped children experience a different number of stressful life events than families with nonaffected children?
3. Do individual family members and families as a whole with chronically ill and handicapped children have different family role expectations from individual family members and families as a whole with nonaffected children?
4. Do individual family members in families with chronically ill or handicapped children differ in their intrafamily relationships from individual family members in families with nonaffected children?

Theory

The family ecosystems perspective served as the conceptual framework for this study. This approach has been recognized as a valid way to conceptualize the family (Andrews, Bubolz & Paolucci, 1980; Holman & Burr, 1980). A property of the family ecological perspective, that lends particularly well to this study, is the recognition that the family is the unit of central importance. Within the

context of the family ecosystem, the family is a unity of interdependent individual members.

The family ecological approach is derived from a systems perspective and is rooted in ecology. Buckley (1967) was instrumental in transferring the concepts used to explain systems functioning in the natural sciences to sociology by applying them to humans. This way of viewing the functioning of individuals and groups is now widely accepted. The term ecosystem has been attributed to Tansley (1935) and encompasses the biological and physical environments in which humans reside and are dependent upon to sustain life. The family ecosystems approach merges these orientations into a holistic perspective that encompasses the biological, the physical and psychosocial aspects of the family and its various environments.

The concept of the family as an ecosystem reflects the belief that family life and its immediate environment... form a complex, dynamic living system ... By viewing the family as an ecosystem, one can begin to understand how family life may be... the product of environmental forces... (Melson, 1980, p. 1).

Components of the Family Ecosystem

Paolucci, Hall and Axinn (1977) characterized the family ecosystem as being composed of organisms and environments, which are interdependent. The organism or the family unit has also been referred to as the

enviored unit (Andrews et al., 1980) and the family system (Broderick & Smith, 1979; Bubolz & Whiren, 1984; Kantor & Lehr, 1975; Melson, 1980). The family is composed of individuals in certain structural positions, in dynamic interaction with each other, and because of this unique relationship of the members within the system, the total family unit is influenced by changes that affect their members.

The environment has been conceptualized as being divided into three components (Hook & Paolucci, 1970). First is the natural environment which supplies all the resources to maintain life such as air, water and food. Second is the human constructed environment which includes modifications made by humans of the natural environment's physical and biological components and other social and cultural constructions (Bubolz, Eichler, & Sontag, 1979). The human constructed environment includes not only tangible components such as houses and modern machinery, but also encompasses "such constructions as language, values, norms, social patterns, systems, and institutions, which provide the basis for communication, order and coordination of human activities" (Andrews et al., 1980, p. 33). Third is the human behavioral environment. In this context, the family is considered the environment for the individual. The human behavioral environment is essential for meeting biological and physical needs for love, relationships, communication, knowledge, and self-fulfillment (Bubolz et

al., 1979).

The family is a unit of interacting individual members which can be conceptualized as an environment as well as an organism. The intrafamily environment is the milieu in which the member's grow and develop as well as function. The intrafamily environment provides the arena in which youngsters first learn about themselves in relationship to other family members and about the reciprocal nature of those relationships. Within this family environment members hold positions and enact the roles ascribed to particular positions (Dudley & Keefe, 1978). Behaviors learned in the family then form the basis for later interactions and associations outside the family. The individual's satisfaction, mood, self-esteem and personal growth are directly related to their perception of that environment (Insel & Moos, 1974). The family provides an environment where individuals inside the system have a higher level of interaction among themselves than with individuals outside the system (Broderick & Smith, 1979). Therefore, the reciprocity of these interactions influences how the individual develops autonomy, self-confidence and self-esteem (Insel & Moos, 1974). If high levels of stress are present in the family environment, there is the potential that individual development will be impaired and the system's function endangered.

The last component of the overall framework is the interaction between the family and the environment.

Interactions occur when any component of the system itself influences or acts upon the other which in turn can stimulate some type of a reciprocal reaction. This implies an exchange or transformation of energy which may enter or leave the family system as information or matter. Families, over time, develop patterns or rules that determine how energy will be used under normal circumstances (Kantor & Lehr, 1975; Paolucci et al., 1977). In times of uncertainty or stress, the changing environment demands higher levels of energy to enable the family system to adapt and cope with change (Andrews et al., 1980). If the family lacks the flexibility or resources to cope with the perceived input into the system, stress results. Measured amounts of stress have a positive effect and are growth producing, while large amounts of stress have the potential to place a strain upon families and their internal relationships (Bubolz & Whiren, 1984). The intensity of the stress can be overwhelming, so rather than having a positive effect, the potential for disruption and total disintegration of the system arises (Andrews et al., 1980).

Assumptions

1. All families in this study represent semi-open systems whose boundaries allow variable levels of interaction with the environments outside the family demonstrated by their agreement to participate in the study.
2. The family is one of the environments for the

preadolescent individual and other members.

3. Changes affecting one family member affect all family members.

Definitions

Family: a bonded unit of interacting and interdependent persons who have some common goals and resources, and for part of their life cycle, at least share living space...families with different configurations of age, sex, marital status and role patterns can be delineated (Andrews et al., 1980, p. 32).

Self-Esteem: a personal judgment of worthiness that is expressed in the attitudes the individual holds toward himself (Coopersmith, 1967, p. 5).

Family Ecosystem: a semi-closed, mutually interacting system of individuals characterized by long term, intimate relationships (usually blood, marriage, or adoption) and the complex set of environments that surround and sustain them (Melson, 1980, p. 262; Paolucci et al., 1977, p. 15).

Family Role Expectation: agreement by family members regarding acceptable behaviors for enacting roles, usually arising out of general societal consensus and tempered by proscriptions from reference groups such as extended family and religious organizations (Nye & Berardo, 1973, p. 10).

Handicap: figuratively, any disadvantage that

renders success more difficult (Webster, 1961). Any mental, physical or behavioral deficit that poses a barrier to the individual.

Chronic Illness: a sickness or disease of long duration (Osol, 1973).

Hypotheses

Five major hypotheses were proposed for this study.

- H1 There is no difference in self-esteem between individual family members and families as a whole with chronically ill and handicapped children and individual family members and families as a whole with nonaffected children.
- H2 There is no difference in stressful life events between families with chronically ill and handicapped children and families with nonaffected children.
- H3 There is no difference in family role expectations between individual family members and families as a whole with chronically ill and handicapped children and individual family members and families as a whole with nonaffected children.
- H4 There is no difference in family relationships in adolescents in families with chronically ill and handicapped children and in families with nonaffected children.
- H5 There is no difference in family relationships

between fathers and mothers in families with chronically ill and handicapped children and in families with nonaffected children.

Limitations

The classification of the families of the chronically ill and handicapped into one category without regard for the intensity of the condition is a major limitation of this study. A family with a child who has severe physical and mental impairments and a family with a child with episodic asthma attacks may not have the same level of concern for either the child's general welfare or the family's future. Further, great differences may exist in the amount of energy required to maintain the child both in terms of physical care and the resources needed to maintain a state of optimal health to promote growth and development. No attempt was made in this study to directly measure the differences between families with children with the various chronic illnesses or handicapping conditions, if indeed there are differences.

The study did provide a screening method to identify families with a chronically ill or handicapped child. Families were asked to respond positively if they had a child with any one of a number of diseases and/or handicapping conditions. The list was not intended to be all inclusive. No question regarding the severity of the conditions was posed, nor were parents asked directly to

judge the impact of the diagnosis upon the family.

Importance

The questions of how family units adapt to a chronically ill or handicapped child along with the effects on individual family members have not been adequately addressed in the literature. There is some evidence to suggest that these families do adapt and that they are able to function in a healthy manner (Longo & Bond, 1984). Few studies have been reported which compare the target group to a control group to reach their conclusions.

In this study a nonclinical population, scientifically selected from the entire pool of early adolescents attending public and private school within the state of Michigan was used. This methodology is based upon the assumption that these families are representative of the state population and also that the incidence of chronically ill and/or handicapped children within the families is no different than the general population.

No single diagnostic category was isolated as criterion for entry into the study. Rather than focusing upon the etiology of the disability, the purpose of this study was to compare families on a number of variables, regardless of the disability or handicap, in an attempt to better understand how the family unit is affected.

Early adolescents and their parents were included as subjects in the study, thereby, providing information on the

variables from three perspectives. Few studies have been reported using this method of data gathering, but rather have generalized to the entire family based on the report of a single member, usually the mother. The concept of family data is gaining support. Schumm, Barnes, Bollman, Jurich, and Milliken (in press) suggested that family variables will be positively intercorrelated with each other as a consequence of an underlying "family" factor. Comparing and contrasting the individual family members' responses will be an important contribution to the field of family research and will add to our understanding of how families cope with having a chronically ill or handicapped child.

Chapter II

THE REVIEW OF THE RELATED LITERATURE

The review of the literature is organized into five sections. In section one, selected literature related to families with chronically ill and handicapped children is reviewed. In section two, family stress and coping with a particular emphasis on life events are addressed. In section three, relationships in families with early adolescent children are discussed. In section four, family role expectations are reviewed, while in section five self-esteem, particularly the developmental aspects, is reviewed. The literature reviewed in this chapter was selected for its relevance to this particular study.

Families with Chronically Ill and Handicapped Children

The presence of a child with a chronic illness or a handicap has long been recognized as a stressor in the family. The literature on these families has been confined to two themes. First are the those writings reflective of the notions of loss and sorrow suggested by Olshansky (1962) and Solnit and Stark (1961). That is, families will not be

able to adjust and will become dysfunctional, succumbing to the pressure of having a disabled child. Second are the studies and reports of a more optimistic orientation that presume adaptation and coping are possible (Bristol, 1984; Longo & Bond, 1984). These writings acknowledge that the affected child is a stressor, but report ways in which families are able to adapt. Gallagher, Cross and Scharfman (1980) suggested that the key to successful coping may be the family's ability to put this event into perspective by not having it dominate every aspect of the family's life. Venters (1981) proposed that time may be an important factor in adaptation, in that families are able to adjust and mediate the stress of the illness by adjustment in intrafamily processes and relationships.

Impact upon parents. Parents are faced with the loss of their idealized child at the time of diagnosis (Gallagher et al., 1980). Wikler (1981) suggested that for families with mentally retarded children the stresses are exacerbated by unexpected discrepancies between what might have been and what is. Mattsson (1972) noted that with children affected by chronic illness, concerns were related to the medical care of the disease and possibly the life expectancy of the child, but also to the expense of medical care, interference with schooling and leisure activities, and in the long term affects on expected normal adult activities such as career and marriage.

Most writers agree that a chronically ill or

handicapped child does pose a threat to the integrity and functioning of the family system. Nevin (1979) suggested that there was a direct relationship between the severity of the condition and amount of stress incurred. Disagreement exists in identifying what family effects can be precipitated by the presence of a disabled child. Several investigators have presented evidence to support the notion of successful coping. The presence of a strong social support network was identified by Schilling, Gilchrist and Schenke (1984) as a crucial factor in coping. They identified support groups as important primarily because members have a common bond through their affected children and a mutual need to share via the group process. Gallagher, Cross and Scharfman (1981) supported the benefit of both personal and professional networks in coping as do others (Buchanan et al., 1979; Kazak & Marvin, 1984).

Not all studies reviewed agreed upon the value of support networks outside the family. Bradshaw and Lawton (1978), for example, disagreed with these findings. They suggested that outside support in the form of personal support or goods did not significantly alter the stress levels of mothers of severely handicapped children.

Intrafamily processes have also been identified as factors in coping. Role flexibility with both spouses involved in child care and family maintenance is one component (Gallagher, Beckman-Bell & Cross, 1983; Gallagher, Scharfman & Bristol, 1982). Role adjustment was the term

applied to families noted to adhere more rigorously to traditional roles, that is the mother in the home in the caretaker role while the father has little responsibility for the care of the child, but spends his time to provide financially for the family (Kazak & Marvin, 1984). The maintenance of traditional patterns of family role behaviors may provide an element of stability in a situation devoid of traditional markers, thereby supplying a resource for coping. Faber (1959) acknowledged the dynamic nature of family roles as a positive coping measure. He further noted that in cases of mentally retarded children, the developmental progression of the parental role would be arrested at a stage that fit the mental age of the dependent child. Lack of progress through the stages of family development can be an added stressor when the family compares their situation with their reference group. The discontinuity between individual development and family development increases with the passing of time.

Marital satisfaction has been identified as an important element in a family's ability to cope with a disabled child (Friedrich, 1979; Gallagher et al., 1981). Martin (1975) studied marital breakdown using three groups: families with a spina bifida child; families with a diabetic child; and families using an ambulatory pediatric clinic. The findings suggested that families of spina bifida children had divorce rates comparable to the general population and that marriages which did end were unstable

prior to the birth of the spina bifida child. Martin further noted that marriages which remained intact were reported as better than average for the study. The work of Kazak and Marvin (1984) also supported the notion that families of handicapped children do have intact and highly satisfactory marriages.

Impact upon siblings. Evidence presented in the studies focusing on siblings is mixed. Few studies have used the siblings themselves as subjects, but rather have relied on information supplied by parents and teachers. Control groups have been used in only a few studies. Gath (1972; 1973) noted no significant differences between the behavior of siblings of children with Down's Syndrome and the siblings of cleft lip children when those two groups were compared to the siblings of normal children. Conversely, Tew and Laurence (1973) purported the frequency of maladjustment scores in siblings of spina bifida children to be four times that of the control group ($N=35$, 9; $p<0.001$). Crain, Sussman and Weil (1966) in a study of diabetic children and the siblings of diabetic children, concluded that the mother-child relationship was closer with the affected child, possibly because she was playing out her perception of the "good mother" role. The energy expended in that relationship resulted in less attention to the well siblings which in effect handicapped them due to a lack of maternal attention. LaVigne and Ryan (1979) focused upon subjects from three clinics and one normal healthy group via

a behavioral questionnaire completed by the parents. Their results suggested that siblings of chronically ill children are more at risk for behavioral problems which may be due, in part, to a decrease in parental attention.

Two descriptive studies related information elicited directly from the siblings of chronically ill children and have provided some additional insights into sibling's perceptions of their situations. Iles (1979) studied siblings of cancer patients, in various stages of the disease, and summed up her findings in terms of gains and losses. Gains were identified as increased understanding of the parents' dilemma and of the disease process. Loses included disturbed interpersonal relationships both with the parents and the ill sibling as well as feelings of frustration, isolation and rejection. Pinyerd (1983) suggested that families can develop coping mechanisms to deal with the disease condition, but that a danger existed as many parents were not aware of the concerns of their well children, thereby inadvertently neglecting them.

Evidence does exist to suggest that a chronically ill or handicapped child does impose stress upon a family system. Mothers may be the most vulnerable family members (Kazak & Marvin, 1984) and feel overwhelmed by the demands of the child when coupled with other family responsibilities. Fathers want to be included in the child's care, but due to circumstances within the family may be distanced from the day to day routines (Gallagher et al.,

1981). The affected child, if an adolescent, may need to have an active role in management of his/her own care to assimilate the impact of the condition (Crummette, 1983). Siblings are at risk for behavioral problems. The stress associated with having a disabled sibling may be proportional to the severity of the handicap. Also, parents may be oblivious to the needs and concerns of their well children. In the birth order, the older female and the younger male siblings are the most frequent targets for unrealistic parental expectations, perhaps to fulfill the parent's perceptions of what might have been the role of the disabled child (Breslau, Weitzman & Messenger, 1981; Cleveland & Miller, 1977).

Much of the research on families of chronically ill and handicapped children is methodologically weak. Samples are often small and seldom are comparisons made with control groups. The majority of studies have been on subjects drawn from clinical settings, possibly because dysfunctional families attract the attention of health care providers (Kazak & Marvin, 1984). Fathers and children have been almost totally excluded from the studies, with most studies relying upon the report of the mother as informant for the entire family, however, results were often reported as family data.

Stress and Coping

Burr (1982) described family stress as "an event that

produces change in the family social system... anything that changes some aspect of the system such as boundaries, structure, goals, processes, roles or values..." (p. 7). The popular connotation is that stress is bad, a negative experience (Antonovsky, 1979). Some types of stress are negative and threaten the well-being of the family, while other types of stress are growth producing. Writers have dichotomized stress into two categories, normative and nonnormative. For example:

Under the general rubric of "stress," family social scientists have made a concerted effort to document the normative stressor events... including predictable developmental changes over the life span in individual members of the family unit and in the family unit as a whole... and nonnormative stressor events... including unanticipated situational family experiences, which usually place the family in a state of instability and which call for some creative effort to cope with the situation. (McCubbin, Cauble and Patterson, 1982, p. XII)

The family system is constantly adjusting to the impact of some type of stressful situation. Low levels of stress can serve as a stimulus for growth and to strengthen the relationships within the family unit. Normative life-events or stressors should lead to growth through adjustments within the system (Boss, 1980). Olsen characterized "normative stressors as the demands faced over the life

cycle...described in terms of family transitions, family passages, family developmental tasks and family life events" (Olsen, McCubbin, Barnes, Larsen, Muxen, and Wilson, 1983, p. 120).

While in the midst of multiple normative stressors, Antonovsky (1979) suggested that groups or families are only vulnerable to breakdown or disintegration if they are experiencing an overload, that is, internal conflicts and disorganization simultaneously coupled with large amounts of external stress. Families do attempt to maintain the system in a balanced state or homeostasis. This is usually possible providing the magnitude and multiplicity of the stressors are not too great.

Family stress is identified as a tension state that arises from either actual or perceived demands that call for a degree of adjustment or adaptation (Antonovsky, 1979; Melson, 1980; Olsen et al., 1983). The source of tension or strain is the stressor. Aside from those changes normally occurring in families across the life cycle, a variety of unexpected events also occur. The impact of nonnormative events is not the same for all families and is likely to be tempered by a variety of factors. The internal state of the organism or the family has already been presented as one factor.

A second factor concerns the "subjective definition" of a situation (Boss, 1980) or how the family defines the seriousness of an event (Olsen et al., 1983). Researchers,

concerned with the impact of life events, have attempted to quantify these events to aid in understanding the impact upon individuals and families. Holmes and Rahe (1967) developed the Social Readjustment Scale (SRS), one example of a way to measure the impact of nonnormative events. Study participants were asked to rate the seriousness of a number of life events. The high consensus among their study subjects suggested those items have similar meaning to all regardless of demographic, cultural, religious or other differences. One particular correlation for the Holmes and Rahe scale has been cited, that is, the relationship between magnitude of the score and the occurrence of physical illness. Minour and Holmes (1967) suggested that from their studies the "SRS achieved etiological significance as a necessary, but not sufficient cause of illness and accounted, in part, for time of onset of disease" (p. 219). Despite a challenge by Brown (1974) to the validity of retrospective recall about life events and therefore the usefulness of instruments in prediction of illness, scales such as Holmes and Rahe's continue to appear both in the scientific and the popular literature.

A third factor cited as influencing the impact of stress on a family has been characterized as "pile-up" (McCubbin & Patterson, 1982). Pile-up is a term for the additive effect, that is, the addition of a new event coupled with an already stressful situation which has the potential to disrupt the system. For example, families

who continuously deal with high levels of stress such as having a chronically ill family member may not be able to withstand the effects of unemployment. The cumulative effect of continuous stress punctuated by additional life events contribute to the phenomenon of pile-up. "Life events normative and nonnormative, that are experienced by the family as a whole or by any member are all added together to determine the magnitude of a family's life change" (Olsen et al., 1983, p. 20).

Coping strategies, or what people do to feel better in times of stress, are frequently called into play (Pearlin & Schooler, 1978). Antonovsky (1979) identified these responses as generalized resistance resources (GRR) and described them as characteristics of the group that can facilitate effective tension management either by avoiding the stressors completely or if encountered, dealing with the stressor in a direct manner. Coping resources are not limited to a single domain, but rather encompass such areas as cognition, emotions, biological resources, and material resources such as money.

Olsen and associates (1983) divided coping strategies into two categories, internal and external. Internal sources for the individual include psychological and cognitive processes to develop explanations for stressors. At a family unit level, internal system adjustment is evidenced if family members are able to be flexible in their roles and willing to assume the role of another, either

temporarily (Boss, 1980) or in the case of prolonged stress, family members may need to assume new roles on a more permanent basis to maintain stability and unity (McCubbin & Patterson, 1982). Strict adherence to traditional gender roles has been associated with negative coping, thereby supporting the notion of role flexibility as a positive coping resource (Patterson & McCubbin, 1984). Additional internal resources identified with coping are high levels of self-reliance and self-esteem for the individual family members along with maintaining family integration (McCubbin & Patterson, 1982).

External coping resources for a family include social support of a wide variety. Andrews, Bubolz and Paolucci (1980) described the importance of links between the family and support systems. Those were subdivided into three categories: formal support systems such as social service, health care agencies or those organizations which provide the family with goods and services; nonformal support systems such as clubs and support groups; and the informal support system comprised of relatives and friends. In addition to a strong social support network, families must have insights to recognize their need of assistance from the formal system and then be prepared to accept the help offered (Antonovsky, 1979; Olsen et al., 1983). Reiss and Olver (1980) studied ways to assess a family's coping ability. They submitted that families use two types of coping resources: (1) strategies composed of everyday or

usual routines to provide stability through a recognized pattern of behaviors and (2) extraordinary strategies including novelty responses such as guessing to cope with unusual events.

Pearlin and Schooler (1978) suggested that not all coping strategies will be successful. They cited several reasons for altered coping including: failure to recognize the source of stress; lack of skills or knowledge to overcome the problem; and situations that are impervious to all coping efforts and will remain despite whatever tactics are employed. In such cases, it was suggested that a process of internal cognitive activity be employed to explain away the stress.

Coping is a complex process that is employed by the family to maintain the system in a state of equilibrium. Families have a limited tolerance for stress and strain, so must call coping strategies into action at frequent intervals. Families with high levels of internal and external coping resources are most resilient. Those families can overcome stress in a way that causes them to grow and become a stronger unit. Conversely, families with low levels of coping resources are vulnerable to the strain which can lead to disorganization and possible demise.

Family Relationships

The intrafamily system is a complex of interrelating individuals who have dual responsibility; (1) to maintain

the family system and its integrity and (2) to themselves for their own development and self-interests (Kantor & Lehr, 1975). Families with children have varying levels of complexity depending in part on the number of children and their ages. The developmental tasks of children as identified by Erikson (1964) and others involve increasing self-reliance and relationships with persons outside the family. Large families can have members in different life stages, each with its unique set of tasks and each adding a degree of complexity to the intrafamily system (Aldous, 1978).

The family is comprised of three subsystems: the parental system, the sibling system, and the parent-child system (Schvaneveldt & Ihinger, 1979). The relationships within each of these subsystems influence the relationship of the others. Parents in this society feel a sense of responsibility for the care, nurturing and socialization of their children. Children in turn, are dependent upon their parents for physical and emotional support. As children reach the stage of adolescence, the family influence on the child seems to wane while peers become an important part of the youth's life (Hamburg, 1974).

The parental relationship has a strong influence over the other intrafamily relationships. Parents are expected to be role models for their children; to set the tone for how others in the family should relate to each other and to persons outside the family system. The family

environment usually considered best for optimal development of all members involves the intact nuclear family where a positive parental relationship has a history that precedes the addition of the first child. Parish, Dostal and Parish (1981) studied children's evaluation of self relationship to their families. Their subjects were 284 children in the fifth through the eighth grades from families that were classified as happy or unhappy and intact or divorced. Their results suggested that females from happy, intact families have the highest self-concept contrasted with the lowest self concept attributed to boys from unhappy, divorced families.

The sibling subsystem is established with the addition of the second child. The interrelationship of the siblings is complex and depends upon the number and ages of the children. Schvaneveldt and Ihinger (1979) reviewed the sibling literature. One criticism offered by these authors was the inconsistency in terminology describing the sibling subsystem such as birth order, that is who are singletons versus other familial positions of children: oldest, middle or youngest. Regardless of author discrepancies, these writers noted that the presence of children influences family relationships and that the larger the family, the more complex the intrafamily relationships. Siblings in large families tend to be creative in their roles to gain a unique identity within the family. Since only one child can be the youngest or oldest sibling, other roles emerge such

as the most studious, the best athlete or the most obnoxious (Bossard & Boll, 1960 quoted in Schvaneveldt & Ihinger, 1979).

Siblings relate to each other in ways that may seem mysterious. Despite what appears as attention-seeking behaviors, that is fighting and verbal barrage, there exists a bond between the siblings. Siblings develop relationships and establish boundaries that may be known only by them, but nevertheless, exist. Siblings separated by large age gaps will be less likely to form a close bond.

The parent-child subsystem may not receive enough attention by investigators during the adolescent phase of development. Klos and Paddock (1978) were critical of Erikson's omission of the parental relationship during the adolescent and young adult phases of development. They noted that normal adolescents from middle-class families considered their bonds to their parents very important. Youth rely upon their parents for advice and counsel regardless of their increasing interactions outside the family system. Belsky, Lerner and Spanier (1984) supported the notion of continued interdependence between adolescents and their parents. They suggested that adolescents and parents do not have major differences in either attitudes or values.

A study of family relationships by Jessop (1981) purported that adolescents and parents tend to be homogenous in their degree of concordance about family life. In that

study, each participant tended to idealize or enlarge upon their individual contribution to the family relationship by answering in the direction they perceived most acceptable to onlookers.

Several researchers have suggested that the well-being of adolescents is positively related to the perceived quality of the parental relationship. The notions of attachment postulated by Bowlby (1969) and others, were applied to the adolescent-parent relationship by Greenberg, Siegel and Leitch (1983) as they examined the differential effects of perceived parent and peer relationships on the self-concept of the adolescent. That study supported the continued importance of a strong parental bond. Adolescents with poor adjustment resulting from weak attachment were more vulnerable to life change, that is the effects of high stress were modulated by a positively perceived parent-adolescent relationship.

Family Roles

...a role is doing what one is expected to do. Role information includes who is to do what, when, and how often, as well as what kinds of attitudes each is to maintain toward the other and the environment. In the family, information of this kind helps define the obligations and rights of each family member and of the family as a unit. (Paolucci et al., 1977, p. 76)

Family roles are fairly universal in type or variety,

but how family roles are enacted is particular to individual family units. Familial roles may appear to be constant, but Nye and Berardo (1973) contended this was not true and that these roles are in a constant state of flux, both within the family as well as within society in general. Normal life events influence role behavior. Campbell (1970) studied family role changes as children were added to a family. Those findings supported the notion that additional children contribute added dimensions to the parental role. Mother's work loads increased proportionately to the number of children. Campbell further suggested that fathers in his study stayed relatively uninvolved with the family until there were several children, at which time fathers became more involved with childrearing decisions and at the same time, mothers became more active in family decision-making.

Family roles can be enacted in three ways: (1) traditional or segregation of men's and women's work with shared child rearing, (2) egalitarian or androgenous family roles where all tasks are shared without regard for sex-stereotyping, and (3) interchangeability of roles or tasks ascribed to a role (Nye & Berardo, 1973). Despite changing roles, particularly for women, elements of traditional beliefs still permeate women's thinking. Ambivalence may be one reason for the low numbers of women in the upper managerial levels of the work force. Peterson-Hardt and Burlin (1979) studied occupational roles and familial roles to gain some understanding of the paucity

of female executives. Women in that study were described as not as motivated to succeed in business as men, but also that women had less time and energy to devote to a career because of unequal family role demands. This supports a popular notion, that even in more egalitarian households, women may still assume major responsibility for the family.

The homemaker role has recently gained recognition. Prior to the recent technological explosion, women's familial roles were labor intensive, demanding a great deal of time and energy to fulfill. The current availability of labor saving devices and the role of the education system in socialization of children are but two reasons that make it easier for women to expand their number of roles to include some roles traditionally ascribed to males including employment outside the home (Rollings & Nye, 1979). At the same time, men are seen as more active participants within the family. Changes in women's roles will necessitate changes in the roles of all other family members (Campbell, 1970; Paolucci et al., 1977), that is more flexible role relationships and shared power which lead to an optimal environment for personal growth and integrity of the system (Pratt, 1976).

Women continue to experience conflict regarding work roles outside the home. Despite the large number of women in the work force, a perception of censure still plagues many women. The notion that it is all right to work a "little" to help get the extras is fairly acceptable,

providing, of course, there are no small children (Dowdal, 1974). Attitudes towards work and family roles are part of a woman's basic identity and are strongly influenced by factors such as religion, social class, and national origin. Education, socioeconomic and occupational status are factors that temper, to some extent, attitudes towards work (Dowdal, 1974; Nye & Berardo, 1973; Peterson-Hardt & Burlin, 1979). That is, people with more education, holding white collar jobs who are in the middle socioeconomic class are more accepting of careers and out of home employment for women.

The roles of adolescent children within the family receive less attention in the literature than do adults roles. Hill (1980) suggested that changes in early adolescents are not only biologically based, but also, are mediated by the same situational variables that affect adults including family, peers, and social class. Adolescents are usually given a more active role in intrafamily processes such as decision-making. Increases in physical size and cognitive ability give children more credibility and leads quite naturally to a more active role in family affairs. Intrafamily experiences continue to be important for adolescents and help them to confirm their sense of identity. Middle-class youth, particularly, tended to comply with their parents' values and standards on the various aspects of life both inside and outside the family (Hamburg, 1974).

Research reported on family roles has often used data

from husbands and wives. Previous research suggested that few differences exist between husbands and wives in their perceptions of family role enactment (Grandbois & Willett, 1970). In those studies, much of the data has been reported as aggregate data, that is all husbands and all wives in the study. Grandbois and Willett challenged that method of analysis and suggested that only by looking at individual family units will subtle differences begin to emerge. An earlier study by Maxwell, Connor and Walters (1961) supported the methodology of gathering data from several family members as a way to better understand role performance. Their study indicated considerable similarity between spouses on parental role performance, but noted that adolescent responses provided an added dimension to the scoring on relationships. Adolescents generally viewed their relationship with their parents as more favorable than did the parents, suggesting that parents may be more affected by the changes occurring at adolescence than their children. Larson (1974) concurred that children may see relationships differently than parents. Spouses tend to be similar in their appraisal of power in families, but children viewed the father as more powerful than the mother. To understand intrafamily processes and attitudes toward role enactment, research studies must include children's opinions to provide a comprehensive picture.

Self-Esteem

Self-esteem is the feelings of regard that an individual holds towards himself. Rosenberg (1965) suggested that self-esteem is a value judgment and consists of both favorable as well as unfavorable orientation towards the self. Self-esteem is manifest in the behaviors one exhibits as s/he presents himself or interacts with others. Children develop self-esteem along with the other facets of their cognitive and affective selves. Wylie (1979) in a critical review of the literature on self-esteem, devoted considerable attention to self-esteem across the life span. Self-esteem appears to be well-developed by early childhood and then changes relatively little across the life of the individual.

The numbers of studies, sizes of samples, and the consistency among the more methodologically adequate studies (employing commonly used self-report test) suggest that these null trends represent a true lack of association in the age range studied between any one of these types of self regard scores and age. (Wylie, 1979; p. 26)

Savin-Williams and Demo (1983) challenged the practice of using single administration measures of self-esteem. These authors contended that longitudinal studies are necessary to detect changes over time. Their study used a variety of standard self-report and observational measures to study adolescents over a period of several years. These

investigators supported the notion that self-esteem is consistent overtime, being more influenced by personality characteristics than by environmental influences.

Despite evidence in support of the stability of self-esteem over time, doubt may exist regarding the period of adolescence. Adolescence has been referred to as a crisis period, a period of high stress, a time of disorganization in behaviors and attitudes, with these notions being perpetuated in the popular literature (Offer, Ostrov & Howard, 1981).

Adolescence was conceptualized as a time of turmoil resulting in support for several of the currently accepted stereotypes (Simmons, Rosenberg & Rosenberg, 1973). Subjects in that study had a lowered self-image, and more negative feelings about themselves at ages 12-14 than at ages 8-11 years. It was further suggested, that while self-esteem does not increase appreciably in late adolescence, youth become more realistic in their expectations of self thus mediating their scores. This evidence, while interesting, is not strong enough to refute the works cited earlier in support of a constant predictable development of self-esteem across the life time of an individual (Savin-Williams et al., 1983; Wylie, 1979).

Individual development of self-esteem is first influenced by parents, then later by teachers and peers (Coopersmith, 1981). Even though children's associations change as they become older, parents continue to wield a

strong influence over their child's development. A supportive, caring environment is important to the development of positive self-esteem. Adolescents value their parents approval and alter their behavior to meet their parents' expectations (Bledsoe & Wiggins, 1973; Coopersmith, 1967).

Positive self-regard is related to life experiences which involve family, peers and other associations (Coopersmith, 1959). The environments in which an individual develops are many. For children this begins in the family. Considerable evidence exists to support optimal development of self-esteem by the child and is related to patterns of family communication (Matteson, 1974); positive parental perceptions (Bledsoe et al., 1973); close parental relationships (Hollender, 1973); level of parental regard (Wylie, 1979); and a positive view of parenthood (Coopersmith, 1967). "The self-esteem behavior that the individual displays is presumably based, to a great extent, upon his prior positive and negative experiences " (Coopersmith, 1959, p. 93).

Self-esteem scores were found to decrease in youth moving from elementary to junior high school in one study. The decline in scores remained even when other factors were controlled, suggesting this was a stressful period for the study subjects (Simmons et al., 1973). Factors that lead to an unstable family environment such as divorce or unemployment are also associated with low self-esteem scores

(Coopersmith, 1967). Conversely, Wylie (1979) in summarizing the relationship between the family and the child's level of self-esteem suggested that while many studies purport a relationship between self-esteem levels and family variables, scant evidence exists to support this. She emphatically contended that no evidence exists to support variations in self-esteem related to birth order or father absence.

Positive self-esteem in parents is likely to produce positive self-esteem in their offspring. Parents who hold themselves in positive regard are more receptive to allowing children a more active role in family functioning. Matteson (1974) suggested that adolescent perceptions of parental communications with them is strongly associated with adolescent self-esteem. The low self-esteem adolescents in that study perceived parent-youth communication less positively than their parent. Parents tend to be positive in their perceptions about adolescents and in agreement over their individual rating (Bledsoe et al., 1973). Adolescents who have a close relationship with their father have higher self-esteem (Hollender, 1973). Children with high self-esteem have parents who provide them with experiences where they can be successful, thereby further enhancing their levels of self-esteem (Coopersmith, 1981). Evidence has been presented that suggests congruence between parental and children's levels of self-esteem. Studies reviewed make scant reference to intrafamily concurrence on self-esteem,

but rather highlight specific dyad relationships. The inference one might make is that high self-esteem by more than one member of a family should mean high levels for all family members.

Self-esteem is characterized as multidimensional and too complex to test with a single measure (Savin-Williams & Demo, 1983). Further, the particular facet of self-esteem that is of interest should be identified and then an appropriate instrument selected (Bedeian & Zmud, 1977). Self-report is commonly used to measure the experienced self. Instruments by Coopersmith (Coopersmith Self-Esteem Inventory, SEI) and Rosenberg (Rosenberg Self-Esteem Scale, RSE) are commonly used. Both instruments were constructed to be used with children. Coopersmith's (1981) SEI has been adapted to include a Short Form and an Adult Form. Investigators who firmly believe in the multidimensionality of self-esteem (Bedeian et al., 1977; Savin-Williams, et al., 1983) challenge the use of single comprehensive instruments. Despite this challenge, the single measure instruments remain in use. The challenge by Savin-Williams and Demo (1983) to use multiple measures is interesting particularly because they found a strong correlation between the experienced and the presented self along with stability of scores over time. Studies reviewed here do not present sufficient evidence to confirm or negate the use of multiple instruments over the common practice of using a single instrument to measure self-esteem.

Chapter III

METHODOLOGY

The purpose of this study was to examine the differences between families with a chronically ill or handicapped child and families with nonaffected children on selected intrafamily variables: self-esteem, stressful life events, family role expectations, and family relationships. Data from these variables were obtained from the Michigan Early Adolescent Survey (MEAS). MEAS was supported by funding from the Michigan Agricultural Experiment Station and the Michigan Cooperative Extension Service. The project was carried out by the Department of Family and Child Ecology and 4-H Youth Programs, Michigan State University, East Lansing, Michigan.

MEAS was a cross-sectional survey of 304 early adolescents and their parents. Respondents were assessed in a structured interview conducted in the family's home. Study data included written responses by parents to a survey questionnaire; verbal responses from youth to survey questions, which were recorded by trained interviewers; and verbal responses by parents to a number of household resident questions on a household questionnaire, also

recorded by the trained interviewer. Interviewers were instructed to conduct the questioning of the adolescent at the same time as the adult family members completed the written questionnaire, but in a location separate from the adults for privacy and to insure confidentiality of the adolescent responses.

Interviewers were residents of the participating counties and were recruited into the study by local county 4-H officials. The interviewers, as volunteers, were prepared for their role during ten hours of training. Training was conducted by the primary research staff in February, 1983. The MEAS study was explained in some detail so each interviewer would understand the purposes of the study and the tools that would be used in carrying out the interview process. Training involved: information dissemination on early adolescence and interviewing techniques, role playing to become familiar with the interviewer role, practice with interviewing adolescents in a group setting, and critique of video taped interviews.

Potential study families were contacted with an introductory letter to explain the survey and to request their participation. Families were instructed that an interviewer would contact them by telephone to confirm the family's willingness to participate in the study and to schedule an interview appointment. Most interviews were completed by June, 1983, although a few interviews were delayed until September, 1983, due to staffing time

shortages in local 4-H offices.

Human Subjects Protection

Once the study, the Michigan Early Adolescent Survey, was designed, it was submitted for approval to the University Committee on Research Involving Human Subjects. Data collection was started when approval was granted that confirmed protection of the rights of sample subjects.

Sampling Procedures

An Overview

Early adolescent subjects for this study were drawn from the population of Michigan youth in grades five through eight, who lived in family households and whose names appeared on the official Department of Education head count record of public and private schools for the 1982-1983 school year. Stratified multi-stage cluster sampling was used to identify subjects for the study.

The sample was chosen using an equal probability selection method. This method insured that state youth meeting the selection criteria had an equal probability of being drawn for inclusion in the study. This probability sampling is necessary if the results of the study are to be generalized to a larger population. Cornfield and Tukey (1956) made a distinction between a statistical generalization, dependent upon random sampling, and a nonstatistical generalization, which relies upon a thorough

knowledge of the research subject. Hence, most researchers report generalization based upon the statistical analysis, but also call upon their knowledge of the subject to project their findings to a population broader than just the study sample. The sampling technique employed in this study allows study results to be generalized to the Michigan population of early adolescent youths and their families.

Michigan counties were stratified by the size of their early adolescent population. Counties were randomly chosen; two school districts, within each county, were chosen using a table of random numbers; the same procedure was applied in selecting schools within each school district. At the final stage of sample selection, cluster sampling was employed in each school. Each cluster contained 12 students which were also chosen using a random numbers table. The sampling procedure was designed to interview equal numbers of male and female young adolescents equally divided between grades five, six, seven and eight.

County Selection

Michigan counties were stratified to form homogenous subgroups. Youth population size was the single criterion chosen as the stratifier since a comprehensive measure of family socioeconomic status was impossible to obtain. The researchers did consider an additional stratifier of household income of the counties. The counties within each stratum were almost identical, differing only in the rank ordering within the stratum. It was therefore decided to

use only population. The three substrata were: (1) highly urban, (2) counties with large cities and rural areas, and (3) highly rural counties. Eighteen counties were selected to represent the identified strata.

The eighteen counties initially chosen represented approximately one-fourth of the total number of Michigan's counties. This number of counties was chosen for two reasons: a sample large enough to be representative of the state's population of early adolescents, but yet small enough for data to be manageable; and because it was anticipated that there would be county 4-H staff to assist in the study at the local level. Once the county stratification process was completed, each county's population of early adolescents, ages 10 to 14 years old, was assigned random numbers according to its population. In order to correctly represent the proportion of early adolescents in each stratum, the cluster system was used. Stratum 1 needed eight clusters; stratum 2 needed nine clusters; and stratum 3 needed eight clusters. The list of counties with their respective numbers of clusters is shown in Table 1.

Problems became apparent as the initial county and cluster selection was examined. The most urban counties, Wayne and Oakland would be unable to complete the designated number of interviews due to insufficient numbers of 4-H staff to supervise the large number of volunteer interviewers needed. Closely related to the issue of staff

Table 1

Michigan Early Adolescent Survey: Participating Counties (1983)

Initial Counties and Number of Clusters for Sample*			
Wayne	(5)	Eaton	(1)
Oakland	(3)	Lenawee	(1)
Macomb	(1)	Allegan	(1)
Kent	(1)	Van Buren	(1)
Saginaw	(2)	Tuscola	(1)
Washtenaw	(1)	Chippewa	(1)
Kalamazoo	(1)	Emmett	(1)
St. Clair	(1)	Benzie	(1)
Calhoun	(1)	Delta	(1)
Final Counties and Number of Clusters for Sample*			
Wayne	(2)	Eaton	(1)
Oakland	(2)	Lenawee	(1)
Macomb	(2)	Allegan	(1)
Kent	(1)	Van Buren	(1)
Saginaw	(2)	Tuscola	(1)
Ingham	(1)	Marquette	(1)
Kalamazoo	(1)	Presque Isle	(1)
Genessee	(2)	Jackson	(1)
St. Clair	(1)	Benzie	(1)
Calhoun	(1)	Delta	(1)

1 cluster = 12 children

Total sample = 304

shortages, was the concern that an adequate number of volunteers could not be recruited to accomplish the large number of interviews. The researchers decided that substitutions were in order to insure an adequate number of subjects to be representative of the substrata. Three of Wayne county's clusters were reassigned to Genessee and Jackson counties. Wayne county's sample was to have been drawn from the Detroit Public Schools, primarily a black, inner-city group. In order to insure the inclusion of a similar group of youths, Flint and Jackson public schools were chosen because their respective student bodies, also represented an inner city population with similar demographic characteristics and therefore, would be very similar to the originally identified sample. One cluster from Oakland county was assigned to Macomb county, again geographically and demographically most like the original county.

A second problem occurred when some counties chose not to participate in the study necessitating further substitutions. To insure sampling representative of the substrata, county substitutions were made as follows: Ingham for Washtenaw, Presque Isle for Emmett, and Marquette for Chippewa. The least satisfactory substitution was in the upper penninsula as Marquette and Chippewa counties are dissimilar demographically. Despite the bias that this substitution brought into the sample, it was decided to maintain the commitment to include an upper penninsula

county. The final county list with the associated number of clusters is illustrated in Table 1.

School District Selection

Two school districts per county were selected using the same selection procedure that had been used for county selection. Random numbers were assigned all school districts, public and private, based upon their population. School districts were unable to provide information regarding the exact number of 10 to 14 year olds in their districts, therefore selection was based upon the total number of students enrolled in the district. There is a possibility of bias in the selection process at this point if there were disproportionate numbers, larger or smaller, of early adolescents compared to the total school population.

School districts in fourteen of twenty counties cooperated to provide student names. It was necessary to make substitutions in the six remaining counties as the school district initially identified refused to participate in the study. In four counties, permission was secured from the next district chosen by random selection. Oakland county needed to contact four school districts before receiving permission to sample in two districts. Jackson Public Schools refused to participate so the Catholic schools in the city of Jackson were substituted and sampling took place from their inner city schools. This brought the largest amount of bias into the sample, both in terms of

possible racial and religious difference.

Student Selection

Student selection occurred in two ways. Some school districts provided lists of fifth, sixth, seventh, and eighth graders. In these cases, student lists for each grade were numbered and four names were selected for each intended interview position using a table of random numbers. This was the case most often in smaller school districts. In large districts, schools were assigned random numbers based upon their population of 10 to 14 year olds, and then two schools were selected for each school district. Students were assigned random numbers based upon their population of 10 to 14 year olds, and then two schools were selected for each district. Students were assigned random numbers and selection took place using a table of random numbers. Four potential students were selected for each position necessary to conduct the study.

Students for each position were randomly numbered so that no bias would enter into the order in which families were selected. For example, if male eighth graders were needed, four names were randomly selected and then randomly numbered as to order in which the interviewer would contact them. Slightly over two times the number of families needed had to be contacted in order to fill the designated interview positions. The most difficult subjects to recruit into the study were the fourteen year old males.

Weighting the Sample

At the conclusion of the data collection period data had been collected from 285 youth, 19 fewer than the number designated for the study. Some counties were unable to interview sufficient respondents to fulfill their assigned number. To insure that strata were proportionately represented, weighting was used to bring each stratum up to the desired number and thus more nearly representative of the stratum. Stratum 1, the urban group, had the most difficulty with data collection and therefore underrepresented the youth living in urban areas. The total number of actual respondents for each stratum was identified and then divided by the target number for the stratum resulting in the number used for weighting for the particular stratum. Weights for the strata were: Stratum 1, (86.45% response) 1.1566265; Stratum 2, (95.5% response) 1.046729; and Stratum 3, (98.95% response) 1.0105263. The weights were of a proportion that did not grossly violate the original sampling design nor did they increase the numbers by such a large proportion to make statistical inference invalid (Backstrum & Hursh-Cesar, 1981).

Michigan Early Adolescent Study Families

The subjects for this study were 304 Michigan early adolescents and their parents. The parental group included 283 mothers and 212 fathers. The following sample description is from the Michigan Early Adolescent Survey:

Final Report (Keith, Hoopfer, Nelson, Covert & Bond, 1985). Characteristics of the MEAS families are shown in Table 2.

Early adolescents. The youth group was almost equally divided between males and females. The sample included 150 males (49.5%) and 154 females (50.5%). The youth, students in grades five, six, seven, and eight, were almost evenly divided among the four grades. The ages of youth ranged between 10 and 14 years, with three-quarters of them aged 11, 12, and 13, while the other one-quarter was comprised of 10 and 14 year olds.

Parents. The majority of MEAS parents were between 31 and 45 years of age (n=160, 77%). Five percent (n=20) of the parents were under thirty years of age and approximately fifteen percent (n=36) were over 46 years of age.

MEAS parents were more educated than their counterparts in Michigan. Almost twice as many parents in the sample were college graduates, with many of them having completed graduate or professional school. Likewise, half again as many parents in in the MEAS sample as compared to the Michigan census data had some college education.

The majority of parents in the sample were Caucasian (n=243, 83%). Blacks made up approximately 16 percent (n=48) of the sample while just over one percent (n=6) identified themselves as Mexican-American. This is similar to the distribution within Michigan.

Most adults, both men (n=192, 91%) and women (n=177, 63%), were employed outside the home. Most fathers were

Table 2

Characteristics of Participants in the Michigan Early Adolescent Survey
as Reported by Fathers, Mothers and Adolescents (1983)

Characteristic	n	Frequency [*]		Percentage [@]
Age in Years				
Fathers	210			
25-30		7		4
31-35		33		16
36-40		73		35
41-45		54		26
46-50		25		12
51-60		18		8
Mothers	282			
21-30		20		7
31-35		95		34
36-40		94		33
41-45		43		15
46-50		23		8
51-60		6		2
Adolescents	304	<u>Boys</u>	<u>Girls</u>	
10		20	17	12
11		34	35	23
12		37	44	27
13		38	39	25
14		22	19	13
Education				
Fathers				
High school or less		83		40
College		127		60
Mothers				
High school or less		142		51
College		139		49
Adolescents				
5		78		26
6		68		23
7		77		25
8		79		26

Table continued

Table 2 (con't)

Characteristic	n	Frequency [*]	Percentage [@]
Income			
Less than \$20,000		92	32
\$20,001 - \$30,000		86	31
More than \$30,001		105	37
Number of Children			
1		33	11
2		112	37
3		90	30
4		44	15
5		12	4
6		8	2
7 or more		4	1
Employment Status			
Fathers employed		192	91
Mothers employed		177	63
Occupation			
Fathers			
Professional		35	17
Management		33	16
Unskilled		95	46
Clerical		4	2
Farmer		13	6
Service worker		10	5
Mothers			
Professional		33	12
Management		13	5
Unskilled		17	6
Clerical		63	22
Farmer		5	2
Service Worker		13	5
Homemaker		83	30

* missing data causes some totals to be less than actual number subjects

@ totals may not add to 100 due to rounding

employed by someone other than themselves (n=150, 72%). One-fifth of the fathers were professional people, with approximately another one-fifth of the fathers in management positions. Almost 20 percent (n=42) were self-employed. Over half of the fathers reported themselves as skilled workers. Ten percent of the mothers were self-employed and fifty percent reported they were employed by someone other than themselves. Many women were engaged in office work (n=63, 33%). Thirteen percent of the mothers were professional people. Twenty seven percent of MEAS mothers were fulltime homemakers.

Families. The majority of the youth lived in two parent homes. Sixteen percent of the youth (n=49) who lived in single parent homes resided with their mothers while less than two percent (n=4) lived with their fathers. These proportions are very similar to the Michigan census data.

Ninety-five percent of the youth lived with their natural mothers; 76 percent lived with their natural fathers. Adoptive mothers and fathers accounted for only about two percent of the sample; step-mothers, another one percent; and step-fathers account for almost five percent of the sample. The number of children in the families was as follows: one, 11 percent (n=33); two, 37 percent (n=37); three, 30 percent (n=90); four, 15 percent (n=44); five, 4 percent (n=12); six, 3 percent (n=8); and seven or more, less than 2 percent (n=5).

The income of the MEAS sample was very much like the

Michigan census information on families with early adolescents. Almost one-third of the households earned between \$20,001 and \$30,000 (n=61); with another one-third (n=80) in the \$30,001 to \$55,000 income bracket. About one-fifth (n=37) of the families had incomes between \$10,000 and \$20,000. Fourteen percent (n=37) of the families were in the lowest income category of less than \$10,000. Five percent (n=8) of families had an income that exceeded \$55,000.

A large number of MEAS families, approximately 40 percent, lived in rural areas, another 30 percent reported living in town of 25,000 people or less. Twenty percent lived in large cities and their suburbs.

When examining all the demographic factors most are consistent with the statistics for the state of Michigan. The one major exception is that the parents in the sample are more highly educated than the population of people in that same age range in Michigan.

Instruments

Several instruments were used in this study. These instruments were selected to elicit information about the concepts of interest in an attempt to understand if differences exist between the two family types; families with chronically ill and handicapped children and families with nonaffected children.

Self-Esteem Inventory (SEI). The Coopersmith

Self-Esteem Inventory (SEI) was selected to measure this concept. The SEI was developed for use with children to measure the attitudes and beliefs that an individual employs when presenting him- or herself to the world. "The SEI is designed to measure evaluative attitudes toward the self in social, academic, family, and personal areas of experience" (Coopersmith, 1981, p. 1). The original instrument has been shortened by Coopersmith and adapted for ease of administration and to allow for use with adults as well as children (see Appendix A).

Two forms of the modified SEI were used in this study, the School Short Form and the Adult Form. The School Short Form includes 25 items that were selected from the original questionnaire and which have been shown to have a .86 correlation with the School Form (Coopersmith, 1967). The School Short Form does not allow for the measurement of the subscale scores, but only a total score. The Adult Form, like the School Short Form is comprised of 25 items and allows only for a total score. "The correlation of total scores on the School Short Form and the Adult Form exceeds .80 for three samples of high school and college students (n=647)" (Coopersmith, 1981, p. 2).

The SEI is designed to be self-administered with the respondent instructed to read each item and respond "Like Me" or "Not Like Me." Items responses that match those in the SEI scoring guide are totaled and the raw score is multiplied by four to arrive at the self-esteem score. This

results in the maximum possible score of 100.

Coopersmith did not establish levels of scores to denote levels of self-esteem, but rather leaves interpretation up to the individual situation to allow for the variations which are normally found in different groups. Interpretation will then depend upon the distribution of scores for each sample. Scores are usually skewed toward high self-esteem with the means generally between 70 and 80 (Coopersmith, 1981).

The SEI has been used extensively since it's development. Coopersmith (1981) cited a number of studies which have been reported to attest to the reliability and the validity of this instrument. While most studies report on the long Schol Form of the SEI, Bedeian, Geagud, and Zmud (1977) reported Kuder-Richardson reliability estimates of .71 for females and .74 for males on the Short Form. Reliability scores for the SEI in this study were .75 for the School Short Form and .79 for the Adult Form. Validity is supported by Coopersmith (1967), among others, who determined that SEI scores were significantly related to creativity, academic achievement, resistance to group pressures and perceptual constancy.

Family Events Index. The Holmes and Rahe (1967) Social Readjustment Scale (SRRS) provided the model and the foundation for a tool designed to measure the concept of stressful family events. Information about the occurrence of untoward events was sought but no attempt was made to

attach a quantitative element that would in effect rank order the events or provide a stress score. The SRRS has been used in research studies with a number of different age groups and target populations (Minour & Holmes, 1968; Yeaworth, York, Hussey, Ingle & Goodwin, 1980). Differences have been demonstrated with individual groups of subjects on the ordering of the events, but there has been almost universal agreement about the significance of the identified life events (Holmes & Rahe, 1967).

McCubbin and Patterson (1982) developed a model to understand family adaptation to stress, the Double ABCX Model. The term "pile-up" is used with this model to explain the occurrence of stressful life events and the subsequent effect upon the family. The Double ABCX Model of family stress suggests that families seldom deal with a single stressor and that their ability to cope with adverse situations depends in part on the number of stressors which occur in conjunction with the normal and expected life changes found in a dynamic family system.

Families participating in the MEAS study are intended to be representative of families in the developmental stage of early adolescence. The tasks of each developmental stage impact upon the family as individual family members cope with their own particular stage of development along with the particular stage of family development and its implied tasks. While transitions from one developmental stage to another are expected and also accepted as an ongoing part of

a family's life together, the adjustments called for by the family still may lead to anxiety and feelings of uncertainty (Olsen et al., 1983). The accomplishment of these normally expected tasks is potentially stressful, but when the presence of a child with a chronic illness or handicapping condition is added to the family unit, a milieu for pile-up is established.

A Family Events Index was compiled to measure the number of untoward events that occurred with a family. MEAS subjects were asked to indicate if any of a number of stressful events had transpired within the past year. Positive responses to the items in the index were summed with no attempt to categorize or rank order the scores. Using the concept of pile-up, it was proposed that the larger the number of untoward events, the higher the stress level and the fewer the resources available to the family to cope with their situation. The Family Events Index consists of 10 items adapted from the SRRS and selected because of their potential to impact the entire family rather than an individual family member. The index includes items such as the birth of a sibling or the death of a family member or friend (see Appendix B).

Family Role Scale. Family roles consist of expectations and behaviors that individuals employ in the interactive process with other family members. The interactive nature of roles implies that each family role has a reciprocal set of expectations for example,

mother/child. This concept was measured using a Family Role Scale adapted from the Scale of Attitudes Toward a Dual Role for Women (Dalrymple, Lowe & Nelson, 1971). The Attitudes Scale was devised to assess the effects of mothers' working outside the home upon children. Items used in the Michigan Early Adolescent Survey were adapted from the Attitudes scale to measure characteristics of family roles and the implied complementary roles (see Appendix C).

The Family Role Scale, a multi-item scale was used to try to understand the complexity of the concept of family role expectations that single response items cannot measure. The multi-item scale also avoids the biases inherent in single item measures (Babbie, 1983). On the Family Role Scale, respondents were instructed to give their opinions about the family role statements that comprise the scale. Statements include items that attempt to assess attitudes about maternal employment, fathers' financial support responsibilities and the roles of girls and boys in regard to in home and out of home work. A Likert-type scale was used with four answer choices available to the respondent: strongly disagree to strongly agree. An even number of responses forces people into choosing and is probably an accurate indication of their true attitude (Backstrum & Hursh-Cesar, 1981). Scoring for each item was arranged from low (1), nontraditional to high (4), highly traditional in their attitudes towards the roles of family members.

The Dalrymple Scale, published in 1971, reported

test-retest reliability at .85 on four samples of adolescent girls. Project reliability scores ranged from .80 to .83. Content validity was established by a panel of experts consisting of family specialists and teachers. The target audience for the original instrument was adolescents, therefore input from that age group was elicited and incorporated into the content. The Family Role Scale consists of five items to measure attitudes about roles and was administered to both youth and their parents. In the present study reliability scores for this scale were determined using the SPSS subprogram (Hull & Nie, 1981). Cronback alpha's ranged from .55 for youth, .57 for mothers, to .60 for fathers. Validity measures reported by Dalrymple (1971) were used. Face validity was confirmed by the MEAS research team.

Family Relationships. The dimension of family relationships was measured using two scales developed from items concerning relationships with another family member. Relationship items were placed on both the parental and the youth questionnaires. Adolescents were asked about their relationship with their father, mother and siblings. These three items were combined to form the Family Relationship Scale (see Appendix D). The parental questionnaire contained only one item regarding family relationships, that being how each felt about the child who was participating in the study. Two additional items relating to the adolescent study participant were also included to form a three item

scale, the Adolescent Relationship Scale (see Appendix D). Respondents, both adolescents and parents, were asked to select among four choices ranging from a response that was very negative to a response that was very positive to characterize their relationships with other family members. The higher the respondent's score for the scale, the more positive their relationship with the other family member(s).

The development of feelings proceeds in the direction from specific feelings about an individual to more generalized feelings about groups of individuals. Feelings about individual family members, if one would use these directional notions, are then an indicator of one's feelings of family relationships as a whole. "Feelings about family are so organized that one can overlook occasional bursts of anger and cope with bouts of illness and handle limited interpersonal stresses without altering one's basic commitment to and evaluation of one's family" (Andrews & Whithey, 1976, p. 15).

A limitation of using this type of a self-report item is the chance for the respondent to be less than totally honest. Campbell, Converse and Rodgers (1976) also suggested that subjects tend to feel reluctant to describe their feelings for other family members as less than average. Backstrom & Hursh-Cesar (1981) labeled this phenomenon "diluted truth." A dynamic method of measuring relationships is most valid as it has built into the methodology a way to uncover subtle changes which occur over

time, something that is lacking in this particular MEAS one-time interview survey.

Two family relationships scales were developed and used, one for parents (fathers and mothers) and one for adolescents to relate their feelings about other family members. Each of the three item scale instructed respondents to select from choices ranging from very poor feelings about another family member to a very good feelings about the individual. Scores on both of the family relationship scales could range from one to a high of four. Reliability scores for the three item Adolescent Relationship Scales were .42 for mothers and .46 for the fathers adolescents. The reliability score for the three item Family Relationship Scale was .62 for the adolescents. The validity measure for this particular scale was face validity confirmed by the MEAS research team. Andrews and Whithey (1976) suggested that "Measures without validity are worthless, but measures with high validities are not necessarily useful. One must also be concerned about... the practical relevance of a measure and...the degree to which it permits discrimination among the objects being measured" (p. 176). These social indicators have a subjective quality about them that the researcher must not lose sight of when trying to answer the research question.

Families With Chronically Ill or Handicapped Children

Families with chronically ill or handicapped children

were identified by responses to a set of questions on the MEAS Household Questionnaire. The questions were designed to serve to screen families and thereby permit the separation of families into two categories: nonhandicapped and handicapped. A variety of chronic illnesses and handicapping conditions were listed without regard for the potential severity of the conditions, but rather to elicit a positive response if a child in the family was affected by any of the conditions identified. Hyperactivity and learning disorders were also included in the list because of misunderstandings surrounding these conditions and the problems associated with diagnosis. The list was generated from a review of the literature and the author's clinical experience in working with Pediatric clients and their families (see Appendix E).

Data Analysis

The data for this study were from the Michigan Early Adolescent Survey (MEAS). Variables were identified that would best measure the concepts of interest for this study. The family had been identified as the primary unit of study so it was necessary to select matching items from all three respondent questionnaires. Four composite variables were identified after a thorough investigation of mother, father and adolescent instruments and responses.

The decision-making process included identification of all possible variables, examination of frequency of response

scores, use of measures of association to determine the extent of relationships between variables, and where appropriate, tests of reliability. The composite scores for the dependent measures are: (1) self-esteem scores, (2) family relationship scores, (3) family role expectations scores, and (4) family events scores.

[Analysis of variance] is used to check the amount of variation in the mean scores between groups against the variation of mean scores among members within the group (Iverson & Norpoth, 1976). This type of analysis is necessary to obtain a clearer understanding of how the variance which may exist within the family constellation is related to the variance between groups, that is, between families with nonaffected children and families with chronically ill or handicapped children. [A probability of .05 or less was considered to be sufficient evidence to reject the hypotheses that no difference exists between the families with nonaffected children and families with chronically ill and handicapped children.]

Repeated measures analysis of variance was used to examine differences between family members in two family types on the dependent measures. Repeated measures tests allow for analysis of information obtained when the researcher has chosen to gather data from more than one family member, providing for a within family factor (Ball et al., 1983). In this study, the family unit was the focus. To better understand if differences did exist between the two

family types, scores of the three family members were used. This study had two between family factors corresponding to the two family types and three within family factors representing the three family members. "The within-subjects factor is synonymous with the repeated measures factor..." (Huck, Cormier & Bounds, 1974, p. 106).

Schumm and associates (in press) contend that even in the study where only a slight correlation is demonstrated between family member scores, that it is inappropriate to use statistical methods that assume independence. The dependence of the responses by individual family members must be assumed by the nature of their relationship and by the fact of their continued interaction time. Pearson product moment correlation was used on the dependent measures to describe the relationship between the variables for the individual family members.

If analysis of variance were to be used without repeated measures, family member differences could be masked as one examines composite results. The critical element within the repeated measures design which makes it useful for family research, that is using responses from more than one family member, is the capability of the design to sort out and remove the variability attributable to individual differences (Myers, 1979; Winer, 1971). A repeated measures design adds to analysis in family research by adding greater power through the testing of family member main effect, thereby strengthening the results of the statistical test

(Ball et al., 1983).

Chapter IV

THE RESULTS

The family unit was the focus of this research study. Families with chronically ill and handicapped children were compared with families with nonaffected children by examining data from fathers, mothers and early adolescents. A primary hypothesis was formulated for each of the concepts being investigated. If the hypothesis was rejected, alternate hypotheses were investigated to more clearly understand the differences between the two family types. The results of the data analysis are presented as follows: (1) characteristics of the study families; (2) differences in self-esteem; (3) differences in stressful life events; (4) differences in family role expectations; and (5) differences in family relationships.

Characteristics of the Study Families

Data for this study were obtained from the Michigan Early Adolescent Survey (MEAS). MEAS respondents included 304 adolescents, 283 mothers and 212 fathers. The focus of this study was the family unit rather than the individual family members, necessitating that data from all three

family members be used. The particular focus of this study meant that the original sample had to be narrowed so that each family would supply data from the father, the mother and the adolescent. Approximately 65 percent of the original families met these criteria, (n=197) and formed the respondent family pool for the current study.

Families for this study were divided into two groups: families with chronically ill and handicapped children (referred to as handicapped families) and families with nonaffected children (referred to as nonhandicapped families). There were 56 handicapped families and 141 nonhandicapped families in the respondent family pool (see Table 3).

Family size as measured by the number of children 18 years old and younger, ranged from one to eight children. The family size of the nonhandicapped group was, on the average, smaller with 55 percent indicating one or two children, while only 41 percent of the handicapped families reported having one or two children. Adolescents in this study all resided in two parent homes.

Early adolescent subjects for this study formed groups very similar to the MEAS youth (Keith et al., 1985). This sample included 197 early adolescents, 97 males and 100 females. Youth were almost equally divided between grades five, six, seven and eight. Three-fourths of the youth were almost evenly distributed over the ages 11, 12 and 13 with the remaining one-fourth almost equally divided over the

Table 3

Demographic Characteristics of Nonhandicapped and Handicapped Families

Characteristic	Nonhandicapped		Handicapped	
	n=141		n=56	
	Frequency [*]	(%) [@]	Frequency [*]	(%) [@]
Family Size				
1	18	(13)	8	(14)
2	58	(42)	15	(26)
3	38	(27)	22	(39)
4	16	(12)	6	(11)
5 or more	9	(7)	5	(10)
Adolescents				
Males	62	(44)	35	(62)
Females	79	(56)	21	(38)
Age in years				
10	17	(12)	7	(12)
11	30	(21)	13	(23)
12	40	(29)	13	(23)
13	37	(26)	14	(26)
14	17	(12)	9	(17)
Grade				
5	32	(23)	16	(29)
6	36	(26)	13	(23)
7	34	(24)	13	(23)
8	37	(27)	14	(25)
Age in Years				
Fathers				
Less than 30	4	(3)	3	(5)
31-40	68	(48)	30	(55)
41-50	56	(40)	18	(33)
41-60	13	(9)	4	(7)
Mothers				
Less than 30	9	(6)	5	(10)
31-40	87	(62)	37	(71)
41-50	43	(31)	8	(15)
51-60	1	(1)	3	(6)

Table continued

Table 3 (con't)

Characteristic	Nonhandicapped		Handicapped	
	Frequency *	(%) [@]	Frequency *	(%) [@]
Education				
Fathers				
High school or less	35	(36)	21	(59)
College	63	(65)	15	(41)
Mothers				
High school or less	65	(51)	32	(60)
College	64	(49)	21	(40)
Employment				
Fathers				
Employed	129	(92)	50	(89)
Unemployed	3	(2)	3	(6)
Missing	9	(6)	3	(5)
Mothers				
Employed, fulltime	47	(33)	13	(23)
Employed, parttime	40	(28)	25	(45)
Homemaker, fulltime	46	(34)	14	(25)
Missing	8	(6)	4	(7)
Occupations				
Fathers				
Unskilled	70	(53)	31	(59)
Skilled/Professional	62	(47)	21	(40)
Mothers				
Unskilled	6	(7)	6	(15)
Skilled/Professional	82	(93)	33	(85)
Family Income				
\$20,000 or less	42	(32)	21	(42)
\$20,001 - \$30,000	40	(31)	22	(42)
\$30,001 or more	49	(37)	8	(16)

* missing data causes some totals to be less than actual number subjects
 @ totals may not add to 100 due to rounding

ages 10 and 14. The percentage of boys was somewhat higher in families with handicapped children.

The majority of adults in this study, both mothers and fathers, were forty years of age or less. Fifty-four percent of the fathers and 71 percent of the mothers were in this age range. Mothers and fathers in the handicapped group were younger than the nonhandicapped group, while at the upper age limits, fifty years of age and older, the two family groups were almost equally divided.

Formal education of the adults was examined. Mothers had less formal education than fathers, with 47 percent of the mothers as compared to 58 percent of the fathers having completed at least some college. The parents from the handicapped group had less formal education with the majority of both mothers and fathers (approximately 60 percent) having no more than a high school education.

The income level for families in this study was almost equally divided between three categories: 35 percent with less than \$20,000; 34 percent with \$20,001 to \$30,000 incomes; and 31 percent in the \$30,001 and above income levels. The majority of the handicapped families were clustered in the \$30,000 or less category (84 percent) compared with an almost equal distribution of the nonhandicapped families across the three income categories.

The majority of the parents in this study worked outside the home: fathers, 91 percent and mothers, 64 percent. Maternal employment outside the home was similar

for both family types.

Differences in Self-Esteem

Self-esteem was measured by scores obtained on the Coopersmith (1981) Self-Esteem Inventory; Adult Form for parents and the School Short Form for adolescents. Low positive correlations were found between family member's scores on the self-esteem scale: $r=.21$, $p<.01$, for fathers' and mothers' scores; $r=.21$, $p<.002$, for mothers' and adolescents' scores; and $r=.12$, $p<.09$, for fathers' and adolescents' scores. The positive correlations between family member's scores supported the use of a repeated measures design to more clearly demonstrate the family factor that is present due to the interaction patterns of family members. It should be noted that 122 families had complete information for the self-esteem inventory and therefore, formed the subject group used to examine this variable.

Hol There is no difference in self-esteem between individual family members and families as a whole with chronically ill and handicapped children and individual family members and families as a whole with nonaffected children.

Repeated measures analysis of variance was used to examine this hypothesis. Self-esteem scores from fathers, mothers and adolescents were examined to determine if the presence of a handicapped child would influence the

self-esteem in the different family types (see Table 4). The analysis clearly indicates that self-esteem is significantly lower ($p=.009$) in families with handicapped children. The variance due to between family member's scores was also very significant. The significant difference between family members scores is a confirmation of the results of the repeated measures analysis of variance used to examine family member's self-esteem scores without the presence of the independent variable. The variance due to the between families factor was significant ($p<.01$) supporting the idea that families do differ in their levels of self-esteem. The difference between family members was even more significant ($p<.000$) demonstrating the difference in individual levels of self-esteem. Mean self-esteem scores were: fathers', 74.67; mothers', 70.13; and adolescents', 66.38 (see Table F-1). The member by handicapped family interaction term was not significant and probably reflects the gap in self-esteem between handicapped and nonhandicapped family members. Based upon these results hypothesis 1 was rejected.

Families with handicapped children had lower self-esteem than families with nonaffected children. Rejection of the hypothesis served as the impetus to try to better understand where the differences in the families might rest. Alternate hypotheses were proposed and post hoc procedures were performed to examine intrafamily differences.

Table 4

Repeated Measures Analysis of Variance of Self-Esteem According to
Fathers, Mothers and Adolescents for Nonhandicapped and Handicapped
Families

Source	df	SS	MS	F	p
Between families	120				
Handicap (A)	1	2783.90	2783.90	7.10	.009
Error	119				
Within families	242				
Member (B)	2	4068.85	2034.42	7.62	.001
A x B	2	177.76	88.89	.33	
Error	236				
Total	362				

Hol.1a There is no difference in self-esteem between fathers in handicapped and in nonhandicapped families.

Hol.1b There is no difference in self-esteem between mothers in handicapped and in nonhandicapped families.

Hol.1c There is no difference in self-esteem between adolescents in handicapped and in nonhandicapped families.

These hypotheses were tested using the t test for independent samples due to the unequal cell size for the two family types (see Table 5). Adolescents from families with handicapped children were significantly different ($p < .01$) with lower mean self-esteem scores. A large standard deviation indicated a wide range in scores for the adolescents in the handicapped group. Based upon the result of the t tests, hypotheses 1.1a and 1.1b were not rejected. Hypothesis 1.1c was rejected due to the statistically significant t test for differences in self-esteem with adolescents.

Hol.2a There is no difference in self-esteem between mother-father dyads in handicapped and in nonhandicapped families.

Repeated measures analysis of variance was used to test this hypothesis. Mean self-esteem scores for fathers were higher than for mothers, although scores for both family members were lower for the handicapped group

Table 5

t Tests for Self-Esteem Scores of Fathers, Mothers and Adolescents in Nonhandicapped and Handicapped Families

Member Groups	Nonhandicapped		Handicapped		t
	n=86		n=35		
	M	SD	M	SD	
Fathers	76.13	15.72	71.15	17.60	1.54
Mothers	71.48	20.65	66.89	20.05	1.13
Adolescents	68.83	14.03	60.48	20.39	2.61 [*]

^{*} $p \leq .01$

(fathers' 76.13 versus 71.15; mothers' 71.48 versus 66.89). This difference was not statistically significant (see Table 6). Self-esteem scores were not significantly lower in families with a handicapped child. Hypothesis 1.2a was not rejected.

H01.2b There is no difference in self-esteem between mother-adolescent dyads in handicapped and in nonhandicapped families.

The self-esteem scores of mothers and adolescents were examined using repeated measures analysis of variance to determine if differences were present between handicapped and nonhandicapped families (see Table 7). In this analysis, the presence of a handicapped child was found to be significant ($p=.02$) indicating that there is a difference in mean self-esteem scores for mother-adolescent dyads in the two types of families. The actual member differences in self-esteem were nonsignificant indicating that mean scores for mothers and adolescents were close within each family type (mothers', 71.48 versus 66.89; adolescents', 68.83 versus 60.48). Hypothesis 1.2b was rejected.

H01.2c There is no difference in self-esteem between father-adolescent dyads in handicapped and in nonhandicapped families.

Mean self-esteem scores for fathers were considerably higher than mean scores for adolescents in both handicapped and nonhandicapped families (see Table 8). Fathers' mean scores were more than ten points higher for each family type

Table 6

Repeated Measures Analysis of Variance of Self-Esteem According to
Fathers and Mothers for Nonhandicapped and Handicapped Families

Source	df	SS	MS	F	p
Between families	120				
Handicap (A)	1	1163.39	1163.39	2.88	.09
Error	119				
Within Families	121				
Member (B)	1	1008.37	1008.37	3.63	.059
A x B	1	2.03	2.03	.007	.93
Error	119				
Total	241				

Table 7

Repeated Measures Analysis of Variance of Self-Esteem According to
Mothers and Adolescents for Nonhandicapped and Handicapped Families

Source	df	SS	MS	F	p
Between families	120				
Handicap (A)	1	2123.35	2123.35	5.72	.02
Error	119				
Within families	121				
Member (B)	1	1040.88	1040.88	3.40	.067
A x B	1	179.46	179.46	.59	.45
Error	119				
Total	241				

Table 8

Repeated Measures Analysis of Variance of Self-Esteem According to
Fathers and Adolescents for Nonhandicapped and Handicapped Families

Source	df	SS	MS	F	p
Between families	120				
Handicap (A)	1	2256.71	2256.71	8.06	.005
Error	119				
Within families	121				
Member (B)	1	4098.25	4098.25	16.83	.00007
A x B	1	143.31	143.31	.59	.44
Error	119				
Total	241				

(fathers', 76.13 versus 71.15; adolescents', 68.83 versus 60.48). The difference in self-esteem scores between fathers and adolescents was significant although the interaction effect of member by handicap was not significant and probably reflects the wide gap between the mean self-esteem scores for fathers and adolescents. Hypothesis 1.2c was rejected based upon these results.

Differences in Stressful Life Events

The Family Events Index was adapted from the Holmes and Rahe (1967) Social Readjustment Scale. Respondents were asked to indicate "yes" or "no" to a series of ten items suggesting the occurrence of untoward events within the past year. The total possible score for positive responses was ten with a range from zero to ten. Indexes with nine or more completed items were used to measure this concept, therefore, it was necessary to consider missing data. Babbie (1983) suggested one method to handle missing data when using an index is to treat missing data the same as one of the available responses. The presence of one missing response was interpreted to mean "no" and treated then as a complete index and included in the data analysis.

The scores of fathers, mothers and adolescents were included in these analyses. Complete data were available for 132 families, when using the technique for the inclusion of missing data previously described. Weak to moderate positive correlations were found: $r=.42$, $p=.001$, mothers'

and fathers'; $r=.22$, $p=.04$, mothers' and adolescents'; $r=.26$, $p=.017$, fathers' and adolescents'. These positive correlations supported the use of the repeated measures design, taking into account the family factor shown to exist in these families.

Ho2 There is no difference in stressful life events between families with chronically ill and handicapped children and families with nonaffected children.

The number of stressful life events which were reported was not significantly different for the nonhandicapped and the handicapped families (see Table 9). The variance due to the difference in reports by family members was significant suggesting several possible explanations: (1) that individual family members (see Table F-2) may not remember what has happened to their family over the past year, (2) using the phrase "over the past year" was an imprecise measure or that (3) the phrasing of the items left the items open to broad interpretation. In reviewing the items, the second or third reasons seem most likely. The interaction effect was not significant. Hypothesis 2 was not rejected based upon the nonsignificant differences between the two family types.

Differences in Family Role Expectation

The attitude of family members toward family roles was measured using the Family Role Expectation Scale. The scale

Table 9

Repeated Measures Analysis of Variance Stressful Life Events According to Fathers, Mothers and Adolescents for Nonhandicapped and Handicapped Families

Source	df	SS	MS	F	p
Between families	131				
Handicap (A)	1	.059	.059	.029	.862
Error	130				
Within families	264				
Member (B)	2	78.28	39.14	25.15	.0000
A x B	2	2.83	1.41	.91	.403
Error	260				
Total	395				

contained five item statements to reflect a variety of family roles. Respondents were asked to indicate level of agreement with statements of family roles. Responses were arranged to reflect traditionality in attitudes with a low score of five for the scale being very nontraditional, to a high score of twenty which would indicate a very traditional attitude toward family roles. The nature of the content for this concept necessitated the inclusion of only families for whom complete data were available. One hundred and twenty-one (121) families formed the respondent pool for these analyses. No systematic relationship was found between the members on the family role variables: $r=.045$, $p=.27$, fathers and mothers; $r=.09$, $p=.108$, mothers and adolescents; $r=.07$, $p=.18$, fathers and adolescents.

Ho3 There is no difference in family role expectations between individual family members and families as a whole with handicapped children and individual family members and families as a whole with nonaffected children.

Attitudes about what is expected of family members in their various roles was measured by responses to a five-item scale. Scores could range from low or nontraditional to high or very traditional. The effects of the handicapped child on family role expectation proved to be not significant as illustrated in Table 10. The difference in attitudes among family members do indeed differ in their views of intrafamily roles. The differences between

Table 10

Repeated Measures Analysis of Variance of Family Role Expectation
According to Fathers, Mothers and Adolescents for Nonhandicapped and
Handicapped Families

Source	df	SS	MS	F	p
Between families	121				
Handicap (A)	1	8.19	8.19	2.11	.148
Error	120				
Within families	244				
Member (B)	2	113.20	56.60	18.63	.0000
A x B	2	2.47	1.24	.41	.67
Error	240				
Total	365				

individual family member's role attitudes in this analysis were very similar to differences found in the individual member's role expectation scores when examined without the effects of the independent variable (see Table F-3). The variance due to between families was nonsignificant indicating that families are more alike than different in their attitudes toward family roles. The differences between individual family members was very significant ($p < .0000$) demonstrating the existence of individual differences between persons in their attitudes about family roles. Adolescents were the least traditional in their attitudes, although all members' mean scores (fathers', 13.08; mothers', 12.21; adolescents', 11.67) were clustered in the middle between nontraditional and highly traditional (see Tables F-4 through F-8). The interaction effect of member by handicap was also not significant, suggesting that a gap does exist in the member's view of their family roles in the two types of families. Hypothesis 3 was not rejected based upon the nonsignificant differences between the two family types.

Differences in Family Relationships

The intensity of feelings for other family members was measured using two separate measures, one for adolescents and one for the parents, in that similar items were not available on the two questionnaires. Adolescents were asked to rate their feelings about other family members including

their father, mother and siblings. Ratings were from a low of one, indicating a very poor relationship, to a high of four, or a very close relationship. These three items were combined to make up the Family Relationship Scale for adolescents.

The parental questionnaire for the MEAS study contained only one family relations item, that being the relationship with the child participating in the study. Two additional items related to the mother's and father's relationship to their adolescent and their family were added to make up the three item Adolescent Relationship Scale for parents. A moderate correlation between the mother's and father's scores ($r=.54$, $p=.001$) was found. The nature of the relationship scales necessitated that parents and adolescents be considered separately.

Ho4 There is no difference in family relationship score between adolescents in families with chronically ill and handicapped children and in families with nonaffected children.

The independent samples t test was used to examine mean scores for the adolescents from the two family types. Adolescents related positive feelings about other family members as measured by scores on the Family Relationship Scale (see Table 11). Feelings about other family members in the handicapped families were slightly less positive than feelings of adolescents in the nonhandicapped families, although not a statistically significant difference.

Table 11

t Tests for Family Relationship Scores of Adolescents in Nonhandicapped and Handicapped Families

	Nonhandicapped		Handicapped		
	n=89		n=35		
Members	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	t
Adolescents	3.41	.67	3.21	.60	1.56

Table 12

Repeated Measures Analysis of Variance of Adolescent Relationships According to Fathers and Mothers for Nonhandicapped and Handicapped Families

Source	df	SS	MS	F	p
Between families	128				
Handicap (A)	1	.918	.918	1.65	.20
Error	127				
Within families	129				
Member (B)	1	.002	.002	.011	.91
A x B	1	.172	.172	1.03	.31
Error	127				
Total	257				

Hypothesis 4 was not rejected based upon the nonsignificant t test.

Ho5 There is no difference in family relationships between fathers and mothers in families with chronically ill and handicapped children and in families with nonaffected children.

Repeated measures analysis of variance was used to test this hypothesis. Mean family relationship scores from families with complete data were used (n=129). Mothers and fathers both indicated positive feelings toward their adolescent children (see Table 12). Feelings towards adolescents were slightly less positive in handicapped families as illustrated in Table F-9. Mean adolescent relationship scores for fathers were 3.23 in nonhandicapped families compared with 3.16 for handicapped families. Mothers scores were 3.31 for nonhandicapped families versus 3.11 for handicapped families. There were no statistically significant differences in family relationships between the two family types or between the family members. Hypothesis 5 was not rejected.

Summary

In this study two types of families were examined: families with chronically ill and handicapped children and families with nonaffected children. A comprehensive examination of each of the family types was undertaken by using responses from three family members to items designed

to measure the concepts identified for this study. Concepts of interest in the families included: self-esteem, stressful life events, family role expectations and family relationships. Five major hypotheses were proposed to examine differences between two family types. Alternate hypotheses were examined if the major hypothesis was rejected and significant differences were found between the two family types (see Table 13). Hypothesis 1, there is no difference in self-esteem between the two family types was rejected. Alternate hypotheses were tested which revealed significant differences in self-esteem between members in handicapped and nonhandicapped as well as differences between groups of member dyads, that is, mothers and adolescents and fathers and adolescents. Hypothesis 2, there is no difference in stressful life events between the two family types was not rejected. Hypothesis 3, there is no difference in family role expectations between the two family types was not rejected. Hypothesis 4, there is no difference in family relationship for adolescents in the two types of families was not rejected. Hypothesis 5, there is no difference in family relationships for mothers and fathers of adolescents in the two family types was not rejected.

Table 13

Summary of Hypotheses

Hypothesis	Research Hypothesis	Significance Level
1 (self-esteem)	rejected	$\leq .001$
1.1a	not rejected	NS
1.1b	not rejected	NS
1.1c	rejected	$\leq .01$
1.2a	not rejected	NS
1.2b	rejected	$\leq .02$
1.2c	rejected	$\leq .0000$
2 (life events)	not rejected	NS
3 (role expectations)	not rejected	NS
4 (family relationships)	not rejected	NS
5 (adolescent relationships)	not rejected	NS

Chapter V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Little is known about how the presence of a chronically ill or handicapped child actually impacts upon the individual family members and upon the family as a whole. Recently, evidence has been presented to indicate that up to 40 percent of all families may have one or more children who fit the criteria for a chronic illness or a handicapping condition, if the classifications are broadly defined to include previously unrecognized disorders such as learning disabilities and emotional problems in addition to such standard diagnoses as cerebral palsy, asthma and blindness (Mattsson, 1973). Literature which does exist about these families tends to emanate from the health care field thereby focusing upon a specific clinical population. Further, existing literature tends to report data from one family member which was then generalized to be family data. Another limitation of those studies was that the individual was the primary focus to the exclusion of other family members. The use of control groups has seldom been reported in this literature thereby adding methodological weaknesses to the list of identified shortcomings in the existing

literature.

Changing social practices and political policies have resulted in deinstitutionalization of developmentally delayed individuals and their subsequent appearance in our communities. Children diagnosed with any number of chronic illnesses such as diabetes now live long, full-lives when their disease is controlled by medication and appropriate health care supervision. These contemporary practices have alleviated a number of stressors in the lives of these individuals and their families while imposing still others. The initial crisis of the diagnosis (Feetham, 1980) may be replaced by chronic stress, which becomes manageable and families are able to live out their lives under conditions to which they have adapted (Venters, 1981).

Family ecosystems was used as the conceptual framework for this research. The family is central to family ecosystems as it was to this study. The intrafamily environment consists of the various family members in interaction with each other. The presence of a chronically ill or handicapped child has the potential to compromise the intrafamily environment causing stress and demanding adaptation from all family members if equilibrium of the system is to be maintained. The potential inequalities in distribution of resources, both human and material, can further potentiate a labile situation demanding adjustment far beyond the normal exchanges which take place in a dynamic family system. The impact of the external

environment upon the family is acknowledged in this research indirectly and was only indirectly measured. The primary focus was the internal family environment.

The major purpose of this research was to examine families to attempt to discover if the presence of a chronically ill or handicapped child could result in a difference in any of four intrafamily factors: (1) self-esteem, (2) number of stressful life events, (3) family role expectations and (4) family relationships. Subjects for this study were drawn from a larger study, the Michigan Early Adolescent Survey (MEAS). Criteria for entry into this study necessitated data from three family members. One hundred ninety-seven of the original 304 MEAS families met the eligibility requirements. Families were divided into two groups, those with chronically ill and handicapped children and those with nonaffected (nonhandicapped) children by means of a self-report item on the household questionnaire which made no attempt to assess the severity of the condition, only to acknowledge the presence of the affected child. Statistical tests included t tests for independent samples and repeated measures analysis of variance.

This study led to several conclusions:

1. The self-esteem levels of fathers, mothers and adolescents were comparable to findings from other studies. Fathers, mothers and adolescents had different levels of self-esteem with fathers having

the highest levels and adolescents the lowest levels.

2. Self-esteem was significantly lower in families with chronically ill and handicapped children than families with nonaffected children.
3. Adolescents from families with chronically ill and handicapped children had significantly lower self-esteem.
4. Families reported a low number of stressful life events, an average of less than two out of ten possible events.
5. Fathers, mothers and adolescents were significantly different in their report of stressful life events, with adolescents reporting the highest number of events.
6. Family members were more traditional than nontraditional in their family role expectations.
7. Fathers, mothers and adolescents have different family role expectations with fathers being the most traditional in their beliefs followed by mothers and then adolescents.
8. Families with chronically ill and handicapped children were not significantly different in their family role expectations than families with nonhandicapped children.
9. Fathers, mothers and adolescents reported positive feelings toward other family members.

Discussion of Findings

Family Ecosystems Theory

Family ecosystems theory provided a holistic way to view the family. Study results indicated that while family members may differ significantly on the various factors under consideration, that families when considered as a unit were more alike than different. The family factor suggested by the positive correlation of member scores on the variables was supported by the nonsignificant differences between family types on all measures studied except self-esteem.

This research study, one of few studies using multiple family members as respondents, contributed to the confirmation that family ecosystems is a viable choice to provide the framework to study different family types. While family ecosystems has received some recognition as an important theory to be used in the study and consideration of families, only through continued use of this theory will more total acceptance be gained (Holman & Burr, 1980).

Self-Esteem

Families were examined for differences in self-esteem to understand what, if any, was the effect of chronically ill or handicapped child on the self-esteem of the family as a unit. Differences in mean self-esteem scores were found to be statistically significant when comparing the two types of families. Mean scores for the entire sample of

individual family members ranged between 66.38 for adolescents' to 70.13 for mothers' to 74.67 for fathers' (see Table F-1) and reflect mean levels of self-esteem reported by Coopersmith (1981).

Mean self-esteem scores for all family members were high when compared to results reported by Coopersmith (1981). It should be noted that fathers had the highest levels of self-esteem, followed closely by mothers. Adults' self-esteem levels tend to remain stable, having been developed during their youth (Wylie, 1979). The high levels of self-esteem of the parents in this study suggest the presence of a supportive environment for the development of children's self-esteem which was reflected in the mean self-esteem scores for the adolescents.

The self-esteem level of adolescents in this study were lower than that of their parents. Studies by Offer et al. (1981) and Simmons et al. (1973) suggested that the alteration in the adolescent's school environment, that is, the transition to junior high school (or middle school) may lead to a time when self-esteem levels could dip due to the ambiguities of the new school situation. This may be true of the adolescent self-esteem scores in this study, which were somewhat lower than parental mean self-esteem scores. A comparison of adolescent self-esteem scores between the two family types yielded significant differences with self-esteem scores of adolescents in the handicapped families being lower.

Self-esteem is a characteristic of an individual and not of the total family unit. The consideration of the family as a system necessitates the examination of the individuals who comprise the system and what each contributes to the integrity of the system. The use of the repeated measures design for analysis provided a method to account for those differences by looking at the individual scores, but yet to reflect the broader family picture of self-esteem. When scores of individual family members were considered in the two types of families, significant differences were found, suggesting that the presence of a chronically ill or handicapped child may impact upon the family system in such a way as to cause members to have lower feelings of self regard. The self-esteem literature is devoid of studies to either support or refute this finding, although this finding is not surprising when considered by using the family ecosystems framework which is based upon the assumption that what happens to one family member affects all other family members. It is important then for individual family members to maintain a sense of well-being which will aid in their ability to cope with their family situation (Bristol, 1984).

Stressful Life Events

The presence of a chronically ill or handicapped child has been well documented to cause stress in a family. Adaptation to that stress has also been acknowledged (Bristol, 1984; Longo & Bond, 1984; Venters, 1981). A

question asked in this study, concerned the number of stressful life events: Do families with chronically ill and handicapped children experience more stressful life events than families with nonaffected children?

A considerable amount of work has been done to assess the impact of nonnormative stressful events upon individuals. Holmes and Rahe (1967) did pioneering work to quantify the impact of a variety of stressful events by measuring the amount of life adjustment called for to adapt to a variety of stressful life events. Subsequent studies (Minour & Rahe, 1967; Yeaworth et al., 1981) have added to that body of knowledge. This study did not attempt to quantify stressful life events, but only to document the occurrence of those happenings in keeping with the notion of "pile-up" (Olsen & Patterson, 1981).

This study found that families did not report large numbers of events. Mean scores ranged from 1.15 for fathers' to 2.34 for adolescents' for the ten item Family Events Index (see Table F-2). It should be noted that adolescents reported the largest number of events which may have reflected the way in which items or the time frame were interpreted. Fathers were the most conservative in their reports leaving mothers' reports in the middle. Mothers' reports may indeed be the most accurate as often the mother by virtue of her role in the family may be the most aware of events that touch the life of the family. Adolescents have a reference group separate from the family which may

account, in part, for their higher report. Since this index was a retrospective measure, differences in recall could have influenced the way people responded to the items listed on the index.

The presence of a chronically ill or handicapped child did not result in a significant difference in the numbers of stressful life events reported. It was thought that the presence of nonnormative stressors coupled with the presence of the affected child might place these families in jeopardy for the "pile-up" phenomenon. This study did not include any measure of the family's interpretation of the happenings and therefore some families may be affected by pile-up. The results of this study suggest that families with chronically ill and handicapped children are no more at risk than are other families at this life stage.

Family Roles

Attitudes about family roles were measured in this study with the Family Role Scale. Traditionality, or attitude toward roles of various family members, was assessed in an attempt to understand if the presence of a chronically ill or handicapped child would influence role attitudes. Flexibility in family roles has been well documented in the literature as a coping strategy for families with affected children (Boss, 1980; Farber, 1959; Gallagher et al., 1982; Gallagher et al., 1983; Koch, 1984). Studies such as these document a shift in attitudes away from the traditional family roles to more egalitarian or

flexible roles.

Role attitudes were not congruous for participants in this study (see Tables F-4 through F-8). Fathers were the most traditional in their beliefs followed by mothers and then adolescents. All member groups were slightly more traditional than nontraditional in their role beliefs. Socialization may have been the underlying cause of these observed differences with youth exposed to more egalitarian notions from a number of sources including the media and their peers. Also, since a large number of mothers in this study were employed (65 percent), youth may interpret this trend as being more flexible for mothers' roles. The parents may view the mother's employment as necessary to provide sufficient resources to maintain the family, but nevertheless, still cling to the more traditional role expectations. A comparison of role attitudes to actual role behaviors would be one way to provide a clearer picture of how roles were actually being enacted in the family in comparison to beliefs.

The notion of role flexibility has been suggested as necessary to accomodate the normative changes which occur in the family, but which may also happen in subtle ways that go unnoticed by family members. The family environment must be somewhat flexible to accomodate individual family members and "changes which occur in the accustomed structure, patterns, and roles of the individual family members call for a reevaluation of old roles an establishing of new

patterns" (Farrell & Hutter, 1983, p. 151).

The presence of the chronically ill or handicapped child did little to influence members' role expectations. While each of the member groups from the handicapped families were slightly less traditional than their counterparts in their role attitudes, these findings were not statistically significant.

Families in this study may not have been truly representative of all families of chronically ill and handicapped children, or the results of studies suggesting that role flexibility was a coping mechanism for families, may have been drawn solely from clinical populations with severely affected children. The lack of agreement in this study's role expectations with a number of other studies focusing on families with handicapped children may have been due to two factors. First, the instrument used in this study was adapted from a scale (Dalrymple et al., 1971) which was several years old and may have been too dated for this study. Second, the original scale was designed to measure attitudes towards roles of mothers. These two factors may have been sufficient to distort the ability to accurately measure the role expectations of the individual family members, and to uncover differences between the two family types.

Family Relationships

This concept was measured using two scales: one for adolescents and a second one for mothers and fathers. The

adolescent scale was more comprehensive than the parental scale, as it included responses regarding relationships with other family members. Mothers and fathers were asked for a response regarding their relationship with the adolescent participating in the study only and not other family members. Positive family relationships were reported by each of the three member groups. These positive feelings continued to be present in families with a handicapped child.

Parental feelings toward other family members do much to influence the intrafamily environment for family relationships (Schaneveldt & Ihinger, 1979). This may have been implied by the report of positive feelings among family members. Adolescents in this study reported less positive sibling relationships than parental relationships, which may reflect the little known ways that siblings relate to each other rather than the presence of an affected sibling.

The use of single report items has been cited as a weakness in assessing family relationships (Campbell et al., 1976) as respondents may answer with a socially acceptable response rather than provide a true measure of their feelings. The reports of positive family relationships found in this study, create what would appear to be a positive intrafamily environment, but nonetheless, can only be accepted if one is mindful of how these results were obtained.

Conclusions

This study was unique in several respects. The use of several family members as participants in a study of the family has seldom been done due to the difficulty in recruiting sufficient families into the study with all identified members participating. The costs of family research, including both financial and time expenditures, if one would use a sufficiently large sample, randomly selected are becoming prohibitive thereby mitigating against such efforts (Schumm et al., in press). The value of including responses from more than one family member has been touted particularly in the area of including children as subjects as they provide an added, and sometimes different perspective on the family (Ball et al., 1983; Klein, 1983; Larson, 1974).

Previous studies of families with chronically ill and handicapped children have emanated from clinical populations. The very nature of the association of families with the health care providers may provide a somewhat distorted view of how families adjust to their affected child and the resultant life situation. Day to day family life functioning has received some attention (Hymovich & Baker, 1985), but more often the focus of these studies has been on pathology of individual members (Breslau et al., 1981; Burden, 1980; Cairns et al., 1979; Gayton et al., 1977), particularly the child afflicted by any of a number of disabling conditions. The use of the family ecosystems

framework as a basis for considering how an affected child may impact on a number of family variables provides an added dimension to this literature.

This study included 197 families, more than 25 percent of which have children with a chronic illness or handicapping condition. Large-sized studies with a reference group are all too rare. Both the size of this study sample and the use of a control group lend strength to the conclusions one can draw from this study. The results of this study suggest that families with chronically ill and handicapped children are at higher risk, particularly for lowered self-esteem among adolescents than families with nonaffected children.

Recommendations

The recommendations that come out of this study are two-fold: first, recommendations for incorporation of these findings into professional practice with families with chronically ill and handicapped children, and second, recommendations for further research. The findings of this study confirm the need to look beyond the person presenting with a chronic problem to include the family unit. It was clearly demonstrated in this study that all family members are affected on more than a single dimension, particularly in self-esteem. The use of a family ecological framework supports a holistic perspective of care. Siblings have too often been the family group excluded from the attention of

the helping professional as siblings are not usually present at the time of interaction with the affected child and the parents (often only the mother). Fathers also need to be encouraged to assume an active family role as avenues for coping and adaptation are explored.

Clinical practice involving children with chronic illnesses and/or handicapping conditions must be designed to involve the entire family and not just the individual. Assessment must be comprehensive and include bio-psycho-social aspects of the family to allow for a data base that will support problem identification and then intervention. The process of assessment should ideally include a home visit. This may not be practical for all families, but the option should be exercised in selected cases to better understand the family through an expanded assessment which includes their normal family environment.

Our knowledge of family systems is limited as is our knowledge about families with chronically ill and handicapped children, consequently additional research is needed to expand our knowledge base. This study produced some interesting findings and should be replicated with certain modifications. The concept of family role expectations has been cited as being an important coping mechanism which was not demonstrated in this study. A different instrument should be used which would uncover subtle differences in expectations. If an existing instrument is not available, a tool must be developed that

will be more inclusive to detect differences which may exist in attitudes toward family roles and ferret out differences in different family types if those differences do indeed exist. A clearer conception of family roles might be explored through the comparison of attitudes with actual role behaviors.

Family relationships are too complex to be measured with a single report item or even a small scale such as was used in this study. The incorporation of multiple strategically placed items in the respondent questionnaires would be valuable to detect if families with an affected child do truly have more negative family relationships. A longitudinal study would also be useful in assessing the patterns of relationships and attitudes over time.

Replication of this study using expanded measures of family role expectations and family relationships would be of interest to understand if these results were from the instruments or truly a reflection of families with chronically ill or handicapped children. The use of families with children in different stages of development would provide additional information and allow for more consideration of normative changes as well as nonnormative changes. A longitudinal study would allow for better understanding of how the normative family life cycle changes are impacted by the presence of a chronically ill or handicapped child. Studies to include different family configurations such as the single parent family should also

be conducted to add still another dimension to our understanding of families with chronically ill and handicapped children.

Future research endeavors should include families recruited from clinical populations, particularly where the intensity of the condition can be more closely measured. The severity of a child's handicap may be inversely related to a family's stress level. A child with less obvious deficits may pose a more significant stress to a family, as these children are often either misdiagnosed or undiagnosed, leaving families uncertain and wondering if their concerns are unfounded (Bristol, 1984). Since no attempts to measure the severity of the condition were included in this study, questions still remain in regard to both the impact of the initial diagnosis upon the family followed then by the impact upon the daily living pattern of families with children with varying levels of severity of their conditions.

The process of assessment should lead to intervention in an attempt to modify or eliminate stressors to the family and assist them to adapt to their situation. A program of research related to families will not be complete until intervention strategies are tested to determine possible courses of action one might take to assist families to their optimal state of functioning.

Family research, in many respects, is still in it's infancy. Experimentation with research methodologies is

still in order as are further studies on statistical analysis of family data. The use of data from more than one family member has been demonstrated to aid in the understanding of the "family factor" which has so often been deleted in family research. Methodologies to further ferret out family factors will do much to enrich our quest to understand the complexity and uniqueness of families in a variety of life stages and situations.

APPENDICES

Appendix A

Coopersmith Inventory

School Form

The following is a list of statements about feelings. If a statement describes how you usually feel, circle the number in the column "Like Me." If the statement does not describe how you usually feel, circle the number in the column "Unlike Me." There are no right or wrong answers.

	Like Me	Unlike Me
1. Things usually don't bother me.	1	0
2. I find it very hard to talk in front of the class.	1	0
3. There are lots of things about myself I'd change if I could.	1	0
4. I can make up my mind without too much trouble.	1	0
5. I'm alot of fun to be with.	1	0
6. I get upset easily at home.	1	0
7. It takes me a long time to get used to anything new.	1	0
8. I'm popular with kids my own age.	1	0
9. My parents usually consider my feelings.	1	0
10. I give in very easily.	1	0
11. My parents expect too much of me.	1	0

Appendix A

School Form (con't)	Like Me	Unlike Me
12. It's pretty tough to be me.	1	0
13. Things are all mixed up in my life.	1	0
14. Kids usually follow my ideas.	1	0
15. I have a low opinion of myself.	1	0
16. There are many times when I'd like to leave home.	1	0
17. I often feel upset in school.	1	0
18. I'm not as nice looking as most people.	1	0
19. If I have something to say, I usually say it.	1	0
20. My parents understand me.	1	0
21. Most people are better liked than I am.	1	0
22. I usually feel as if my parents are pushing me.		
23. I often get discouraged with what I am doing.	1	0
24. I often wish I were someone else.	1	0
25. I can't be depended on.	1	0

Appendix B

Family Events Index

In every family there are many changes that happen. Some are good and some are bad, but they all affect the people in the family. Have any of the following things happened to you (your child) in the past year? Check the column yes or no for each item.

	Yes	No
1. A parent died	1	2
2. Close family member died	1	2
3. Serious illness in family or friend	1	2
4. Parents separate, divorce or remarry	1	2
5. Parent lost job	1	2
6. Mother went to work	1	2
7. Birth of a brother or sister	1	2
8. Older brother or sister left home	1	2
9. Trouble with grandparents or other relatives	1	2
10. Moved to another city or different part of town	1	2

Appendix C

Family Role Scale

Circle the number in the column that most nearly expressed your opinion.

	Stongly Disagree	Disagree	Agree	Strongly Agree
1. A woman should not work after she has children because the father should support the family.	1	2	3	4
2. Working mothers aren't able to keep a proper and clean home.	1	2	3	4
3. Girls need to be taught to work both at home and out of the home.	1	2	3	4
4. Boys need to be taught to work both at home and out of the home.	1	2	3	4
5. It is the woman's responsibility to keep the home clean.	1	2	3	4

Appendix D

Family Relationship Scale

Circle the number that most nearly expresses your opinion.

1. In general, what words best describe your relationship with mother?

Very close, very good	4
Close, good	3
Not so close, fair	2
Not close at all, poor	1

2. In general, what words best describe your relationship with your father?

Very close, very good	4
Close, good	3
Not so close, fair	2
Not close at all, poor	1

3. In general, what words best describe your relationship with your brothers and sisters?

Very close, very good	4
Close, good	3
Not so close, fair	2
Not close at all, poor	1

Appendix D

Adolescent Relationship Scale

Circle the number that most nearly expresses your opinion.

1. In general, what words best describe your relationship with your child?

Very good, very close	4
Good, close	3
Fair, not so close	2
Poor, not close at all	1

2. Families often have good times and bad times. Think about your family in the past year or two. Check the words that best describe how you feel about your family:

It has been a very <u>good time</u> for our family	4
It has been both good and bad, but <u>mostly good</u> .	3
It has been a <u>somewhat difficult time</u> .	2
It has been a <u>very difficult time</u> .	1

3. I enjoy being a parent of a 10-to-14 year old.

Strongly disagree	1
Disagree	2
Agree	3
Strongly agree	4

Appendix E

Disabilities Among Michigan Early Adolescent Survey Study Families

<u>Disability</u>	<u>Number</u>
Physical Handicap	4
Developmental Delay	3
Chronic Ill	9
Learning Disorder	11
Diabetes	2
Cystic Fibrosis	0
Asthma	24
Mental Retardation	6
Epilepsy	4
Hyperactivity	13
Cerebral Palsy	1
Deaf	1
Blind	1
Other	14

TOTAL= 71 Families

Chronic Ill: 36 Families

Handicap: 35 Families

Appendix F

Table F-1

Repeated Measures Analysis of Variance: Self-Esteem Scores According to Fathers, Mothers and Adolescents

Source	df	SS	MS	F	p
Between Families	121	49651.62	410.34	1.41	$\leq .01$
Within Families	244	70858.32	290.40		
Between family members	2	4223.65	2111.83	7.67	.000
Residual	242	66634.67	275.34		
Total	365	120509.94	330.16		

	<u>M</u>	<u>SD</u>
Fathers'	74.67	16.38
Mothers'	70.13	20.50
Adolescents'	66.38	16.511

Table F-2

t Tests for Stressful Family Events of Fathers, Mothers and Adolescents in Nonhandicapped and Handicapped Families

Member Groups	<u>Nonhandicapped</u>		<u>Handicapped</u>		t
	n=96		n=36		
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	
Fathers'	1.19	1.18	1.07	1.28	.50
Mothers'	1.79	1.32	2.02	1.34	-.91
Adolescents'	2.42	1.44	2.22	1.87	.75

Appendix F

Table F-3

Repeated Measures Analysis of Variance: Family Role Expectations
According to Fathers, Mothers and Adolescents in Nonhandicapped and
Handicapped Families

Source	df	SS	MS	F	p
Between Families	120	467.77	3.90	1.12	n.s.
Within Families	242	845.24	3.49		
Between family members	2	121.77	60.89	20.23	
Residual	240	723.47	3.01		
Total	362	1313.01	3.63		.0000

	<u>M</u>	<u>SD</u>
Fathers'	13.08	2.06
Mothers'	12.30	1.64
Adolescents'	11.67	1.73

Table F-4

t Tests for Family Role Expectation of Fathers, Mothers and Adolescents
in Nonhandicapped and Handicapped Families

Member Groups	Nonhandicapped		Handicapped		t
	n=87		n=35		
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	
Fathers'	13.11	2.11	13.02	1.97	.20
Mothers'	12.41	1.71	12.02	1.41	1.19
Adolescents'	11.82	1.74	11.30	1.67	1.50

Appendix F

Table F-5

Repeated Measures Analysis of Variance of Family Role Expectations
According to Fathers and Mothers for Nonhandicapped and Handicapped
Families

Source	df	SS	MS	F	p
Between families	121				
Handicap (A)	1	2.81	2.81	.76	.38
Error	120				
Within families	122				
Member (B)	1	35.63	35.63	10.81	.001
A x B	1	1.17	1.17	.35	.55
Error	120				
Total	243				

Table F-6

Repeated Measures Analysis of Variance of Family Role Expectations
According to Mothers and Adolescents for Nonhandicapped and Handicapped
Families

Source	df	SS	MS	F	p
Between families	121				
Handicap (A)	1	10.29	10.29	3.40	.07
Error	120				
Within families	122				
Member (B)	1	21.55	21.55	8.53	.004
A x B	1	.20	.20	.078	.78
Error	120				
Total	243				

Appendix F

Table F-7

Repeated Measures Analysis of Variance of Family Role Expectations
According to Fathers and Adolescents for Nonhandicapped and Handicapped
Families

Source	df	SS	MS	F	p
Between families	121				
Handicap (A)	1	4.52	4.52	1.11	.29
Error	120				
Within families	122				
Member (B)	1	112.61	112.61	35.20	.000
A x B	1	2.34	2.34	.73	.39
Error	120				
Total	243				

Table F-8

t Tests for Adolescents Relationship Scores of Fathers and Mothers in
Nonhandicapped and Handicapped Families

Members	Nonhandicapped		Handicapped		t
	n=89		n=35		
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	
Fathers'	3.23	.56	3.16	.81	.58
Mothers'	3.31	.59	3.11	.49	1.78

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