

**THE CRITICAL ROLE OF DISTANCE
ON THE SUBJECTIVE AND OBJECTIVE IMPACTS OF FAMILIES CARING
FOR A CHILD WITH A CHRONIC CONDITION**

By

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ABSTRACT

Children with chronic conditions and their families face many similar challenges that can be stressful for the family including, daily caregiving activities, financial difficulties caused by unexpected expenses, and increased use of health services to treat and help manage the condition. The impacts of these challenges establishes the importance of studying factors that may help mitigate the effects on the family. One factor, not often considered, is the impact of distance to access the most comprehensive level of health care.

Family behaviour is conceptualized within a framework of *adoption* and *harmonization*. This framework is used as a guide to the analysis of data originally collected by Burke et al. (1994 to 1996). In this study, the Burke et al. (1994 to 1996) data of repeatedly hospitalized children and their families is used to explore a geographical dimension of family impact, distance. The distance between the family's residence and the hospital is divided into 3 categories: those living near the hospital (0 to 15 kilometers); those living a medium distance from the hospital (16 to 80 kilometers); and those living a far distance from the hospital (81 to 220 kilometers).

The Feetham Family Functioning Survey (FFFS) and The Questionnaire on Resources and Stress (QRS), used to examine subjective family impacts, were collected 2 weeks before and 3 months after the hospitalization. The objective family impacts of direct costs for out-of-pocket expenses, and the indirect costs of time spent caring for the child during hospitalization were collected 2 weeks after the child's discharge from hospital.

Significant distance differences were found for items pertaining to the amount of help from both neighbours and friends, family concerns regarding institutional care, car transportation costs, and the number of hours that primary caregivers and other family members spent caring for the child. Distance differences, although not significant were found for other subjective and objective measures of family impact.

This thesis provides evidence demonstrating the critical role of distance in adoption and harmonization in the lives of children with a chronic condition and their families. The importance of required distance to access the most comprehensive level of health care is discussed in terms of interventions for identifying and helping families cope with the hospitalization experience, and implementing government policy to help mitigate the subjective and objective impacts of families caring for a child with a chronic condition.

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CHAPTER 1

INTRODUCTION

Families caring for children with chronic conditions face many challenges such as financial and time pressures, concerns over the well-being of the child, anxieties over life long care, social reaction and stigma, and aspects of future prognosis that can all lead to stress, maladjustment and psychosocial problems in both individual members and the family unit as a whole. Many children who have a chronic condition require ongoing treatment and management of the condition. Often the health centers with the necessary equipment, and specialized medical personnel are at a distance from the family home. Traveling to health centers to access the most comprehensive level of health care may cause even more challenges for families caring for a child with a chronic condition.

There are 2 key reasons for selecting this topic: (1) the lack of geographical research on children in general, and in particular on children who are challenged with a chronic condition; and (2) the personal experiences and challenges that my family and I have had to face in living with a chronic condition.

As a severe asthmatic along with other health difficulties and complications both my family and I have had to cope with the several challenges of living with a chronic condition. Once a week for a period of about 4 years I had to travel to a special respiratory clinic at the Hospital For Sick Children in Toronto, a distance of approximately 225 kilometers or a 3 hour drive from our home in Owen Sound. This meant missing at least 1 day of school every week, and for either my mother or father being absent from work. There were also additional costs of wear and tear on the car,

meals, arrangements for extra child care for my younger sibling, and then the psychological distress of the long drive, and the time this took from other activities. Although the care received at the clinic was exceptional, the additional concern of traveling a long distance increased the many challenges which my family confronted.

The primary purpose of this research is to examine the impacts of distance to comprehensive health care on families with a child with a chronic condition. The secondary aim is to highlight the tremendous strength and courage of children and their families who are dealing and coping with childhood chronic conditions.

Chapter 2 of this thesis, which is divided into 2 sections, establishes a theoretical framework for studying the familial impacts of childhood chronic conditions. The conceptualization of childhood chronic conditions is examined in terms of justifying the use of a non-categorical approach for classifying childhood chronic conditions, and demonstrating the importance of including the developmental processes of children. The critical inclusion of the family is emphasized by summarizing the effects of childhood chronic conditions on both individual family members and the family unit as a whole. The terms subjective and objective burden which are used frequently in the caregiving literature are critiqued, and an alternative conceptualization of subjective and objective *adoption* and *harmonization* is provided.

The second part of chapter 2 explores the geographical dimensions of family impacts depicting distance, time and transportation as barriers to accessing health services. Hagerstrand's (1975) concepts of time and space as limited resources are used to highlight the additional caregiving and other family tasks that families caring for a child with a

chronic condition often face. This in turn increases the difficulty of allocating, and distributing space and time resources for these families.

The three research questions addressed in this thesis are addressed at the end of Chapter 2. The first asks if the distance required to access the most comprehensive level of health care for children with chronic conditions is an important factor when examining family functioning and caregiver and family impact. The second asks if the distance required to access the most comprehensive level of health care for children with chronic conditions is an important factor in the amount of direct and indirect costs incurred by the family. The third asks if the distance required to access the most comprehensive level of health care for children with chronic conditions is an important barrier to families.

Chapter 3 presents the data and methodology used to address the three main research questions in this thesis. The first section introduces the repeated hospitalization study by Burke et al. (1994 to 1996), which is the data source for this thesis. An explanation of using distance as a predictor variable, and the division of the distance variable into 3 categories (near, medium, far) follows. The subsequent analysis of the distance differences for variables associated with the hospitalized child, the hospitalization history for the child's lifetime, and the family and parent characteristics determines if any confounding variables are present.

The second section of chapter 3 describes the purpose and composition of the subjective measures of the Feetham Family Functioning Survey and the Questionnaire on Resources and Stress, and the objective measures of the family's direct and indirect costs.

And the third section identifies the methods of analysis used to examine the impacts of distance to hospital on families with a child with a chronic condition.

Chapter 4 provides an analysis of the findings concerning the significance of distance to the subjective measures of family impact. The visual representations and statistical analysis of the impacts of distance on the Feetham Family Functioning Survey and the Questionnaire on Resources and Stress are reported.

Chapter 5 which is divided into 2 sections, provides an analysis of the findings concerning the significance of distance to objective measures of family impact. In the first section statistical analysis is used to demonstrate the impacts of distance on direct costs such as meals and accommodation expenses, for families. The second section examines the indirect costs of caregiving time for both the primary caregiver, and other family members involved in the child's care while they are in hospital.

Chapter 6 addresses 3 main themes based on the findings of this thesis. The discussion begins with a re-emphasis of the importance of using a non-categorical approach when classifying childhood chronic conditions, the use of Rolland's (1987) framework is revised in light of data limitations and emphasis on the family, and the importance of differentiating between subjective and objective adoption and harmonization is shown. The next section uses in-depth analysis of the items composing the factors of the Feetham Family Functioning Survey, and the scales of the Questionnaire on Resources and Stress, to determine possible reasons why only some of the factors and scales are affected by distance. The implications for this thesis regarding the ability of families to adopt and harmonize the impacts of traveling distance to health services is also discussed.

The final section discusses possible explanations of why distance does not affect all direct and indirect costs, and compares the findings of this thesis with the findings of other studies of the familial impacts of childhood chronic conditions.

The seventh, and final chapter of this thesis is divided into 3 parts. The first highlights some of the key results of the thesis. The second reminds the reader of the critical limitations of the data set and methodology. The final section highlights the implications for continued research regarding the impacts on families with children with chronic conditions, and recommendations for health policy arising from this thesis.

CHAPTER 2

LITERATURE REVIEW: DEVELOPING THE THEORETICAL FRAMEWORK

2.1 Introduction

Household data from the Health and Activity Limitation Survey (HALS) conducted in 1991 reveal that 534,430 (7.2%) of children and youth between the ages of 0 to 19 years in Canada have at least one disability (CICH 1994). Of these children 85% have mild disabilities, 11% have moderate disabilities, and 4% have severe disabilities (CICH 1994). In 1991 approximately 73% of children 0 to 14 years with disabilities lived in households, and of these children 76% had a health problem or chronic long-term condition (CICH 1994). Chronic conditions, medical conditions and limitations of function affect about 1 in 5 Ontario children between the ages of 4 and 16 years (Cadman et al. 1986). These statistics demonstrate the importance of childhood chronic illness as a research and policy issue in Canadian society, yet children with chronic conditions continue to represent “a group of children neglected in recent public attention” (Perrin 1985a, pg.x).

2.2 Conceptualizing Childhood Chronic Conditions

The academic and general policy literature is inconsistent concerning the use of the words illness, disease and condition. Some feel that illness implies physical symptoms such as fever or fatigue, which are not applicable to various chronic conditions such as, spina bifida and cerebral palsy. The term disease, being associated with the medical model, often implies health problems due to infection, discomfort or pain. The

social construction of other terms such as ‘disability’, ‘handicap’, and ‘impairment’, as having a deficit, or not being ‘normal’ makes their use problematic. Since, “the term ‘condition’ has a more neutral connotation and is more encompassing and less restrictive than the alternatives”, it will be used throughout this thesis (Perrin et al., 1993, pg. 789).

2.2.1 Justification For The Use Of A Non-Categorical Approach

Various definitions exist for chronic condition¹, with the most general being a condition that interferes with daily functioning for more than three months in a year, causes hospitalization for more than one month in a year, or (at the time of diagnosis) is likely to do either of these (Perrin 1985b). The tendency of classifying chronic conditions according to physiological elements of disease dictated by the medical model fragments childhood chronic conditions into discrete entities such as diabetes, cancer, and muscular dystrophy, and interferes with an holistic approach.

Chronic conditions can share many common characteristics including:

- high direct medical treatment costs;
- costly long-term care such as nursing, equipment and special diets;
- a majority require prolonged care;
- requirement of intermittent medical care for diagnosis, establishment of treatment regime, follow-up care and periods of crisis; and
- family responsibility for the daily treatment regimes which can be difficult, painful, and burdensome.

(Perrin 1985b)

Regardless of diagnosis, families dealing with childhood chronic conditions face similar challenges such as, anxieties over life long care, physical limitations and suffering

¹ For readability chronic condition is used in the singular sense, however, many children have multiple conditions and the choice of wording is not meant to ignore the child’s or family’s experiences.

associated with the condition, social reaction and stigma, financial concerns, and aspects of future prognosis that can all lead to stress, maladjustment, and psychosocial problems in both individual members and the family unit as a whole. Recognition of these similarities promotes development of programs and services, research and implementation of policy that benefits all families, and presents a united advocacy for children with chronic conditions and their families.

Several methodological reasons support using a non-categorical approach (one that does not use disease specific diagnoses) in defining childhood chronic conditions. While childhood chronic conditions affect 7.3% of children in Canada, the small incidence rate for each disease category (Table 2.1) makes obtaining an adequate sample size for analysis difficult, and leads to obstacles in justifying the cost and effort of studying every condition.

Table 2.1 Incidence Rates For Some Childhood Chronic Conditions^a

Condition	Rate /1000 total population
Kidney Disease	2.2
Diabetes	1.1
Cerebral Palsy	2.3
Spina Bifida	0.8
Heart Disease	5.3
Epilepsy	2.4
Arthritis or rheumatism	1.1
Moderate to Severe Asthma	10.0

^a According to HALS 1991
(adapted from CICH 1994)

Thus, only those conditions which are easy to identify and occur with moderate frequency are likely to receive attention; difficult to define or rare illnesses will likely be neglected. These methodological considerations mean that “condition-specific approaches compromise the generalizability of findings and comparability among research efforts, foster competition for resources, and may prevent some children from qualifying for needed services” (Perrin et al., 1993, pg. 788).

Analysis of variance of psychological and social parameters affecting both child² and family, using the grouping variable of diagnosis showed, “a striking similarity” among the diagnostic groups for most of the measures (Stein and Jessop 1989, pg. 773). No significant differences among the diagnostic groups existed for child’s and mother’s psychological adjustment, the impact on the family (except for financial), social resources of the family, or satisfaction with care (Stein and Jessop 1989). Therefore, diagnostic labels are a poor descriptor of many of the areas of concern in the lives of children with chronic conditions and their families. More importantly, it is not the label attached to the condition but the extent of the psychsocial and economic impact of the condition and treatment on the family and child that is critical.

The importance of formalizing a definition for childhood chronic conditions still exists when employing a non-categorical approach. Distinct differences do exist between the effects, course, and level of impairment, meaning that defining chronic conditions requires clarity about both duration and condition. For example, the effects on the child

² The word child (0 to 19 years) is used for the sake of readability and clarity. It should be noted that some families have more than one child diagnosed with a chronic condition, and the choice of wording is not meant to neglect their circumstances or experiences.

and family of well controlled diabetes are different than those of a child with Duchene's muscular dystrophy, whose health will constantly deteriorate over time. An actual or expected duration of three months or more is the general criterion for delineating chronic illness (Perrin 1985b; Pless and Satterwhite 1975). Duration can also be used to describe whether the condition is dynamic (changes over time, such as muscular dystrophy, or is episodic, such as asthma), static (diabetes), and the likelihood of death in childhood.

The bio-medical model has categorized conditions according to the organ system involved; however, many conditions are complex and do not fit into neatly defined categories. One solution is to classify children along a series of continua, avoiding clear-cut categories, and allowing for changes in the treatment, course and prognosis of the condition (Perrin et al., 1993). Figure 2.1 illustrates an example of the continua used to describe childhood chronic conditions.

This type of framework facilitates the selection of the dimensions most appropriate for the research. However, the difficulty, is selecting enough dimensions to describe the children, yet not choosing too many to become burdensome in the analysis. Another problem is determining whether to ask the parents, primary caregiver, medical practitioner, teacher, or the actual child to help with the classification process. Studies have shown existing discrepancies between families, the individual child, and health care professionals regarding aspects of treatment and care (Barker, Wright and Gonick 1953; Jessop and Stein 1985).

Figure 2.1: Dimensions For Describing Childhood Conditions

A. Duration	<----->
	brief lengthy
B. Age of onset	<----->
	congenital acquired
C. Limitation of age appropriate activity	<----->
	none unable to participate
D. Visibility	<----->
	not visible highly visible
E. Expected Survival	<----->
	usual longevity threat to life
F. Mobility	<----->
	not impaired severely impaired
G. Physiological Functioning	<----->
	not impaired severely impaired
H. Cognition	<----->
	not impaired severely impaired
I. Sensory Functioning	<----->
	not impaired severely impaired
J. Course	<----->
	stable progressive
K. Uncertainty	<----->
	episodic predictable

(adapted from Perrin et al., 1993)

2.2.2 The Developmental Process Of Children

The rapid physical, cognitive, emotional and social development occurring throughout childhood creates unique challenges for studying childhood chronic conditions.

There has been a tendency to view adjustment difficulties, impacts on the family, and

coping resources as a function of the disease, independent of the child's developmental process (Eisler 1993). Theoretical frameworks must encompass the change and non-predictability of these developmental phases. For example, the familial impact of dressing a toddler with a motor impairment is different than having to dress a teenager, because the toddler's family expects this task. Helping a teenager with this activity of daily living (ADL) is considered abnormal by society's standards, is a constant reminder of the disease, and creates discrepancies between the afflicted family's regime and those of other families.

Recognition is now being given to the importance of the child's developmental phase in their ability to comprehend and deal with their condition, resources they can utilize, health consequences, and the capacity to utilize external resources (Eisler 1993). This is also important because one of the crucial descriptors for a non-categorical approach to chronic childhood conditions is examining the limitations on age-appropriate activity imposed by the illness. However, before these decisions can be made age appropriate activity must be defined either through Erikson's cognitive approach (1959;1964), Piaget's model of childhood development (1929;1952), social ecology theory, or some other type of developmental theory.

The problem with Erikson's and Piaget's theories is that they focus on cognitive processes, and fail to account for the social and cultural context of children's development (Eisler 1993). Presently, the social ecology theory is the most comprehensive, as it emphasizes relationships between the developing child and social contexts such as, the family, school or hospital, and other settings that indirectly affect the child such as their

parents' place of employment. This theory assumes that all children require some basic resources to support their development, avoids stereotyping children with chronic conditions as unable to perform certain tasks, avoids predetermining the ability of chronically ill children, and acknowledges that chronically ill children need to undergo many of the same developmental stages as other children; they just have to overcome extra challenges to accomplish a task successfully (Joe and Rogers 1985).

2.2.3 The Importance Of The Family

Studies of the family impact of childhood chronic conditions show that individual family members have a higher propensity towards various psychological difficulties. A positive relationship exists between the increased dependency of a child with a chronic condition and the mother's higher psychological distress (Wallander and Venters 1995). Fathers are also deeply involved psychologically with their child (Sabbeth 1984).

According to family theorists, the family system must be the area of focus when examining the impact of childhood chronic conditions, because looking at individual members fails to capture the interactions between family members, and these may be one of the greatest impacts of chronic illness (Sabbeth 1984). Massie, a hemophiliac, emphasizes the importance of family when he states, "chronic illness does not strike individuals; it strikes the whole living unit of the family" (Massie 1985, pg. 15). Many reasons exist for focusing on the impact of childhood chronic conditions on the family: (1) challenges of daily caregiving responsibilities; (2) emotions such as anxiety, guilt, and sorrow that surface; (3) financial burden caused by unexpected expenses; (4) uncertain

future which may include financial concerns and the premature death of the child, and (5) requirement of services, beyond the traditional medical services to aid with daily management of the condition. Another reason for analyses of family impact is that, “the family is the constant in the child’s life, whereas service systems and providers within those systems fluctuate” (McDonald, Couchonnal and Early 1996, pg.512). McDonald, Couchonnal and Early’s (1996) study on the impact of major events on the lives of families caring for children with disabilities has established three points: (1) the importance of a family-centered approach to the child’s care, determined by the specific needs of the caregivers and the children including daily treatment and management, respite care, and access to services; (2) recognition of family strengths, individuality, and unique coping methods, and (3) flexible and accessible services which are responsive to the needs identified by the family.

Several studies have demonstrated the impact of childhood chronic conditions on the family. Bouma and Schwetizer (1990) compared the stress of families of children with a physical chronic condition (cystic fibrosis), a psychological chronic condition (autism), and neither physical nor psychological chronic condition. Mothers of each family completed a shortened Questionnaire on Resources and Stress (QRS) containing questions examining dependency on the family, terminal illness stress, physical limitations of the child, and family disharmony, designed to assess the impact of chronic illness and disability on families. The mean overall stress scores for the autism, cystic fibrosis (CF) and control groups were 29.08, 20.04 and 13.17 respectively. Thus, families with children with a chronic condition had significantly more stress compared to families with healthy children

and families with children with autism had higher stress levels than those with children with CF. Results showing varying levels of family stress imply that family-based intervention programs need to consider the nature of the child's condition, or the disease typology (Rolland 1987).

Holroyd and Guthrie (1986) used the QRS completed by mothers to assess the impact of Duchene's muscular dystrophy, CF, and renal disease on family functioning, with each clinical group matched by age and sex ratio to a control group. All three clinical group families reported higher stress from physical incapacitation compared to their control group cohorts. Families caring for children with Duchene's were much more stressed than those caring for children with CF or renal disease. Families having children with Duchene's felt the child was disabled in many ways, anticipated life-time care, were constantly aware of the terminal implications, felt financially pressured, and had insufficient support from others. Examination of the life-cycle model can help explain this stress on these families. The progression of this disease creates a backward experience to what families would expect, "Normal children grow stronger and more independent, children with Duchene's grow weaker and more dependent" (Travis, as cited in Holroyd and Guthrie 1986, pg.558).

Families caring for children with CF scored higher on 6 scales: lack of social support; physical incapacitation; anticipation of life-time care; realization of the illness' terminal nature, and feeling financially pressured. Whereas, families caring for children with renal disease were more stressed due to financial pressures, physical incapacitation and limitations on family opportunities. Comparisons between the three clinical groups

showed similarities in stress caused by the child's physical incapacitation and financial pressures; however, variations in other indices illustrate the necessity to "think in a more differentiated fashion about the difficulties that these families face" (Holroyd and Guthrie 1986, pg.558).

2.2.4 The Challenge

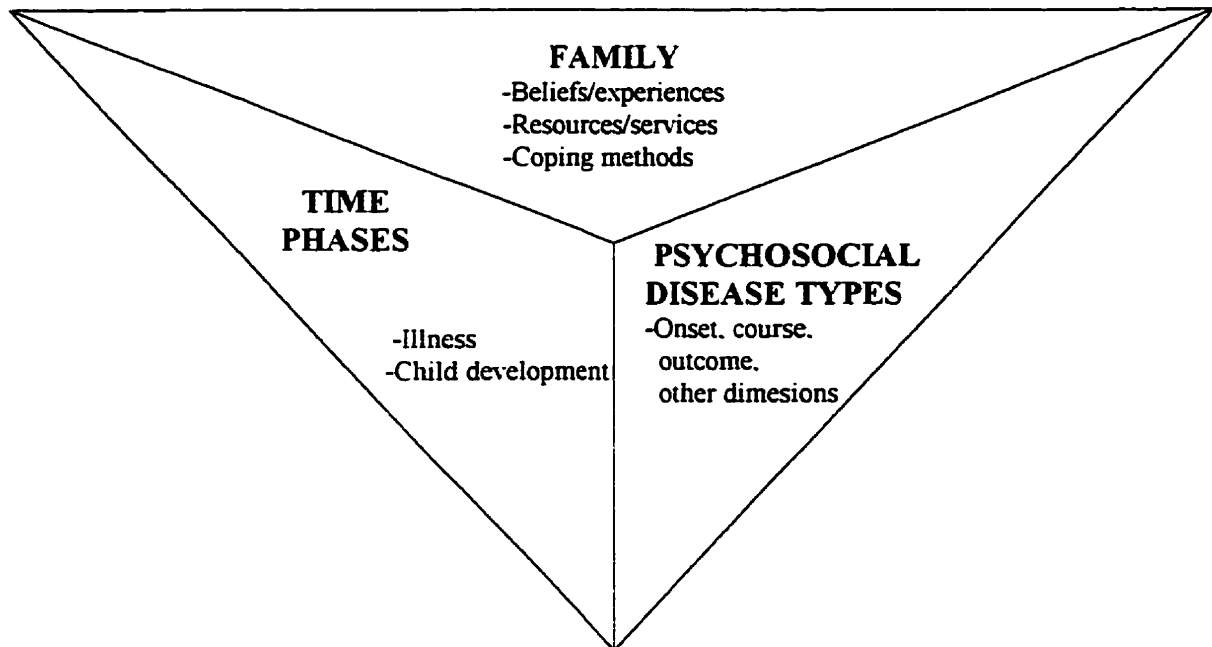
Capturing and interrelating the developmental phases of the child, disease and family form a unique challenge to studying the impacts of childhood chronic conditions on the family. Rolland's (1987) conceptual framework for chronic illness and the life cycle provides a starting point for conceptualizing the intertwining of illness, individual and family life cycles. This shift from a medical to a family view facilitates "a different classification schema which may provide a better link between the biological and psychosocial worlds, and thereby clarify the relationship between chronic illness and the family life cycle" (Rolland 1987, pg. 204).

The potential psychosocial disease types are generated using the concepts of onset, course, and outcome. Onset is categorized as acute such as acute leukemia, or gradual such as cystic fibrosis. The course of disease is characterized as progressive (Duchene's muscular dystrophy), constant (non-progressive mental retardation), or relapsing/episodic (asthma). Outcome refers to the extent the disease is likely to cause death, the degree it may shorten the life span, and the amount of incapacitation. This characterizing of psychosocial disease types could also be expanded to include some of the dimensions found in Figure 2.1.

Time phases of illness are also included in recognition that “chronic illness is an ongoing process with landmarks, transitions and changing demands” (Rolland 1987, pg.206). The three main time phases of crisis (diagnosis), chronic, and terminal are associated with transition and change periods. Along with the time phases of illness it is essential to include the time phases of child development when studying childhood chronic conditions. The interaction of time phases with illness typology establishes a framework that acknowledges the importance of certain tasks occurring in particular periods regardless of disease type. For example, a period of socialization towards the illness occurs in the transition to the chronic phase, when individuals must harmonize living with a chronic condition to the other aspects of their life such as school, occupation, family life and hobbies. However, this conceptualization also illustrates that individuals and conditions are individualistic and their impacts can vary.

The addition of a ‘components of family functioning’ dimension enhances the framework by providing an opportunity to show, “the importance of strengths and weaknesses in various components of family functioning in relation to different types of disease at different phases over the illness life course” (Rolland 1987, pg. 209). The strengths of Rolland’s conceptualization of chronic conditions such as viewing the illness as having typologies and time phases, and combining these with components of family functioning are utilized in developing a preliminary model of factors affecting the impact of childhood chronic conditions on the family (Figure 2.2).

Figure 2.2 Model Of Factors Affecting The Impact Of Childhood Chronic Conditions On The Family



(adapted from Rolland 1987)

2.3 Conceptualizing Burden

The concept of *burden* is often used in describing the caregiving experience (Braithwaite 1996; Dwyer and Miller 1990; Poulshock and Deimling 1984). Researchers often distinguish between subjective and objective burden, with subjective burden defined as the feelings, attitudes and emotions arising from the caregiving experience, and objective burden referring to the events and activities associated with caregiving. In a study conducted with 80 people caring for, or aiding an elderly relative³ different factors

³ Although this study focuses on elderly caregiving the authors note that the conceptualization of burden also applies to caregivers of children with degenerative conditions.

were found to be related to subjective burden compared to objective burden. Factors affecting subjective burden were the age and income of the caregiver, whereas, specific caregiving tasks that confine the caregiver both geographically and temporally influenced objective burden (Montgomery, Gonyea, and Hooyman 1985).

Another way to discuss family impact is through *stressors*, a term used in the stress and coping literature. Stressors in this population are considered sporadic and intermittent in nature, can be considered either negative or positive, and vary in significance among families. Hymovich (1988, as cited in Burke et al., 1996) identifies 13 Situational Tasks and Stressors some of which include meeting the needs of all family members, managing financial burden, obtaining adequate health care, and understanding and coping with the emotional impact. After diagnosis, hospitalizations are the second most stressful events in the lives of families with children with chronic conditions (Burke et al., 1989). The key stressful issues for these families include: (1) maintaining consistency or changing the child's daily health care management such as, medication, physiotherapy and diet; (2) maintaining the child's unique daily care activities such as feeding, and toileting; (3) cultivating and preserving relationships with health care professionals, and (4) harmonizing family life during hospitalizations (Burke et al., 1989; Robinson 1987; Webster and Moss 1986, as cited in Burke et al., 1998b).

The severity of the impact however, varies. A survey of 75 families caring for children with severe and/or long-term conditions found that approximately 50% of parents

reported that lengthy out patient visits and/or hospitalizations had a slight to a very negative personal impact (Burke and Kauffmann 1990).

While it is true that children with chronic conditions and their families face stressful conditions, there are several problems with associating burden and caregiving. The concept of burden is problematic as it lacks clarity in definition, and is inconsistent in its conceptualization and operationalization. Both these factors decrease its relevance in public policy (Braithwaite 1992). The word burden has been constructed in a negative sense, thus, its use assumes that caregiving is a negative experience. However, family caregiving is only associated with increased levels of distress in certain circumstances, and it is incorrect to assume that caregiving negatively affects all families (Avison et al., 1993). One of the problems with using burden is that it indirectly imposes guilt or blame. If burden is linked with disability then the care-receiver is seen as a burden, if it is associated with caregiver distress then the caregiver is deemed weak and unable to manage, however, if burden is conceptualized as arising from a conflict of needs then neither party feels guilty, and attention is focused on the situation rather than the individuals. Thus, caregiving can be defined as “the extent to which the meeting of caregiving demands threatens satisfaction of the caregiver’s basic needs of a physiological, safety, social and self-esteem kind” (Braithwaite 1992, pg. 19).

The concept of burden is rejected because of these limitations. The caregiving experience is conceptualized in terms of subjective and objective *adoption* and *harmonization*. The words *adoption* and *harmonization* have been coined by the author. Although other models of the caregiving experience exist which use words such as

adaptation, normalization and coping, it is felt that these represent incremental changes that families and individuals utilize to help minimize the challenges of living with a chronic condition. The model of *adoption* and *harmonization* used in this thesis depicts the ensemble of lifestyle changes that families ‘adopt’ and then ‘harmonize’ or balance within the various facets of family life, enabling the family to cope with the many challenges of childhood chronic conditions.

Through adoption families discover particular ways of coping with the chronic condition such as, involving the child in all aspects of family life, with modifications depending on the child’s abilities⁴. For example, even though some children with a chronic condition can not attend school on a full time basis, many parents expect the child to reach their full academic potential. Through harmonization families make actual changes to their home and lifestyle to minimize the affect of childhood chronic conditions. Many families install ramps, widened doorways or hallways and elevators, or lift devices to help the child navigate around the family home.

This use of the terms adoption and harmonization to signify individual coping and changes in lifestyle is supported by the Lazarus et al. (1985) study demonstrating that stress depends on the interaction between 2 complex systems, the environment and the person. “The concept of appraisal [or the impact of a situation] integrates person variables, such as values and commitments, with the environmental conditions being faced,

⁴ At five years of age I was diagnosed with severe asthma, and for the past twenty years both my family and I have faced many challenges associated with this chronic condition. One two separate occasions (one occurring presently), medication side-effects have caused me to lose muscle control and have pain throughout my body. This has necessitated using a wheelchair, crutches and walker to carry out and participate in daily activities. Many of the examples of adoption and harmonization are examples that my family and I have used to cope with living with a chronic condition.

and provides the bases of individual differences in reaction” (Lazarus et al., 1985, pg. 777, [brackets added]). This idea of individual variables and individual reactions could be expanded to include family variables and family reactions.

2.4 The Geographic Dimension

2.4.1 Barriers And Their Effects On Families Caring For Children With Chronic Conditions

Families having children with chronic health problems face many challenges in their daily lives. “The family resource is at risk of being overwhelmed by the complex problems that families face when they attempt to get decent care for those special children” (Hastings Centre Report 1987, pg.25). Yet studies show that these special needs are not being met. One study found that 28% of respondent families reported unmet service needs (Axtell et al., 1995). The CICH (1994) reports that approximately 25% of youth ages 15 to 19 years did not participate in desired leisure activities because of inadequate transportation, and more than 13,000 children and youth with disabilities have a need for specialized transportation services that are not available in their community. In total 7,984 Canadian children and youth with disabilities need specialized features such as, ramps, widened doorways or hallways, elevators or lift devices that are not available (CICH 1994). All of these things, plus many other experiences constitute challenges that children with chronic conditions and their families negotiate on a daily basis.

Health behaviour theorists define barriers as consumers’ perceptions or beliefs concerning the cost of taking a particular health action, such as visiting a family physician. It is important to note that cost here is not necessarily financial, but can include other

factors such as, inconvenience, waiting time, and transportation difficulties. However, much of the literature examining costs associated with childhood chronic conditions does emphasize financial cost (Newacheck and McManus 1988; Walker et al., 1988).

The overemphasis on financial costs is problematic because it assumes that “ ‘Free’ is a relative term implying that finances are the only costs that families consider in whether or not to use health services” (Friedman 1994, pg.1536). The importance of non-income barriers such as, type of health service environment, population density, and availability of health care providers have been established for populations without chronic illness or disabilities (Rosenberg and Hanlon 1996).

The specialized service needs and increased utilization of services⁵, coupled with the often overwhelming daily challenges these families experience make the identification, conceptualization and analysis of barriers an integral component for geographical research. The conceptualization of barriers provides: (1) a theoretical link between the study of health-related behaviour and health services research; (2) provides a milieu for the expression of the consumer’s view of the health care system; and (3) provides a new way of looking at the dynamic relationship between the consumer and the health care system (Melnyk 1990).

Several barriers have been identified in the general literature including, time, distance and transportation, financial costs, availability of services, organization of services, demographic factors, patient attitudes, health related knowledge, and family

⁵ Findings of the Ontario Child Health Study show that children with no chronic health problem have a lower rate of physician use (550 per 1000), and social and mental health services use (41 per 1000), than children with a chronic condition (679 per 1000) and (105 per 1000) or children with a chronic illness or condition and limitation of normal function (804 per 1000) and (125 per 1000) (Cadman et al. 1986).

characteristics (Melnyk 1988). In a 1996 study on barriers to the use of preventative health care services for children, 55% of parents cited competing family and personal issues as reasons for not accessing the service. These barriers included difficulties in arranging care for other children or family members, taking time off work, scheduling difficulties, limited availability of providers and inadequate transportation (Riportella-Muller et al., 1996). Parents caring for children with severe and/or long-term conditions listed arranging care for family members left at home, accommodation, transportation to health care facilities, and making work arrangements as barriers to accessing Kingston health care services (Burke and Kauffmann 1990). It is expected that these plus other barriers affect the ability of families having children with chronic health conditions to access health services.

Robin Jones, director of The Child Development Centre⁶, whose clients include children with cerebral palsy, spina bifida, muscular dystrophy and other types of neurological conditions emphasized the importance of distance as a barrier to health care. The families are often overwhelmed by the day-to-day activities of caring for the child, and traveling long distances for treatment, therapy or other services creates further challenges. Her experiences with the children for which they provide services show that the further away a service is, the more difficult it is for the family to access. Ms. Jones mentioned the possibility of satellite offices from the larger medical centers to provide more equitable service delivery to rural and northern areas, but she also stated that this would be some time coming.

⁶ Personal Interview. Sept. 3, 1997.

Families living in rural areas experience unique problems which heighten the challenges of coping with chronic conditions. The isolation of these areas makes geographic access to health and related services difficult due to required travel distance and lack of adequate transportation (Perrin 1985c). Lack of experience and skills of primary care providers with specific conditions, due to small prevalence rates in the population often hamper identification, and referrals to more specialized care. The limited economic base in rural areas which leads to increased poverty, coupled with limited access to services suggests that there is an increased number of childhood chronic conditions in rural compared to urban areas (Perrin 1985c).

2.4.2 Time And Space As Limited Resources

Time and distance are obviously linked as barriers for children with chronic conditions and their families. In geography, time and space have been linked in the work of Hagerstrand and his colleagues. One of the key premises to Hagerstrand's time geography is that time and space are limited resources which individuals must access to accomplish tasks in their daily life. Two types of constraints are recognized: (1) circumstances which are beyond the control of science, public policy and planning, and (2) circumstances that can be adapted and modified (Hagerstrand 1975). Both these constraints impact on the lives of families caring for a child with a chronic condition⁷. The psychosocial aspects of the disease such as the onset, course and prognosis are mostly

⁷ When discussing constraints Hagerstrand is usually talking about things restricting an individual's behaviour. However, because of the closeness and integration of the family unit this idea has been extended to include constraints on the family.

beyond the control of the family and other external agencies. However, some of the barriers such as distance, transportation difficulties, and accommodation anxieties can be mitigated in order to help these families. One of the main goals should be to “organize society to make care for the dependent population more just and humane” (Abel 1990, pg. 147, as cited in Braithwaite 1992). Hagerstrand recognizes the importance of constraints with the statement, “In our space-time notation, however, they [daily and lifetime constraints] all come out together as a system of barriers which prevent trajectories from making certain turns and let them move freely ahead in other directions” (Hagerstrand 1975, pg. 11, [brackets added]).

Projects are identified tasks which must be accomplished throughout the day, such as accessing comprehensive health care for a child (Hagerstrand 1973). The project usually involves a specific and necessary sequence of events like taking time off work and school, arranging alternative child care, driving to the health service, waiting for the appointment, and driving back home. These projects are also controlled by several human limitations such as, the ability of only being in one place at a time, restricted spatial mobility (every movement takes time from alternative tasks), and the limited number of hours in a day in which to accomplish tasks. Often these limitations lead to frustration, anxiety and feelings of despair. Results of a study of caregivers for elderly relatives showed that those daily tasks such as nursing, bathing, dressing and transportation which confine the caregiver both temporally and spatially were identified as having the greatest impact on the caregiver’s life (Montgomery, Gonyea and Hooyman 1985).

Families caring for a child with a chronic condition often face excessive caregiving time demands, which often limit time that parents spend in other ways such as, hours of employment, recreation time, time spent with other siblings, and time spent with friends (Leonard, Brust and Sapienza 1992). Additional caregiving time costs include helping with personal care and ADLs, shopping errands for special food, clothing and medication, taking the child to various medical appointments, taking the child to additional services such as speech pathology, time spent waiting for appointments, and time spent monitoring medical equipment (Leonard, Brust and Sapienza 1992). A positive relationship exists between caregiving time and level of functional dependence, measured by the child's ability to conduct ADLs, communicate, and level of sensory impairment (Leonard, Brust and Sapienza 1992).

Travel to medical and specialized therapy appointments place demands on family time and energy. Anyone who has traveled with children realizes that there is advanced planning needed, emotional and physical energy consumed on the trip and extra down time required to recover from traveling with children. For families with a child with a chronic condition travel can take away from parental, partner, sibling and normal child roles and functions. This increased time commitment is demonstrated by Salkever's findings (1986) that children's disabilities on average increase the amount of parental time required to take the child to only the physician by about 17 to 24 hours annually.

One of the key contributing factors of this variability besides the child's health is distance. The amount of time required per trip will increase as distance increases. While the impact of hospitalization and various interventions on families caring for a child with a

chronic condition have been explored (Association for the Care of Children's Health; Burke et al., 1989; Burke et al., 1991; Wells and Schwebel 1987, as cited in Burke et al., 1998a), there is a need to examine the importance of the distance required to access the most comprehensive level of health care as a contributing factor to family impact. Few studies have examined the space-time context of the caregiving experience, and fewer yet have explored the space-time context of families caring for children with chronic conditions.

Duvall's (1977) family development task of the allocation of resources illustrates the negotiation of time-space adjustments in families caring for children with chronic conditions (Duvall 1977, as cited in Burr 1985). Usually financial, space and time resources are allocated according to each individual member's needs. A child with a chronic condition may need an unusually large, disproportionate share of these resources, leaving a limited share for the other members. Leonard, Brust and Sapienza (1992) found that families in their study reported caregiving time for a child with a disability to be 4 hours and 42 minutes per day, with the time allotted to ADLs such as, feeding and bathing, and taking the child to medical and therapy appointments. Thus, appropriate and equal allocation of financial, space and time resources is difficult for these families, and scarce, unavailable, and poorly distributed health resources further heighten the difficulty.

Methodologically it is difficult to assess these time-space adjustments. First, little data or information are available concerning the time-space utilization of families who do not have children with a chronic illness, which would provide a bench mark for comparison purposes. Second, most of the information concerning the costs to families

having children with chronic conditions is strictly financial and does not include caregiving time costs. Third, is the difficulty of developing meaningful questions for both families dealing with chronic conditions and a control group of families, as their experiences may be vastly different. Finally, barriers and caregiving time are difficult to research as data collection is time consuming, costly, and invades family privacy.

2.5 Research Questions To Be Addressed

Many of the barriers identified by families caring for a child with a chronic condition such as transportation, accommodation, and making additional arrangements for child care are centered around difficulties of accessing comprehensive health care. The 3 main research questions addressed in this study are intended to examine these barriers and their impacts on the family. The research questions are:

1. Is the distance required to access the most comprehensive level of health care for children with chronic conditions an important factor when examining family functioning and caregiver and family impact for these families?
2. Is the distance required to access the most comprehensive level of health care for children with chronic conditions an important factor in the amount of direct and indirect costs incurred by these families?
3. Is the distance required to access the most comprehensive level of health care for children with chronic conditions an important barrier to families?

These research questions focus attention on the identified needed research area of the interrelationship among health problems, access and utilization of health services, and the impacts on the child and family (Starfield 1985), and the “relative neglect of the problem of childhood chronic illness” (Perrin 1985a, pg. xii).

CHAPTER 3 DATA AND METHODOLOGY

3.1 Introduction To The Repeated Hospitalization Study

Data used for the analysis were obtained from a study by Burke et al. (1994 to 1996) of repeatedly hospitalized children and their families conducted over a 19 month period from January 1994 to August 1996, from three pediatric ambulatory care clinic settings in Ontario. To determine factors associated with familial hospitalization impacts subjective measures were collected 2 weeks prior to hospitalization (T1), and three months after hospitalization (T3)¹. Hospitalization experiences, and family costs data were collected by telephone interview 2 weeks after the child was discharged from hospital (T2).

The sample is drawn from children who have been hospitalized on at least one other occasion, including birth (if hospitalized for more than 10 days), and who have been scheduled or were expected to be readmitted to the hospital during the study period. One hundred forty children entered the study and 115 completed it. Reasons for non-completion included families withdrawing the child, the child becoming too ill, and the child being too old when finally admitted to the hospital.

¹ The period of three months post hospitalization was selected to try and avoid the period of about 1 month which it takes for most negative effects to dissipate among basically healthy children with short hospitalizations (Lende 1971, as cited in Burke et al., 1998a)

3.1.1 Characteristics Of The Children

Table 3.1 contains the primary diagnoses of the children. The children's ages ranged from 1 to 16 years, with a mean of 7 years, and there were more males (n=66) than females (n=47) in the study.

Table 3.1. Primary Diagnoses Of Children Involved In The Study

Primary Diagnosis	Number of Children
Cerebral palsy	23
Spina bifida	16
Congenital genitourinary defects	15
Cancer responding to treatment	14
Chronic renal disease	12
Cystic fibrosis	6
Congenital hip defects	4
Other orthopedic conditions	8
Cardiac defects	3
Gastrointestinal conditions	3
Muscular dystrophy	3
Cleft palate	2
Diabetes	2
Epilepsy	2
Other conditions	2

3.2 Distance To Hospital As A Predictor Variable

The geographic dimension of family impact could have been examined using either parent-reported distance to hospital measured in kilometers, or parent-reported time to hospital measured in minutes. Distance and time are highly correlated ($r = 0.915$, $p < 0.0001$). Distance is used in the analysis. This follows the methodology in Burke and Kauffmann's (1990) study which examined the impacts of lengthy out patient visits and/or hospitalizations on families caring for children with severe and/or long-term conditions. Distance is categorized into near (0 to 15 kilometers, $n = 39$, 34.5% of families), medium

(16 to 80 kilometers, $n = 42$, 37.2% of families), and far (81 to 220 kilometers, $n = 32$, 22.9% of families)². Table 3.2 shows the descriptive statistics for the various distance categories, and Appendix A displays a graph showing the range and frequency for each distance category.

Table 3.2. Descriptive Statistics For The Distance Categories

Distance Category	Min.	Max.	Mean	Median	s.d.	Type of Distribution
Near (0 to 15 kms)	2	15	9.54	10	3.83	negatively skewed
Medium (16 to 80 kms)	18	80	45.29	40	20.01	positively skewed
Far (81 to 220 kms)	81	220	120.81	110	35.23	positively skewed

3.3 Categorizing Childhood Chronic Conditions

Childhood chronic conditions are categorized using two methods in the general literature. The categorical method uses unique medical diagnoses, such as cerebral palsy and muscular dystrophy to classify chronic conditions. The Health and Activity Limitation Survey (HALS) Disability Index is a measure which explores the child's long-term conditions or health problems. The interviewer filled out as many questions as possible based on casual observation or content from the rest of the interview, then the parent was asked the remaining questions. The yes/no responses are based on whether the child has any conditions or problems such as, cancer, diabetes, and cystic fibrosis.

Each condition is treated as a 2x3 contingency table, with responses of having the condition, and not having the condition forming the rows, and the three distance

² Burke and Kauffmann (1990) categorized children living 80 kilometers or more away, as living at a distance from the hospital, and used 2 categories, those living at a distance, and those not living at a distance from the hospital. This thesis uses 3 distance categories to avoid the extremely unequal number of observations in the far category if only 2 categories are used.

categories forming the columns. A X^2 test, with a yes/no response of whether the child has the condition forming the rows, and the distance categories forming the columns is used to determine whether an association exists between the condition and distance (Table 3.3).³ No significant associations were found for any of the conditions. The small observed numbers of particular individual conditions, leads to 13 of the 17 chi-square tests having cells with expected counts of less than five. This highlights one of methodological constraints with using a categorical approach.

Table 3.3. The Classification Of Childhood Chronic Conditions By Distance³, According To A Categorical Schema

Long-Term Condition or Health Problem	DISTANCE						
	Near		Medium		Far		Prob.
	No.	%	No.	%	No.	%	
Lung condition or disease (yes=26)	7	17.9	8	19.0	11	35.5	0.163
Heart condition or disease (yes=4)	1	2.6	2	4.8	1	3.2	0.861 ^b
Kidney condition or disease (yes = 16)	4	10.3	8	19.0	4	12.9	0.511 ^b
Cancer (yes = 12)	5	13.2	2	4.8	5	16.1	0.257 ^b
Diabetes (yes = 3)	1	2.6	0		2	6.5	0.240 ^b
Epilepsy (yes = 11)	2	5.1	6	14.3	3	9.7	0.384 ^b
Cerebral palsy (yes = 17)	5	12.8	8	19.0	4	13.3	0.695 ^b
Multiple sclerosis (yes = 1)	1	2.6	0		0		0.389 ^b
Cystic fibrosis (yes = 5)	1	2.6	3	7.1	1	3.2	0.563 ^b
Muscular dystrophy (yes = 3)	0		2	4.8	1	3.2	0.414 ^b
Paralysis of any kind (yes = 10)	5	12.8	3	7.1	2	6.5	0.570 ^b
Arthritis or rheumatism (yes = 2)	0		2	4.8	0		0.192 ^b
High blood pressure (yes = 2)	0		1	2.4	0		0.560 ^b
Mental handicap (yes = 26)	9	23.1	11	26.2	6	19.4	0.791
Learning disability (yes = 32)	13	33.3	12	28.6	7	22.6	0.631
Missing arms, legs, fingers, or toes (yes = 4)	2	5.3	1	2.4	1	3.2	0.781 ^b
Other condition or problem (yes = 37)	12	30.8	14	33.3	11	37.9	0.825

^a No significant distance differences

^b At least 1 cell has an expected count of less than 5

³ An alpha value of 0.05 is used to determine significance for this and all other subsequent statistical tests.

It is possible for a child to have more than one condition. A 4x3 contingency table, with the number of conditions forming the rows, and the distance categories comprising the columns, is tested using X^2 to determine whether an association exists between multiple conditions and distance. There are no significant associations for the incidences of multiple conditions ($p=0.588$) (Table 3.4).

Table 3.4. Incidence Of Multiple Conditions By Distance^a

Number of Long-Term Conditions or Health Problems	DISTANCE					
	Near		Medium		Far	
	No.	%	No.	%	No.	%
1 condition	11	39.3	14	37.8	10	38.5
2 conditions	6	21.4	10	27.0	10	38.5
3 conditions	3	10.7	7	18.9	2	7.7
4 or more conditions	8	28.6	6	16.2	4	15.4

^a No significant distance differences

note: 3 cells have expected counts of less than 5.

Instead of using medical, patho-physiological elements for classifying conditions, a non-categorical approach focuses on dimensions in the child's life such as limitation of age appropriate activity to help describe the child's abilities. The Scales of Independent Behaviour (SIB) assess skills needed to function independently in the home, social and community settings. Each task such as social interaction is rated on a four-point scale as to how much help the child requires for each task. Based on this information and data concerning the age appropriate level of assistance for each activity, each individual child is assigned a developmental age for motor skills, social and communication skills, and personal living skills (Burke et al., 1998a). The developmental age for each scale is then

divided by the child's chronological age and multiplied by 100, producing a developmental quotient (DQ) for each scale. Summing the motor, social and communication, and personal living skills developmental quotients and dividing by three produces the overall average DQ for each child (Burke et al., 1998a). The difference in the DQ between pre-hospitalization and post-hospitalization (T3-T1) is used to determine if the degree of developmental regression or developmental gain varies amongst the distance groups.

The SIB has many positive attributes. First, it enables some of the continua found in Figure 2.1 such as, mobility, physiological functioning, cognition and sensory functioning to be taken into account. Secondly, the incorporation of the child's chronological age provides a measure of the limitation of age appropriate activity, and takes into account the child's developmental processes.

ANOVA is used to determine if there are any significant differences between each DQ for T3-T1 and the three distance categories. The null hypothesis (H_0) being tested for each of the DQs and the average DQ, is that the DQ for the near, medium and far distance categories are equal. The alternative hypothesis (H_a) states that at least 1 of the DQs for the distance categories is not equal. Table 3.5 shows that there is no evidence to reject any of the null hypotheses. These results should be approached with caution as there are no normal distributions⁴ for the motor skills DQ, and only the far category is normally distributed for the social and communication skills, personal living skills and the average DQ.

⁴ The Shapiro-Wilk test is used to determine normalcy, with a normal distribution determined by $p > 0.05$.

Table 3.5. ANOVA Tables Of The Change In The Scales Of Independent Behaviour Developmental Quotients By Distance^a

1. Motor Skills

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	1003.306	501.653	0.627	0.536
Within (error)	106	84803.527	800.033		
Total	108	85806.833			

2. Social and Communication Skills

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	2603.806	1301.903	2.088	0.129
Within (error)	106	66087.954	623.471		
Total	108	68691.759			

3. Personal Living Skills

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	2644.222	1322.111	1.453	0.239
Within (error)	106	96474.605	910.138		
Total	108	99118.827			

4. Average

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	1910.916	955.458	1.829	0.166
Within (error)	106	55378.227	522.436		
Total	108	57289.143			

^a No significant distance differences
df = degrees of freedom

3.4 Child And Family Socio-Economic And Hospitalization History Characteristics

ANOVA is used to determine if there are any significant differences between any of the socio-economic and hospitalization characteristics and distance (Table 3.6). For each variable the null hypothesis (H_0) being tested is that the mean for all three distance categories is equal. The alternative hypothesis (H_a) is that at least one of the means is not equal. The study parent's number of years of education is the only socio-economic factor and hospitalization history characteristics significantly associated with distance. According to the Tukey test, the only significant comparison is, however, between the near and far categories ($p = 0.026$). Descriptive statistics show that there is not a large discrepancy between the means (near = 14.58, medium = 13.28, far = 12.94).

The objective of the Burke et al. (1994 to 1996) study was to examine the effectiveness of the Stress-Point Intervention by Nurses (SPIN), a type of intervention that focuses on parents' concerns regarding their child's hospitalization. Similarly a X^2 test shows that there are no significant distance associations between those with SPIN intervention and those without SPIN intervention.

Length of stay of the most recent hospitalization (LOS) (mean = 7.3 days) is an important variable to consider when examining the geographic dimension of family impact. Harrison et al. (1998) have demonstrated the significance of LOS to total expenditures, car travel expenditures, telephone costs, meals and cost of child care. This variable may also be associated with the subjective impacts on families with children with chronic conditions. Information for this variable is taken from (1) parent response and (2) hospitalization records. To maintain as much data as possible, if one of these responses

was missing the other was used, if both were available and a discrepancy existed, the information from the hospitalization record was used. An ANOVA of the mean length of stay of each distance category shows that there are no significant differences (Table 3.6).

The ANOVA results must be treated with caution as some of the distributions are not normal. For the child's chronological age only the far category is normally distributed. None of the distributions for number of week's the child has been hospitalized or the number of hospitalizations for their lifetime or length of stay are normal. Both the near and the far distance categories are normally distributed for study parent's years of education. There are no normal distributions for the annual family income. The number of adults in the home, and number of adults involved in child care, were also considered, however, all means were less than 1, and were approximately equal.

Table 3.6. ANOVA Tables Of Child And Family Socio-Economic And Hospitalization History Characteristics By Distance

1. Child's Chronological Age

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	53.302	26.651	1.922	0.151
Within (error)	109	1511.555	13.867		
Total	111	1564.857			

2. Number of Weeks Child Hospitalized in Their Lifetime

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	1245.560	622.780	1.785	0.173
Within (error)	107	37332.708	348.904		
Total	109	38578.268			

3. Number of Hospitalizations in Child's Lifetime

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	33.428	16.714	0.135	0.874
Within (error)	107	13284.790	124.157		
Total	109	13318.218			

4. Length of Stay of Most Recent Hospitalization

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	154.035	77.018	0.582	0.561
Within (error)	106	14292.956	132.342		
Total	108	14446.991			

5. Study Parent's Years of Education

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	45.600	22.800	4.163	0.018**
Within (error)	110	602.382	5.476		
Total	112	647.982			

** denotes significance at the 0.05 level

6. Annual Family Income^a

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	7813000000	3907000000	0.649	0.525
Within (error)	105	63240000000	6023000000		
Total	107	64030000000			

^a sum of squares, and mean sum of squares not exact values as they have been converted from scientific notation

Sex of the children is treated using a 2x3 contingency table, and tested using X^2 with the number of males and females forming the rows, and the distance categories forming the columns, to determine whether an association between the sex of the children and distance exists. There is no significant association (Table 3.7).

Table 3.7. Children's Sex By Distance^a

DISTANCE

	Near	Medium	Far
number of males	25	24	17
number of females	14	18	15
Total number	39	42	32

^aNo significant distance differences

3.5 Subjective Measures Of Family Impact

The outcome measures of the Feetham Family Functioning Survey (FFFS) and the Questionnaire on Resources and Stress (QRS) were collected two weeks before the hospitalization (T1) and three months after the hospitalization (T3). To isolate the impacts of hospitalization on the family, the results of the change from T1 to T3 are used for the FFFS and the QRS.

3.5.1 Feetham Family Functioning Survey (FFFS)

The 25 item FFFS is sensitive to the critical development and clinical changes in families caring for a child with a chronic condition. It is especially helpful for examining the change in family experiences over time, which is beneficial for exploring the changes in family functioning associated with hospitalization. The survey assesses items related to the following areas of family functioning: house-hold tasks; child care; marital relations; interaction with family and friends (including children); community involvement; and sources and amount of emotional support. Each item contains a scale from 1 to 7 asking how much there is now, and a scale from 1 to 7 asking how much there should be, with a

final discrepancy score between the two ranging from 0 to 6. For example, the first item of the individual relationships factor asks about the amount of time that the respondent spends alone with their spouse. For this item the respondent would report a number from 1 to 7 regarding the amount of time that they would like to spend with their spouse (ideal), and the amount of time that they currently spend with their spouse (actual). A score of 1 would indicate that they do not spend enough time together, and a score of 7 would indicate that they spend the right amount of time together. Then the actual response is subtracted from the ideal response giving a discrepancy score. Higher scores indicate a larger discrepancy between the actual and ideal responses, signifying poorer function.

Roberts (1979) reported that all but five of the items loaded onto three factors (family problems, individual relationships, and family sub-systems) (Roberts 1979, as cited in Burke et al., 1998b). The three factor scores are calculated by summing the discrepancy score for each item relevant to the factor. These factors are supported by McIntyre's (1966) categorization of the three key relationships associated with family functioning: (1) relationships between the family and broader social units- family problems factor; (2) relationships between the family and the individual- individual relationships factor; and (3) relationships between the family and sub-systems- family sub-systems factor (Appendix B-1 summarizes the questions relevant to each factor, and those questions that are not included in any of the factors). The reliability of the total discrepancy score for 103 mothers with infants with myelodysplasia (spina bifida) was

alpha equals 0.81 (Feetham and Humenick 1982). Test-retest reliability measured on 22 of the 103 mothers had a reliability coefficient of 0.85 (Feetham and Humenick 1982).

Feetham and Humenick mention that the FFFS can be used to “consider a specific type of event a family might experience and draw upon the literature to derive a logical time frame for sequentially assessing family function” (Feetham and Humenick 1982, pg. 265). This suggestion is utilized in determining the impacts of hospitalization based on the change of scores from two weeks pre-hospitalization to 3 months post-hospitalization.

3.5.2 Questionnaire On Resources And Stress (QRS)

The QRS, a measure of caregiver and family impact associated with caring for a family member with a chronic condition, has been employed as a research tool in comparing parents of clinical groups with normal controls (Holroyd and Guthrie 1986), differentiating between degrees of physiological and psychological disability within a group of children with the same condition (Dunst, Trivette and Cross 1986, as cited in Holroyd 1988), and examining parent and family status (Beckman 1983; Glidden 1986; Dunst, Trivette and Cross 1986, all cited in Holroyd 1988). A summary of these criteria studied demonstrate, “that the QRS is useful in discriminating populations that differ in diagnosis, degree of handicap, parent attributes, and family characteristics....The QRS can be expected to be useful over a range of situations and samples. Furthermore, the multidimensional nature of the QRS appears to be useful” (Holroyd 1988 pg. 352). The multi-dimensional nature and generalizability of the questionnaire make it a valuable instrument for examining the geographic dimension of family impact.

Six of the eleven scales from Holroyd's short-form of the QRS are used: (1) personal burden of respondent; (2) preference for institutional care; (3) lack of personal reward; (4) limits on family opportunities; (5) terminal illness stress; and (6) life span care. Each item is answered true or false, and depending on the intention of the question either the response true, or the response false is given a point value of one. The items relevant to each subscale are then summed to give the scale score (see Appendix B-2). Five of the scales are composed of 6 items; however, in this study the personal burden scale is comprised of 3 items, as the other items overlapped with those of another measure collected for the Burke et al. (1994 to 1996) study.

3.5.3 Methodological Concerns

There are some methodological concerns with the use of scales (QRS) and factors (FFFS) for exploring the familial impact of childhood chronic conditions. In employing scales and factors with a small number of items, it is possible for the respondent to cancel out the overall effect, if he or she answers positively to three of the questions and negatively to the other three. However, analyzing each item individually makes the incorrect assumption that they are independent of each other. Therefore, although the use of scales and factors are necessary, results should be approached cautiously.

3.6 Objective Measures Of Family Impact: Costs To The Family

The family costs data were collected 2 weeks after discharge from hospital (T2). Since these data were collected by telephone interview recently after discharge it is felt that they are an important indicator of the economic and caregiving time impact on families with a child with a chronic condition.

Various studies concerning the economic impact of caring for a child with a chronic condition describe the impact according to direct and indirect costs (Harrison et al., 1998; Jacobs and McDermott 1989; Lansky et al., 1979; Houts et al., 1984; and Bloom, et al., 1985). Direct costs result from the use of medical care in the diagnosis, treatment, continuing care, rehabilitation, and terminal care of patients, as well as nonmedical expenses, usually out-of-pocket expenses paid by the family or individual (Hodgson and Meiners 1982). Indirect costs are the time and employment earnings lost due to caring for the individual with the chronic condition (Hodgson and Meiners 1982). Although families in Ontario do not have to assume the medical costs of hospitalization, other out-of pocket expenses do result in an economic impact of childhood chronic conditions on the family. The direct and indirect categorization of costs will be used for this thesis.

3.6.1 Direct Costs

The Harrison et al. (1998) analysis of the median value of direct cost items, and total expenditure for families in the Burke et al. study is displayed in Table 3.8. The

significant median cost of \$317 for a single hospital stay highlights the importance of exploring factors that may augment this large cost. Several studies list transportation as a leading out-of-pocket expense for families (Lansky et al., 1979; Houts et al., 1984). Since distance is a key contributor to transportation costs, it is important to study the contributing effect of distance to transportation as well as other costs.

3.6.2 Indirect Costs

Families were also asked to report the number of extra hours that the primary caregiver (usually a parent), and other family members spent caring for the child two weeks before hospitalization, while the child was hospitalized, and up to two weeks after hospitalization. They were also asked to report the number of hours taken off from both paid and volunteer work.

Many studies when determining the indirect costs of chronic conditions approach it strictly as lost productivity, expressed as how much family members would have earned had they worked (Jacobs and McDermott 1989). By representing indirect costs as hours spent either with extra care, or spending time with the child while they are in hospital the importance of leisure time is recognized, and all lost time is treated equally. By using the productivity model (based on earnings) a parent or family member's time who chooses not to work out of the house is undervalued compared to an individual who does work out of the house. Analysis based on hours lost treats each person equally.

Table 3.8. Direct Costs Reported By Parents During Their Child's Hospital Stay

Item	Percentage Reporting Cost	Median For Those Reporting Cost
1. Transportation		
-by car ^a	91	\$59
-by (bus, taxi, or train)	9	\$25
2. Parking	67	\$19
3. Accommodation		
-overnight stay in hospital with child	57	-
-hotel/rotel/hostel	14	\$60
4. Meals	97	\$70
5. Child care ^b	56	\$202
6. Phone calls	52	\$20
7. Miscellaneous (gifts, toys, clothes, snacks)	78	\$40
Total	100	\$317

^aParents reported distance traveled and a reimbursement rate of \$0.23/km was used to calculate the cost.

^bParents reported the number of hours that child care was used, a cost of \$6.50/hour (approximately the minimum wage) was used to calculate the cost.

3.7 Analysis

The clinical differences for each FFFS factor, and the total score were determined using the T1 mean and standard deviation for all families with completed FFFS data (mean = 0.9, s.d. = 14.3). Therefore, family functioning improved for those with a change after hospitalization (T3-T1) of - 0.5 s.d. or more, family functioning declined for those with a change of + 0.5 s.d. or more, and family functioning remained the same for those falling between these two categories. A X^2 test, for each factor and the total score using a 3x3 contingency table, with the family functioning clinical differences forming the rows, and the distance categories forming the columns, is used to determine whether there is an association between distance and the types of changes.

Chi-square is used to assess the association of distance with the difference between T1 and T3 of each of the scales and the overall total QRS score. However, because of the sample size, these differences had to be collapsed into the following three categories: hospitalization had a neutral impact (T3 score - T1 score = 0); hospitalization had a positive impact (T3 score less than T1 score); and hospitalization had a negative impact (T3 score greater than T1 score). It would have been beneficial to differentiate between degrees of positive and negative impact but this is prevented by the small sample size. A 3x3 contingency table for each QRS scale and the total score, with the hospitalization effects forming the rows and the distance categories forming the columns, is tested with X^2 to determine if distance is associated with hospitalization effects.

ANOVA is used in the analysis of distance differences for direct costs both during and up to and including 2 weeks after the actual hospital stay. The individual items (Table 3.8) and the total expenditures are compared amongst the three distance categories. The null hypothesis (H_0) being tested for each item is that the mean cost for the near, medium and far categories are equal (H_0 : mean cost_{near} = mean cost_{medium} = mean cost_{far}). The alternate hypothesis (H_a) is that at least one of the mean costs is not equal. If the null hypothesis is rejected then a Tukey test is used to determine which distance comparisons are significant. The percentage of the family income consumed by the hospitalization is used to compare the economic impact of a single hospitalization experience for each distance category ($\% \text{ of family income} = \text{total expenditures for single hospitalization} / \text{yearly family income} * 100$).

Both a direct and stepwise multiple regression equation is used to determine which variables contribute to the total expenditures for families. The independent variables of change in SIB (T3-T1), the age and sex of the child, length of stay, family income, study parent's years of education and distance are used in this equation. Each independent value is associated with an absolute value of R, if the significance value is less than 0.05 then the independent variable is important to the predictive equation. The format of the multiple regression equation is:

$$y = a + b_1X_1 + b_2X_2 + \dots + b_kX_k$$

where,

y = the value of the dependent variable (total expenditure)

a = the y- intercept or constant

b_1 to b_k = the regression weights or coefficients of the independent variables

X_1 to X_k = array of k independent variables (child characteristics, hospitalization history of child, family and parent characteristics and distance)

Both chi-square and ANOVA are used to examine the indirect costs to the family by distance. Two 2x3 contingency tables are used with a X^2 test to determine if (1) there is an association between distance and the number of primary caregivers who spent more time than usual caring for the child, and those who did not spend more time, and (2) whether there is an association between distance and the number of primary caregivers who took time off work to care for the child, and those who did not take time off. For each contingency table the number of yes/no responses forms the rows and the distance categories forms the columns.

ANOVA is used to determine if significant distance differences exist between the near, medium and far distance categories and the number of extra hours primary caregivers spent with the child. ANOVA is also used to determine if any distance differences exist with the hours of paid and volunteer work that the primary caregiver had to miss to care for the child during the hospital stay. The null hypothesis (H_0) for each ANOVA is that the mean number of hours for the near, medium and far category are equal (H_0 : mean hours_{near} = mean hours_{medium} = mean hours_{far}). If the null hypothesis is rejected then a Tukey test is used to determine which distance comparisons are significant. All analyses (chi-square and ANOVA) are repeated for other family members who helped with the child.

CHAPTER 4

FINDINGS CONCERNING THE SIGNIFICANCE OF DISTANCE TO MEASURES OF SUBJECTIVE FAMILY IMPACT

In this chapter, both the Feetham Family Functioning Survey (FFFS) and the Questionnaire on Resources and Stress (QRS) are used to examine the significance of distance to subjective impacts. These include family functioning and caregiver and family impact on families caring for a child with a chronic condition. The measures were collected 2 weeks prior to hospitalization (T1) and 3 months after hospitalization (T3).

4.1 The Impacts Of Distance On The Feetham Family Functioning Survey (FFFS)

Recall the discussion on page 40 and 41 which explains that all factors of the FFFS (eg. individual relationships) are composed of item scores that represent the difference between a family's actual level of functioning and their ideal level, which are scored on a scale ranging from 0 to 6. Figures 4.1 to 4.12 provide a visual representation of the change in family functioning (T3-T1) for each of the FFFS factors and total score. For example in figure 4.1 a family who scores 6 for time T3 and 3 for time T1 for the family problems factor, has a change in family functioning of 3. This means that the family had a decline in family functioning. The y-axis displays the number of families that have the particular factor score.

There is not much difference between the near (Figure 4.1) and medium (Figure 4.2) graphs representing the family problems factor. Both show quite a dramatic peak at 0, and then taper off as the extreme low and high values are approached. The far distance graph (Figure 4.3) does not have this peak and there is not a steady decline in the number

of families; however, there is still a clustering of values around 0. This similarity between the graphs shows a lack of association between distance and the items composing the family problems factor.

Figures 4.4 to 4.6 depict a larger range of values for the individual relationships factor for the far distance category compared to the other groups. There is also a greater number of families who traveled a far distance whose functioning declined. The mode for the near category (+1) and for the medium category (-1 and -3) are lower than the mode for the far category (+4). The differences in the graphs show that families traveling a far distance have a larger decline in family functioning scores after hospitalization for items composing the individual relationships factor.

The family sub-systems factor graphs for the near (Figure 4.7) and far (Figure 4.9) categories show a larger number of families had functioning decline after hospitalization than families where functioning improved. However, the number of families whose functioning declined, and the number whose functioning improved is approximately equal for those traveling a medium distance.

The wide range of possible values for the total score (-108 to +108) make it difficult to fit each x-axis value on a graph and not have the graph look cluttered. Therefore, the x-axis shows ranges of values in increments of 10 from the lowest to the highest observed value (Figures 4.10 to 4.12). Results show that more families traveling a far distance have a decline in total family functioning compared to the other 2 distance groups. Families in the far group do not exhibit the lower extreme scores as families from the near (lowest scores between -39 to -30) or medium (-49 to -40) distances. However,

since there might be missing values from either T1 or T3 for any of the factors, there are fewer observations and therefore, the results should be approached with caution.

Chi-square helps unravel the relationship between distance to hospital and family functioning. Clinical differences for family functioning are measured by the family problems factor, the individual relationships factor, and the family sub-systems factor, and total score on a scale of improved, stayed the same or declined after hospitalization. Each factor and the total score are cross tabulated by the distance categories. In Table 4.1 the first 3 columns show the counts and column percentages, and the fourth column shows the chi-square analysis where the row variable is either one of the FFFS factors or the total score, and the column variable is distance (near, medium, far). The null hypothesis (H_0) being tested is that there is no association between distance that families travel to the hospital, and whether family functioning improved, stayed the same or declined. The alternative hypothesis (H_a) being tested is that there is an association between distance that families travel to the hospital, and whether family functioning improved, stayed the same or declined.

Figure 4.1

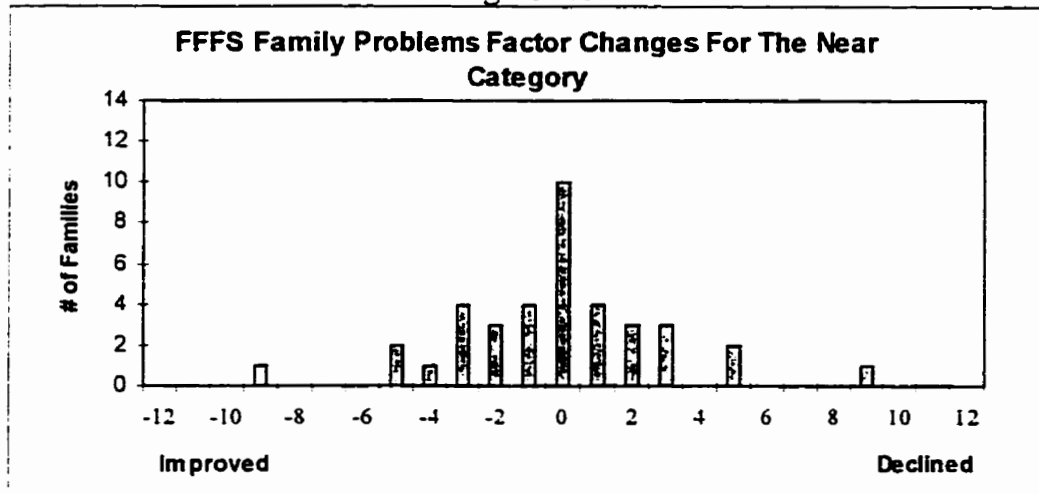


Figure 4.2

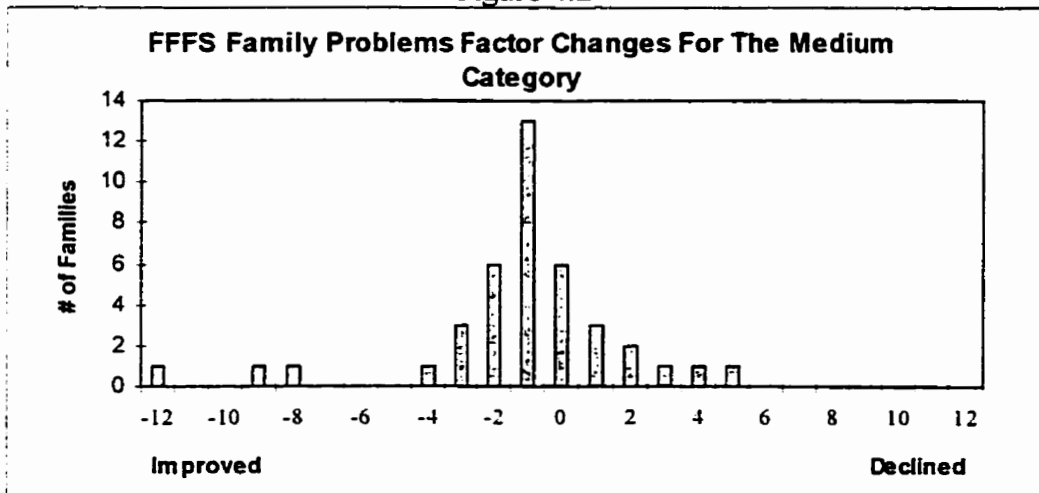


Figure 4.3

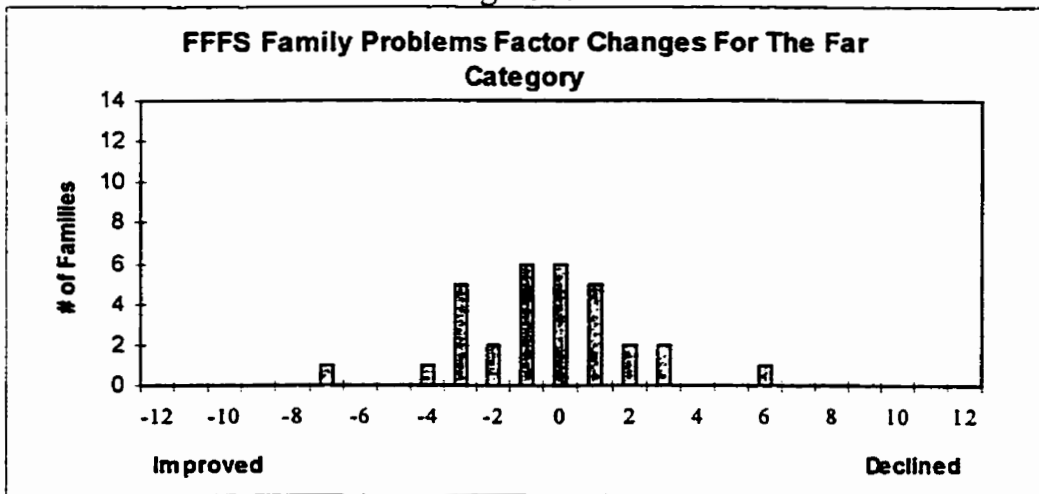


Figure 4.4

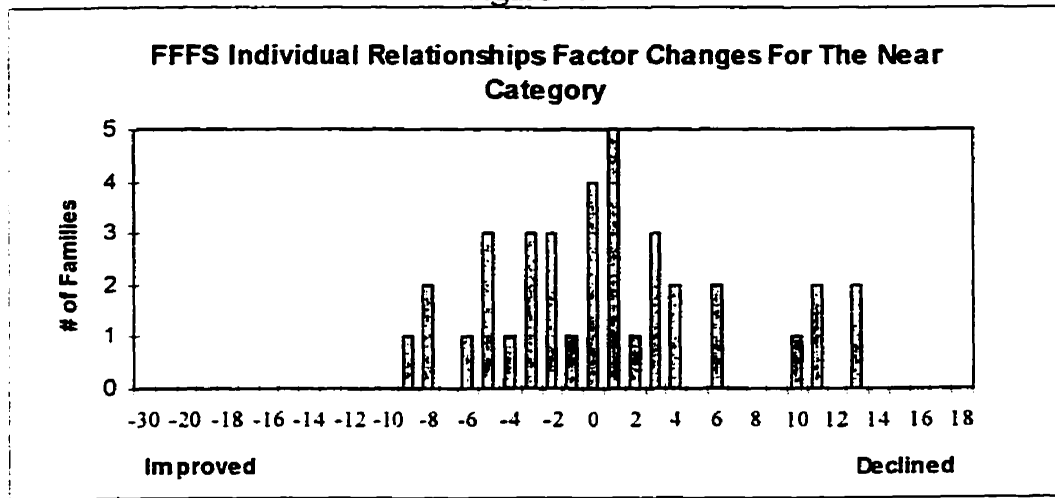


Figure 4.5

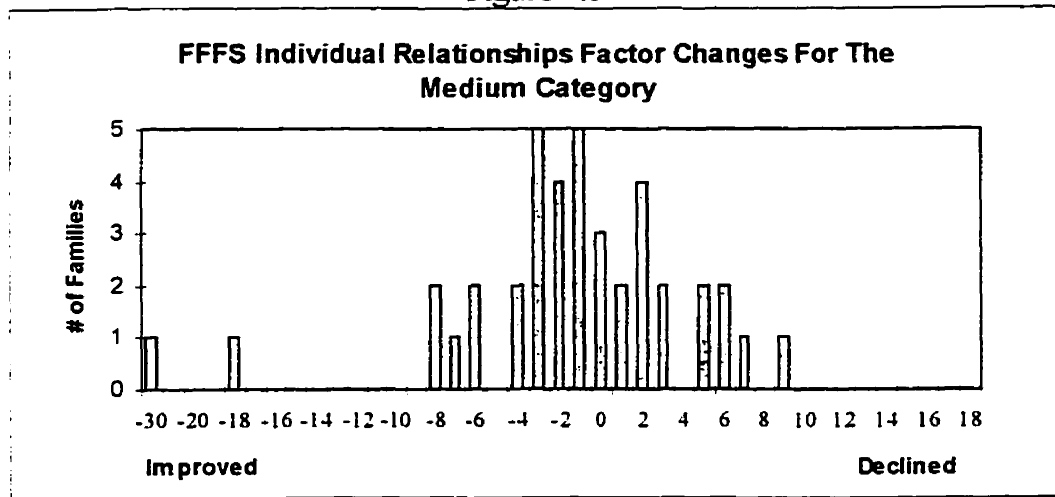


Figure 4.6

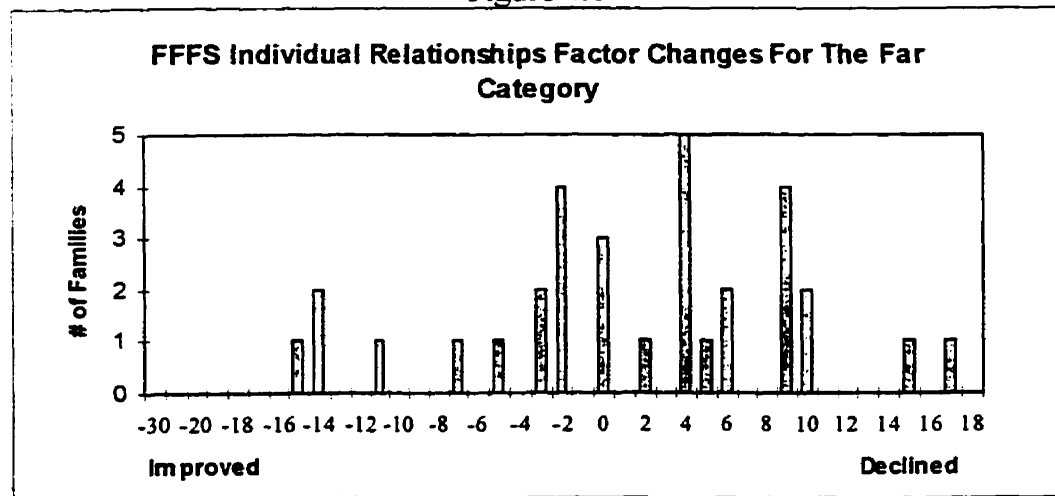


Figure 4.7

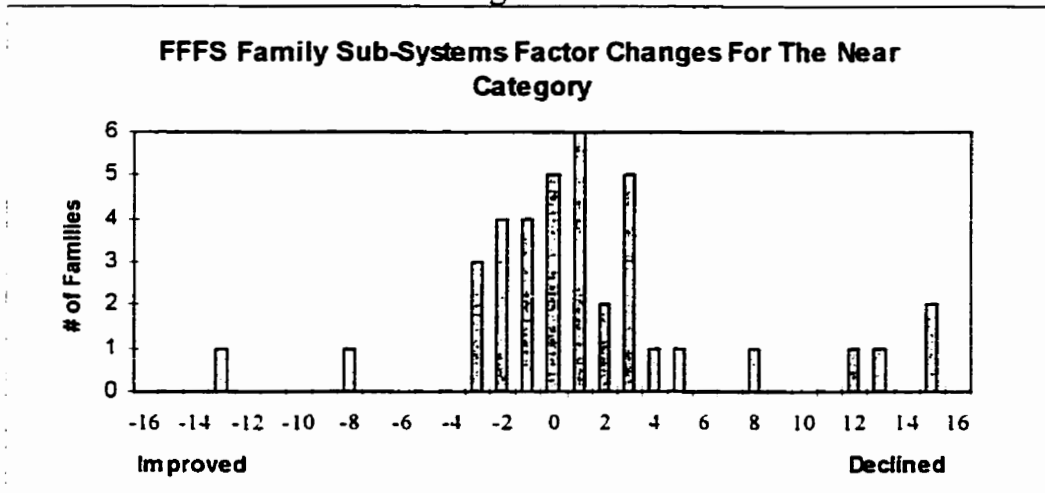


Figure 4.8

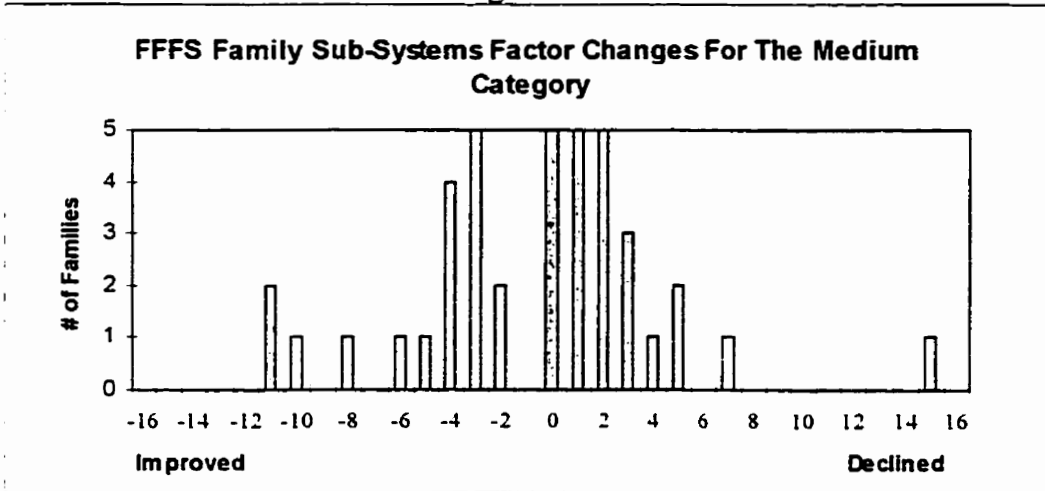


Figure 4.9

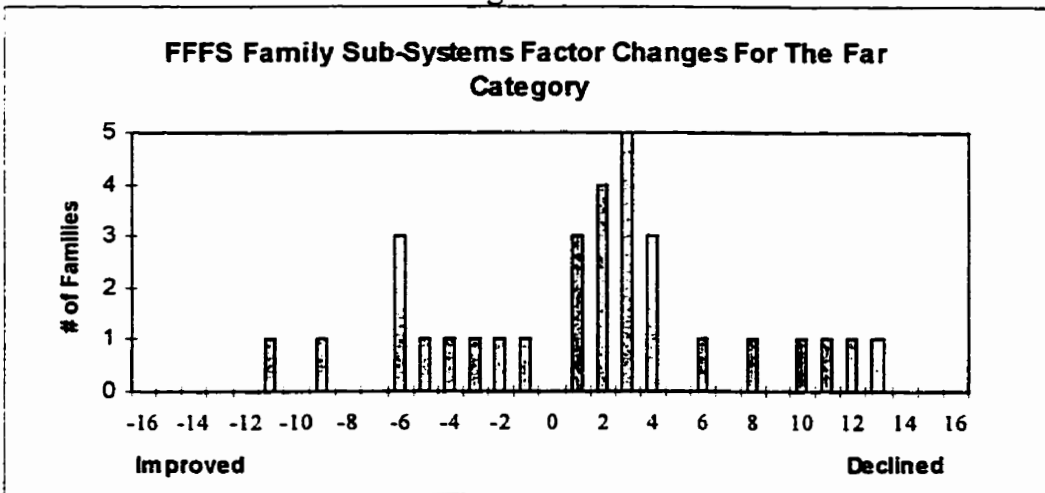


Figure 4.10

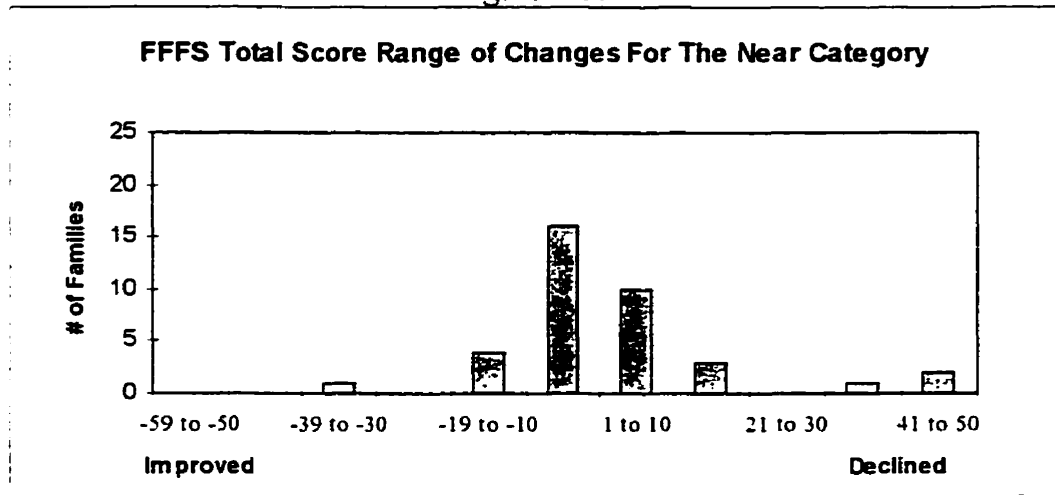


Figure 4.11

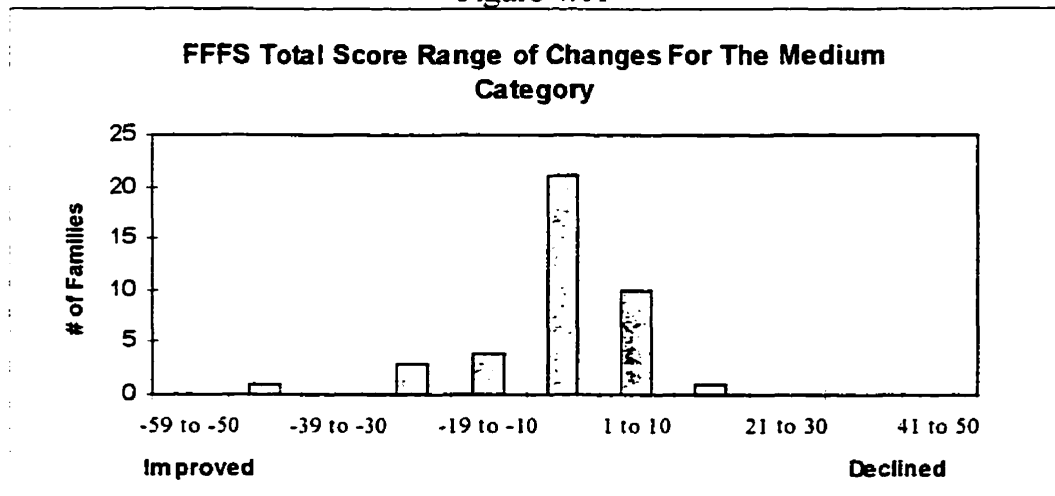
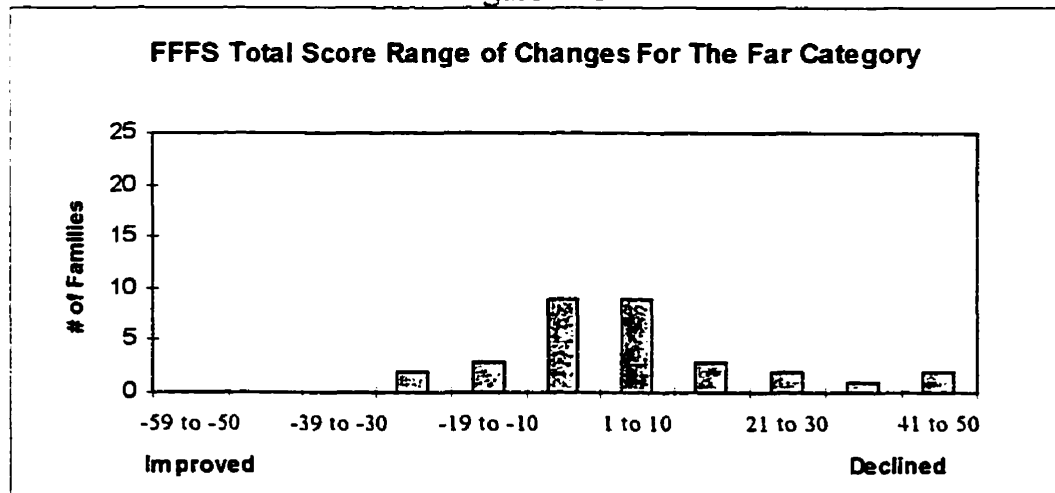


Figure 4.12



No significant associations are found for the clinical differences of the family problems factor ($p = 0.729$), or individual relationships factor ($p = 0.138$). However, the individual relationships factor shows a general trend of the percentage of families whose functioning stayed the same, or improved decreasing as distance increases, and the percentage of families whose functioning declined increasing as distance increases. For the individual relationships factor over 50% of families traveling a far distance had functioning decline compared to 32.4% in the near category and 22.5% in the medium category.

Results for the family sub-systems factor show a significant difference ($p = 0.048$) among the clinical differences. For this factor a larger percentage of those families traveling a far distance declined in family functioning (45.2%) compared to those traveling a closer distance (near = 34.2%, medium = 22.5%).

Similar to the individual relationships factor the total FFFS score also shows that a higher percentage of families traveling a far distance (32.3 %) declined in total functioning compared to those traveling either a near (26.3%) or medium (12.5%) distance. These distance differences are not statistically significant ($p = 0.198$).

4.2 The Impacts Of Distance On The Questionnaire On Resources And Stress (QRS)

Figures 4.13 to 4.19 depict the impacts of distance on each of the QRS scales and the total score. Values at the negative end of the scale mean that values for T3 were less than for T1, thus, hospitalization has a positive effect and the scale decreased. Positive values mean that values for T3 were greater than values for T1, thus hospitalization has a

negative effect and the scale increased. And values of 0, mean that hospitalization has a neutral effect.

Table 4.1. Feetham Family Functioning Survey Clinical Differences By Distance

Family Functioning Clinical Differences	DISTANCE						X ² Analysis
	Near		Medium		Far		
	no.	%	no.	%	no.	%	
Family Problems (n=109)							X ² = 2.037
improved	12	31.6	14	35.0	9	29.0	df = 4
stayed the same	17	44.7	21	52.5	17	54.8	p. = 0.729
declined	9	23.7	5	12.5	5	16.1	
Individual Relationships (n=108)							X ² = 6.935
improved	11	29.7	14	35.0	8	25.8	df = 4
stayed the same	14	37.8	17	42.5	7	22.6	p. = 0.138
declined	12	32.4	9	22.5	16	51.6	
Family Sub-Systems (n=109)							X ² = 9.564
improved	5	13.2	15	37.5	8	25.8	df = 4
stayed the same	20	52.6	16	40.0	9	29.0	p. = 0.048**
declined	13	34.2	9	22.5	14	45.2	
Total Score (n=109)							X ² = 6.018
improved	6	15.8	12	30.0	8	25.8	df = 4
stayed the same	22	57.9	23	57.5	13	41.9	p. = 0.198
declined	10	26.3	5	12.5	10	32.3	

** denotes significance at the 0.05 level

X² = test statistic

df = degrees of freedom

p. = probability value

Examination of the impacts of distance on personal burden (Figure 4.13) needs to be approached cautiously, due to the small number of items composing the scale for the Burke et al. (1994 to 1996) study. However, it can be seen that the largest frequency for all distance categories occurs at 0, after this the frequencies decrease. The large number of observations (10 families) at +1 for the medium distance should be noted. Generally distance has no impact on the personal burden scale.

The preference for institutional care scale (Figure 4.14) shows that the largest number of observations for the medium and near distance occur at 0, with the far category having far fewer families with no impact. However the far category has more families at the positive end of the scale (+1 and +2) than in the negative range (-1 to -2). The medium distance category is the only one with a family at the value of -2. These differences show that more families traveling a far distance are negatively affected by hospitalization compared to the 2 closer distance groups.

Figure 4.15 shows that for a large number of families from all distance categories hospitalization has a neutral impact on the lack of personal rewards scale. Also the number of observations decreases dramatically as the values increase or decrease. Therefore, traveling distance to hospital does not influence the lack of personal rewards scale.

For a large number of families from all distance categories hospitalization has a neutral effect on the limits to the family opportunities scale (Figure 4.16). Of note is the large number of families traveling a medium distance who fall in the positive range of values, and the large number of families traveling a far distance who have a value of -1. Therefore, families traveling a medium distance are more negatively affected than families traveling either a near or far distance by items composing the limits to family opportunities scale.

The terminal illness scale (Figure 4.17) shows a general trend of a greater number of families from all distance categories having a value of 0, with the frequencies declining as the extremes of the positive and negative ends of the scale are approached. There

appears to be a larger number of families traveling a medium distance who are negatively affected by hospitalization. The number of families traveling both near and far distances who experience negative hospitalization effects is similar, and there is a greater number of families in the medium category who have negative hospitalization effects according to the terminal illness scale.

The life span care scale (Figure 4.18) shows a similar trend to the terminal illness scale. For a large number of families distance to hospital does not influence this scale. However, there appear to be more families in the medium category for which hospitalization has a negative effect. Families traveling both a near or far distance experience the same type of hospitalization effects, whereas, families traveling a medium distance experience more negative hospitalization effects.

The QRS total score (Figure 4.19) is more difficult to interpret, and discussion of the graph must involve caution. To have a total score, the family must have responses for all the scales for both T1 and T3. Many families did not answer all the questions and a total score could not be calculated. The possible range of values for the total score includes -33 to +33 (5 scales ranging from -6 to +6, and 1 scale ranging from -3 to +3); however, the actual range of values for the families is -6 to +7. Two key trends are evident from this graph: first, the large number of families in the near category that fall in the range from 0 to -2; and secondly, the large number of families in the medium category with scores in the positive end of the scale. Families in the near and far categories have about the same number of observations in the negative and positive ends of the scale. However, 19 families traveling a medium distance have positive values compared to 7

families with negative values. Thus, for more families traveling a medium distance hospitalization had a negative effect on the QRS total score.

Figure 4.13

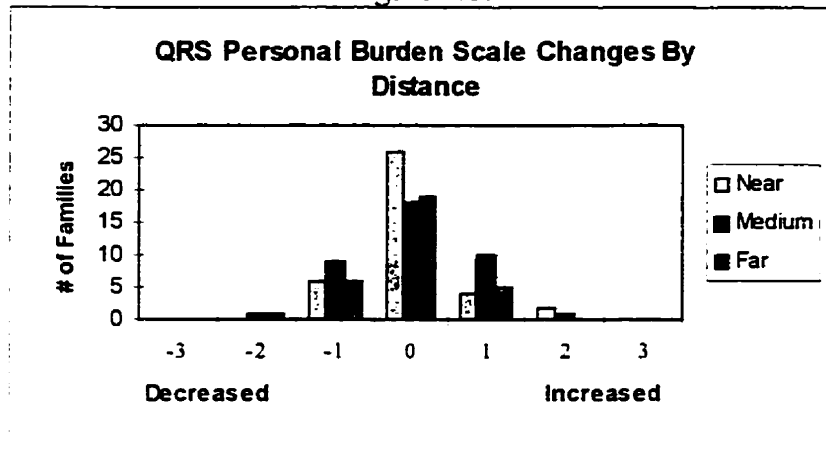


Figure 4.14

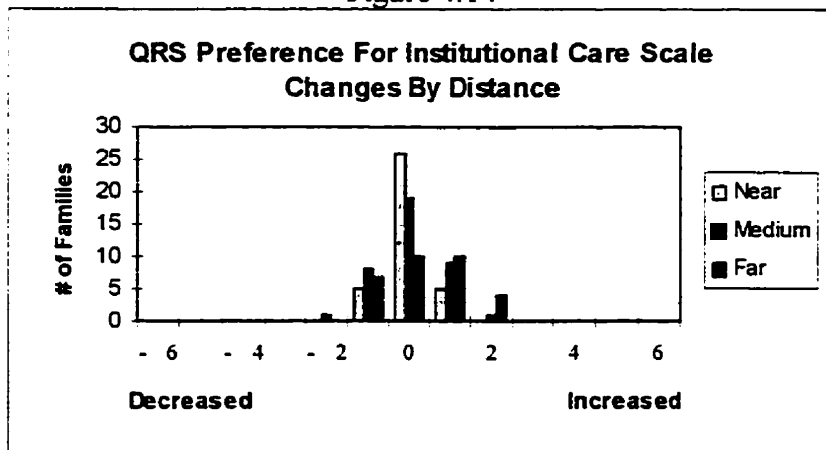


Figure 4.15

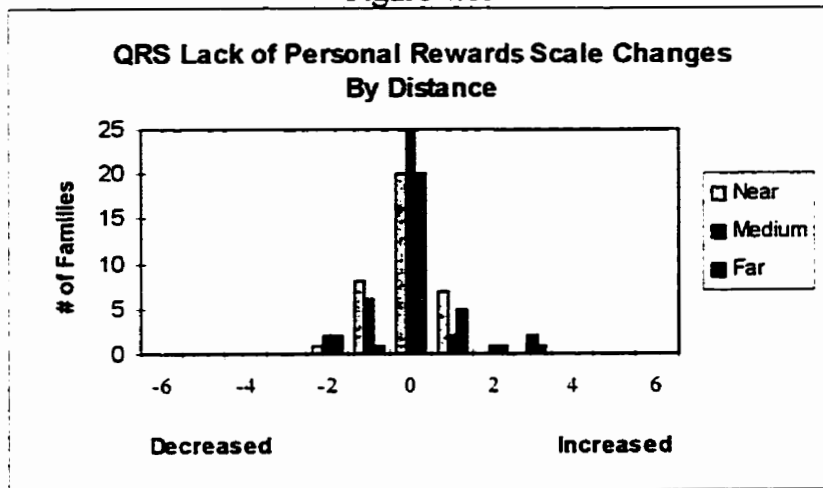


Figure 4.16

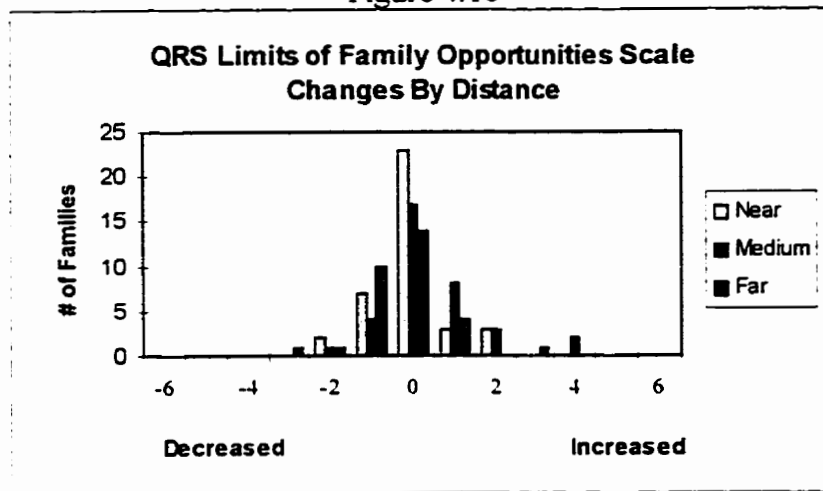


Figure 4.17

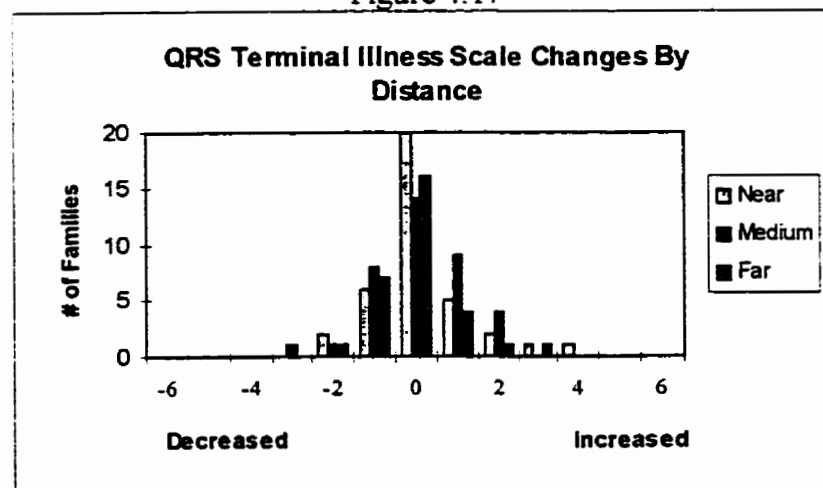


Figure 4.18

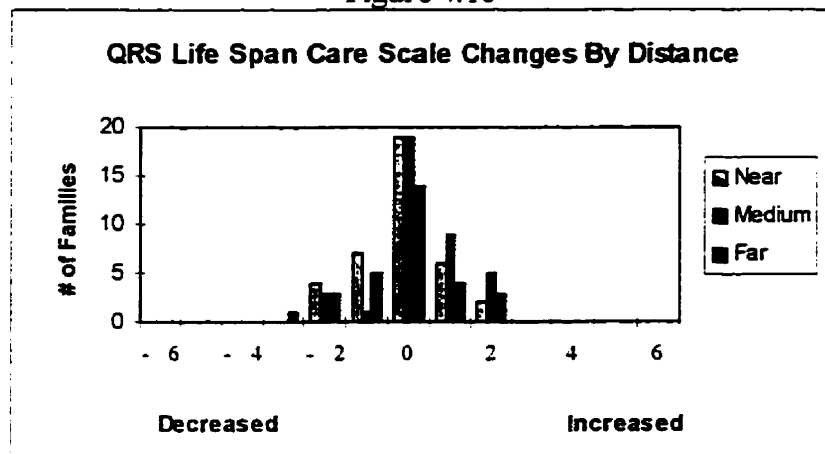
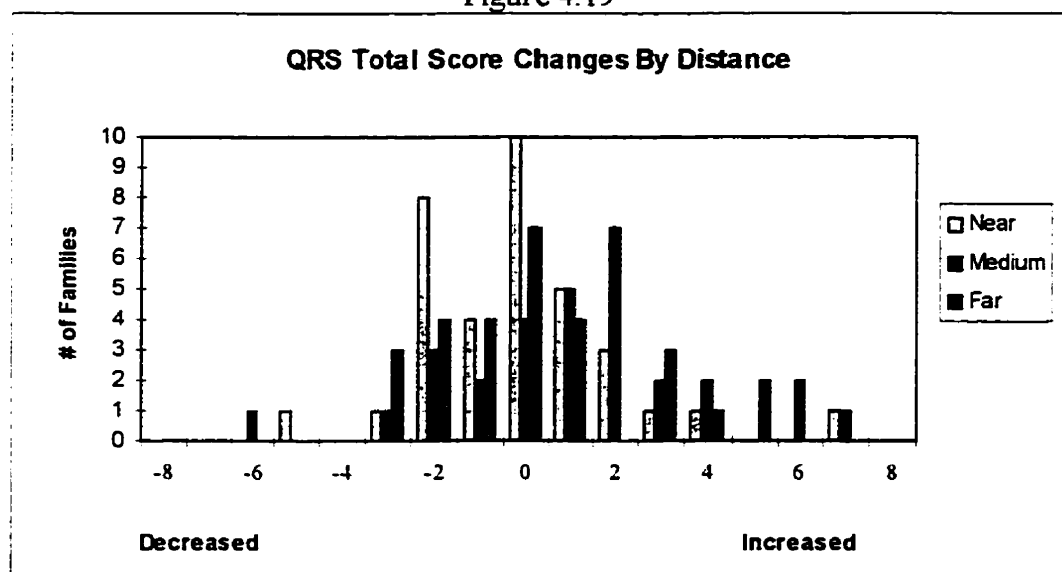


Figure 4.19



Each family scale response is collapsed into three types of impacts after the hospitalization has occurred (T3-T1): (1) hospitalization has a neutral effect; (2) hospitalization has a positive effect, and (3) hospitalization has a negative effect. Chi-square analysis is used to further explore the association with distance for each of the QRS scales and the total score (Table 4.2). Hospitalization effects for caregiver and family

impact are measured by the personal burden, preference for institutional care, lack of personal rewards, limits on family opportunities, terminal illness care, life span care, and total QRS score on a scale of neutral, positive or negative. Similar to Table 4.1 each scale and the total score are cross tabulated by the distance categories. The null hypothesis (Ho) being tested is that there is no association between distance that families travel to access the most comprehensive level of hospitalization, and whether the family experiences neutral, positive or negative hospitalization effects. The alternative hypothesis (Ha) being tested is that there is an association between distance that families travel to access the most comprehensive level of hospitalization, and whether the family experiences neutral, positive or negative hospitalization effects.

Although the preference for institutional care scale is the only one significantly associated with distance ($p=0.017$), the lack of personal reward scale and total score demonstrate a general trend of positive effects of hospitalization decreasing as distance increases, and for negative effects to increase as distance increases. For the total score, this trend can be observed for the near and far distance groups, but must be treated with caution because of the inconsistent results for families classified as living a medium distance from the hospital. The preference for institutional care scale demonstrates distance differences clearly, with the total neutral and positive effects decreasing as distance increases, and negative effects increasing as distance increases. For example, this scale shows that hospitalization as a negative impact is much greater for those traveling a far distance (45.2%), compared to those traveling the two closer distances (near = 13.9%, medium = 26.3%). The other scales (personal burden, terminal illness care, life span care,

and limits on family opportunities) do not follow this trend. These differences may be a result of the individual items that compose each scale. Perhaps families do not have a choice with the issues comprising these scales, therefore, there is no difference whether you live a near, medium or far distance from the hospital.

Table 4.2. Questionnaire On Resources And Stress Hospitalization Effects By Distance

Hospitalization Effects	DISTANCE						X ² Analysis
	Near		Medium		Far		
	no.	%	no.	%	no.	%	
Personal Burden (n=108)							X ² = 4.452 df = 4 p. = 0.348
neutral	26	68.4	18	46.2	19	61.3	
positive	6	15.8	10	25.6	7	22.6	
negative	6	15.8	11	28.2	5	16.1	
Preference For Institutional Care (n=105)							X ² = 12.111 df = 4 p. = 0.017**
neutral	26	72.2	19	50.0	10	32.3	
positive	5	13.9	9	23.7	7	22.6	
negative	5	13.9	10	26.3	14	45.2	
Lack of Personal Reward (n=104)							X ² = 3.437 df = 4 p. = 0.488
neutral	20	55.6	25	65.8	20	66.7	
positive	9	25.0	8	21.1	3	10.0	
negative	7	19.4	5	13.2	7	23.3	
Limits on Family Opportunities (n=104)							X ² = 9.378 df = 4 p. = 0.052
neutral	23	60.5	17	48.6	14	45.2	
positive	9	23.7	5	14.3	12	38.7	
negative	6	15.8	13	37.1	5	16.1	
Terminal Illness Care (n=104)							X ² = 3.071 df = 4 p. = 0.546
neutral	20	54.1	14	37.8	16	53.3	
positive	8	21.6	10	27.0	8	26.7	
negative	9	24.3	13	35.1	6	20.0	
Life Span Care (n=105)							X ² = 5.903 df = 4 p. = 0.207
neutral	19	50.0	19	51.4	14	46.7	
positive	11	28.9	4	10.8	9	30.0	
negative	8	21.1	14	37.8	7	23.3	
Total Score (n=93)							X ² = 7.665 df = 4 p. = 0.105
neutral	10	28.6	4	13.3	7	25.0	
positive	14	40.0	7	23.3	11	39.3	
negative	11	31.4	19	63.3	10	35.7	

** denotes significance at the 0.05 level

X² = test statistic

df = degrees of freedom

p. = probability value

4.3 Summary Of Findings

This analysis has illustrated that traveling distance to hospital does influence the subjective measures of family impact for families caring for a child with a chronic condition. Analysis of the impacts of distance on subjective measures shows that only I of each FFFS factor, and QRS scale are affected by distance. The family sub-systems factor is the only factor which has statistically significant distance associations; however, the individual relationships factor and the total score show a general trend of the percentage of families whose functioning declined increasing as distance increases. The preference for institutional care scale of the QRS shows significant distance associations, with the percentage of families having negative hospitalization effects increasing as distance increases. The lack of personal rewards scale, and the total score for the QRS show a general trend of positive effects of hospitalization decreasing as distance increases, and for negative effects to increase as distance increases.

CHAPTER 5

FINDINGS CONCERNING THE SIGNIFICANCE OF DISTANCE TO MEASURES OF OBJECTIVE FAMILY IMPACT

This chapter is divided into 2 sections, the first deals with measures concerning direct family costs such as meals, accommodation and transportation. The second part examines indirect family costs in terms of caregiving time for either the primary care giver (PCG) or other family members involved in the child's care during hospitalization. Information concerning both measures was collected through telephone interviews 2 weeks after the child was discharged from hospital (T2).

5.1 The Impacts Of Distance On Direct Costs For The Family

The direct costs to families are classified according to 5 categories:

- transportation costs including travel costs by bus, taxi, and car
- the following formula is used to calculate car transportation costs
(number of trips*distance for 1 way trip) *\$0.23;
- parking for the car;
- accommodation costs are mainly associated with a hotel, motel or hostel; however, the percentage of families staying with friends and families, and the percentage of parents staying in the child's room are also reported;
- child care- parents reported the number of child care hours used and a cost of \$6.50/hour (approximately the minimum wage) is used to calculate the total cost;
- cost of all meals;
- miscellaneous items, this is the sum of money spent on gifts, toys, clothes and snacks;
- phone calls;

Total expenditure is calculated from the sub-totals computed for each expense category.

Table 5.1 shows the mean cost and standard deviation for each expense category and the overall total.

Table 5.1. Direct Costs For Families By Distance

Type of Direct Cost	DISTANCE					
	Near		Medium		Far	
	mean cost (\$)	s.d.	mean cost (\$)	s.d.	mean cost (\$)	s.d.
Transportation						
Bus taxi	30.75 (10.3) ^a	16.46	47.85 (9.8)	49.16	20.00 (3.1)	n/a
Car	54.40 (89.7)	61.95	95.89 (90.5)	113.83	114.3 (96.9)	85.30
Car-Parking	31.86 (71.8)	37.53	28.68 (75.6)	19.30*	17.06 (53.1)	15.42
Accommodation Hotel/Rotel/ Hostel	0		140.00 (7.3)	105.36	83.17 (37.5%)	69.35*
Child care	289.55 (56.4)	315.98	283.34 (53.7)	244.93	436.26 (53.1)	593.05
Meals	88.49 (94.9)	88.63	102.36 (97.6)	109.90	124.39 (96.9)	134.31
Miscellaneous	78.69 (74.4)	111.90	50.06 (80.5)	30.58	87.38 (75.0)	106.91
Telephone Calls	30.72 (41.0)	23.85	44.00 (43.9)	70.65	48.73 (75.0)	101.89
Total	393.34	439.92	436.99	377.70	605.98	684.27

* normally distributed according to the Shapiro-Wilk test ($p > 0.05$)

^a Percentage of families reporting cost

n/a cell has too few observations for meaningful statistical analysis

Table 5.2 provides a summary of the ANOVA results for each expense category, and the overall total. The dependent variable is the specific direct cost category and the

independent variable is traveling distance to hospital (near, medium and far). Variation between refers to the variation associated with distance, and variation within refers to variation that occurs within each independent distance group, and is not a result of the distance variable. The null hypothesis (H_0) being tested is that the mean cost for the direct cost category is equal for the near, medium and far distance groups

(H_0 : $\text{mean cost}_{\text{near}} = \text{mean cost}_{\text{medium}} = \text{mean cost}_{\text{far}}$). The alternative hypothesis (H_a) being tested is that at least one of the mean costs is not equal.

Table 5.2. ANOVA Tables Of Direct Costs For Families By Distance

1. Transportation- Bus, Taxi

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	915.922	457.961	0.341	0.724
Within (error)	6	8062.160	1343.693		
Total	8	8978.082			

2. Transportation- Car

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	63102.058	31551.029	3.848	0.025**
Within (error)	101	828191.420	8199.915		
Total	103	891293.479			

** denotes significance at the 0.05 level

3. Car- Parking

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	2424.313	1212.157	1.669	0.195
Within (error)	73	53008.396	726.142		
Total	75	55432.709			

4. Accommodation- Hotel/Rotel/Hostel

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	7752.067	3876.033	0.619	0.555
Within (error)	12	75107.667	6258.972		
Total	14	82859.733			

5. Child care

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	275668.933	137834.466	0.890	0.416
Within (error)	58	8983809.21	154893.262		
Total	60	9259478.14			

6. Meals

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	21896.137	10948.069	0.888	0.415
Within (error)	105	1294920.09	12332.572		
Total	107	1316816.23			

7. Miscellaneous

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	22553.882	11276.941	1.455	0.239
Within (error)	83	643367.711	7751.418		
Total	85	665921.593			

8. Telephone Calls

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	3190.043	1595.022	0.264	0.769
Within (error)	55	332182.474	6039.681		
Total	57	335372.517			

9. Total

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	865569.927	432784.963	1.71	0.186
Within (error)	109	27575609.8	222987.246		
Total	111	28441179.7			

df = degrees of freedom

p. = probability value

Travel by car is the main type of transportation used by families traveling to hospital, and while the child is in hospital. Only 2 families in the near and medium distance category, and 1 in the far category used the bus or taxi. Travel by car is the only cost that is significantly related to distance ($p. = 0.025$) (Figure 5.2 #2). Tukey test results show that the comparison between the near and far groups is significant ($p. = 0.023$). In the far distance category, 4 families had car travel costs over \$200. The mean number of trips taken is about 19 for the near category, 10 for the medium and 5 for the far category. This difference is significant ($p. = 0.002$) between the near and far distances (Table 5.3). The fact that the car cost difference remains even when the number of trips is considered, highlights the importance of distance as a direct cost factor for families with a child with a chronic condition.

It is difficult to examine accommodation expenses as the majority of parents from all distance groups stayed with the child in the hospital, and did not report any accommodation costs (near = 53.8%, medium = 56.1% and far = 62.5%). Significance of distance to hotel/rotel¹ and hostel expenses is not tested as no families in the near category

¹ A rotel is a type of low cost accommodation for families whose child is in hospital. If the family cannot afford the usual fee, then the fee is geared to their income.

reported this expense, and only 3 families in the medium distance category (7.3%) reported the expense. However, families in the far distance category (37.5%) were more likely to stay in a hotel/rotel or hostel. The low counts of families staying with friends or relatives (near = 5.1%, medium = 4.9% and far = 3.1%) made statistical testing difficult.

Table 5.3. ANOVA Of Number Of Trips Made With The Car By Distance

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	3357.119	1678.560	6.525	0.002**
Within (error)	103	26498.239	257.264		
Total	105	29855.358			

** denotes significance at the 0.05 level

Looking at Table 5.1, it appears that families from the far category have more child care expenses than the other distance groups. However, 1 family in the far category required 384 hours of child care, with this extreme high outlier removed the mean decreases to \$307.53. This is only slightly elevated from the mean costs for the near and medium distance categories.

Most of the families experienced some meal costs, with 4 of the 113 families not reporting this expense. Although the results are not significant the total cost for meals does increase as distance increases. There appears to be more variation in the mean within the groups, than between the groups for both miscellaneous items ($p = 0.239$), and telephone calls ($p = 0.769$). Many more families in the far distance category (75%) made telephone calls than those in the other categories (near = 41%, medium = 43.9%). While

some of these calls may be local, it is believed that the majority of calls, especially for the far group are long distance calls back to the place of residence.

There are no significant distance differences for the total expenditure of families ($p = 0.186$); however, the mean total cost does increase as distance increases. The distance difference associated with total expenditure is examined further using percentiles. Table 5.4 displays the 25th, 50th, 75th, and interquartile range (75th-25th) for each distance category. Fifty percent of families in the far distance category have total expenditures ranging from \$259 to \$817, this range is higher than those in the near (\$105 to \$573) or medium (\$182 to \$496). Thus, families traveling a far distance generally have higher total expenditures than those traveling a near or medium distance.

Table 5.4. List Of Percentiles Of Total Expenditure By Distance

Percentile	Near	Medium	Far
25th	105	182	259
50th	212	331	401
75th	573	496	817
Interquartile Range	467	314	558

Annual family income is used to determine the percentage of the family income consumed by this single hospitalization experience. ANOVA is used to determine if the percentage of annual income consumed by the hospitalization experience is related to distance group (Table 5.5). The null hypothesis (H_0) being tested is that the mean percentage of annual income consumed by the hospitalization experience is equal for the near, medium and far distance groups (H_0 : mean percentage of income_{near} = mean

percentage of income $_{\text{medium}} = \text{mean percentage of income}_{\text{far}}$). The alternative hypothesis (H_a) being tested is that at least one of the mean percentages of family income is not equal. Although there is no statistically significant distance differences ($p. = 0.143$), the mean percentage for the far category (2.5%) is greater than that for the other two categories (near = 1.21% medium = 1.26%). However, a major factor in this difference is the large percentage (over 27%) shown by 1 family in the far category, with this omitted the mean drops to 1.71%.

Table 5.5. ANOVA Of Percentage Of Annual Income Consumed By A Single Hospitalization Experience By Distance

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	36.217	18.108	1.984	0.143
Within (error)	104	949.382	9.129		
Total	106	985.599			

df = degrees of freedom

p. = probability value

A total of 7 predictor variables (change in SIB (T3-T1), the age and sex of the child, LOS, annual family income, study parent's years of education, and distance) were used in both direct and stepwise multiple regression analyses, with the total family expenditure as the dependent variable. The two nominal variables (child's sex and distance) were converted into dummy variables, with child's sex converted into 2 variables (male and female), and distance converted into 3 variables (near, medium, far). A stepwise method helps manage the problem of multicollinearity which exists when

predictor variables (male, female) (near, medium, far) are strongly correlated. “Entering all the dummy variables would create a situation of multicollinearity, which would make solving the regression equation impossible. This problem can be overcome by using a stepwise procedure or by excluding one of the dummy variables from the regression equation” (Dieffhoff 1992, pg. 279). A direct multiple regression solution is also used to examine the relationship between the whole set of predictor variables and the dependent variable (total expenditure). In the direct solution the dummy variables female and medium are excluded from the analysis.

Table 5.6 summarizes the direct and stepwise multiple regression solutions, and displays the regression coefficients of the predictor variables, the significance of each predictor variable, the overall fit of the model (R^2), and the overall significance of the model. Comparisons between the 2 models show that the stepwise model, with only the LOS predictor variable has the highest significance ($p = 0.036$), however, it only predicts 4.3 % of the variance in total expenditure ($R^2 = 0.043$). Adding the other predictor variables decreases the actual significance of the model ($p = 0.051$), but the model with all the predictor variables predicts approximately 14.7% of the variance in total expenditure ($R^2 = 0.147$). The results of both multiple regression analyses support the findings of Harrison et al. (1998) that LOS is highly correlated with total expenditure ($r = 0.43$, $p = 0.000$).

The direct regression results help show the relationships between all the predictor variables and total expenditure. The sign of the regression coefficients shows that as the predictor variables, change in SIB (T3-T1), the age of the child, LOS, annual family

income, and near distance, and far distance, increase the total expenditure also increases; the predictor variables male child, and increasing years of study parent's education lead to a decrease in the total expenditure. The LOS ($p = 0.027$) is the only variable that adds appreciably to the predictive power that is provided by the direct regression model. The regression coefficients for the far category (194.412), and the near category (12.938), show that families traveling a far distance to hospital have a higher unit change in total expenditure. This supports the other findings that families in the far distance category have a higher mean, median and interquartile range.

Table 5.6. Summary Of Multiple Regression Results For Predicting Total Expenditure

1. Direct Regression Solution

Model	Regression Coefficient	p.
Constant	666.385	0.048**
Change in SIB	3.443	0.223
Child's Age	10.348	0.462
Child's Sex - Male	-135.648	0.179
LOS	9.988	0.027**
Annual Family Income	0.0004118	0.524
Study Parent's Years of Education	-23.473	0.294
Distance - Near	12.938	0.917
Distance- Far	194.412	0.114

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	8	3934506.84	491813.354	2.027	0.051
Within (error)	94	22807319.8	242631.062		
Total	102	26741826.7			

2. Stepwise Regression Solution

Model	Regression Coefficient	p.
Constant	413.084	0.0001**
LOS	8.945	0.036**

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	1	1139716.11	1139716.11	4.496	0.036**
Within (error)	101	25602110.6	253486.243		
Total	102	26741826.7			

** denotes significance at the 0.05 level

df = degrees of freedom

p. = probability value

5.2 The Impacts Of Distance On Indirect Costs To The Family

The examination of indirect costs to families is divided into 2 parts. The first examines primary caregivers (PCGs) time, and the second examines other family members caring time involved with the hospitalized child's care.

5.2.1 Primary Caregivers Caring Time While The Child Is Hospitalized

Primary caregivers' caring time is explored by looking at the percentage of PCGs who report extra caregiving time², employed PCGs reporting time lost from paid work, and PCGs reporting time missed from volunteer work. Distance differences in the number of PCGs who reported extra caregiving time, the number of employed PCGs, and the number of employed PCGs who took time off work are tested using X^2 (Table 5.7). A

² This is time over and above the time usually spent caring for the child

2x3 contingency table is used to test the associations with the row variable being a yes/no response and the column variable being the 3 distance categories (near, medium and far).

Table 5.8 provides a summary of the ANOVA results for the indirect costs for PCG time. The dependent variables are the hours of caring time, and time taken off paid work, and the independent variable is traveling distance to hospital (near, medium and far). The variation between refers to the variation in PCG mean hours associated with distance, and variation within refers to variation in PCG hours that occurs within each independent distance group. The null hypothesis (H_0) being tested is that the mean hours for the PCG indirect cost is equal for the near, medium and far distance groups (H_0 : mean hours_{near} = mean hours_{medium} = mean hours_{far}). The alternative hypothesis (H_a) being tested is that at least 1 of the mean hours for the near, medium and far distance groups is not equal.

Chi-square analysis shows no distance differences in the number of PCGs who spent extra time caring for their child during hospitalization ($p = 0.945$). However, there is a significant difference in the number of hours that PCGs spent caring for the child ($p = 0.034$) (Figure 5.8 #1). This statement must be approached with caution as the data are not normally distributed, and there are 2 high outliers, 1 in the near and another in the far distance category. If outliers are present it is common practice to examine the medians, as this measure is not as influenced by extreme measures. The median of the far category (67.5) is more than twice as much as the other medians (near = 24.5 and medium = 30.0). Thus, the distance differences in hours spent caring for the child remain even with the consideration of the extreme measures.

Table 5.7. Indirect Costs Of Primary Caregiver Time While The Child Is Hospitalized By Distance

Primary Caregiver Time	DISTANCE						X ² Analysis
	Near		Medium		Far		
	no.	%	no.	%	no.	%	
Extra caring time*	36	92.3	38	92.7	29	90.6	X ² = 0.113 df = 2 p. = 0.945
Time missed from paid work * ^b	19	48.7	23	56.1	15	46.9	X ² = 2.335 df = 4 p. = 0.674
Time missed from volunteer work ^b	4	10.3	2	4.9	2	6.3	n/a

* small counts of no responses means that 3 cells have expected counts of less than 5

^b Time used specifically to care for child in hospital

n/a cell has too few observations for meaningful statistical analysis

X² = test statistic

df = degrees of freedom

p. = probability value

Table 5.8. ANOVA Tables Of Indirect Costs Of Primary Caregiver Time While The Child Is Hospitalized By Distance

1. Extra caring time

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	24070.856	12035.428	3.510	0.034**
Within (error)	92	315491.734	3429.258		
Total	94	339562.589			

** denotes significance at the 0.05 level

2. Time missed from paid work

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	2114.186	1057.093	0.662	0.520
Within (error)	52	83015.196	1596.446		
Total	54	85129.382			

df = degrees of freedom

p. = probability value

The number of employed PCGs does not vary according to distance ($p. = 0.683$), and there are no significant distance differences in the number of PCGs who took time off work to care for the child in hospital ($p. = 0.684$), or the actual number of hours that they missed work ($p. = 0.520$). Part of this may be a result of extremely high outliers in both the near and far distance category. As with other analysis if the observations are excluded, there is more variation between the near and medium, and near and far groups although the differences remain statistically not significant. The small number of PCGs involved in volunteering makes analysis difficult as 6 cells in the chi-square analysis have expected counts of less than 5.

5.2.2 Other Family Members' Caring Time While The Child Is Hospitalized

Other family members' caring time is explored by looking at the percentage of other family members who report extra caregiving time³, other family members who are employed and report time lost from paid work, and other family members who report time missed from volunteer work. Distance differences in the number of other family members who reported extra caregiving time, the number of other family members who are employed, and the number of other family members who are employed and took time off work are tested using X^2 (Table 5.9). A 2x3 contingency table is used to test the associations with the row variable being a yes/no response and the column variable being the 3 distance categories (near, medium and far).

³ This is time over and above the time usually spent caring for the child

Table 5.9. Indirect Costs Of Other Family Members' Time While The Child Is Hospitalized By Distance

Other Family Members' Time	DISTANCE						X ² Analysis
	Near		Medium		Far		
	no.	%	no.	%	no.	%	
Extra caring time ^a	24	63.2	29	70.7	17	53.1	X ² = 2.392 df = 2 p. = 0.302
Time missed from paid work ^a	16	42.1	19	46.3	14	43.8	X ² = 0.146 df = 2 p. = 0.929

^a Time used specifically to care for child in hospital
X² = test statistic

df = degrees of freedom
p. = probability value

Table 5.10 provides a summary of the ANOVA results for the indirect costs for other family members' time. The dependent variables are the hours of caring time, and time taken off paid work, and the independent variable is traveling distance to hospital (near, medium and far). The variation between refers to the variation in other family members mean hours associated with distance, and variation within refers to variation in hours that occurs within each independent distance group. The null hypothesis (Ho) being tested is that the mean hours for other family members' indirect cost is equal for the near, medium and far distance groups (Ho: mean hours_{near} = mean hours_{medium} = mean hours_{far}). The alternative hypothesis (Ha) being tested is that at least 1 of the mean hours for the near, medium and far distance groups is not equal.

A fairly large percentage of family members from a medium distance (70.7%) are involved in the child's care compared to those in the near (63.2%) or those from the far category (53.1%), but these differences are not significant (p. = 0.302) (Table 5.9).

However, these results change when considering the hours spent caring for the child. There is a significant difference in the mean number of hours that other family members spent caring ($p = 0.015$) (Table 5.10 #1). Tukey test results show that other family members caring for children classified as living a medium distance from hospital spend significantly less hours caring for the child than family members from the far category ($p = 0.011$). Also the number of hours other family members in the far category spent caring for the child is more than those in the near category, although this difference is not significant. Therefore, although more family members help with the child's care from the medium category, they spend less hours compared to the fewer family members involved in the child's care from the far category.

Table 5.10. ANOVA Tables Of Indirect Costs Of Other Family Members' Time While The Child Is Hospitalized By Distance

1. Extra caring time

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	6123.314	3061.657	4.461	0.015**
Within (error)	63	43233.353	686.244		
Total	65	49356.667			

** denotes statistical significance at the 0.05 level

2. Time missed from paid work

Source of Variation	df	Sum of Squares	Mean Sum of Squares	Computed Variance Ratio	p.
Between	2	3907.883	1953.941	2.780	0.073
Within (error)	45	31631.596	702.924		
Total	47	35539.479			

df = degrees of freedom

p. = probability value

Distance is not associated with the number of other family members who took time off work during the child's hospitalization ($p. = 0.929$) (Table 5.9); however, there are some distance differences associated with the amount of time taken off although these are not statistically significant ($p. = 0.073$) (Table 5.10 #2). As distance increases it appears that the amount of time other family members take off work also increases. The far category median (31.0) is higher than the median for either the near (13.0) or medium category (20.0). The analysis of volunteering is difficult due to the small number of other family members who participate in the activity.

5.3 Summary Of Findings

Overall, families face large costs in terms of direct and indirect costs resulting from a single hospitalization. Families traveling a far distance by car to the hospital, and while the child is hospitalized have significantly higher transportation costs than families traveling a near distance, even when number of 1- way trips is taken into account. More families traveling a far distance to hospital have costs associated with accommodation in a hotel/rotel/hostel, and telephone calls. And overall total expenditure increases as distance increases, although the high variation of costs within each distance category should be noted.

The number of hours that PCGs and other family members spend caring for the child in hospital are both significantly higher for families in the far distance category. The actual numbers of those involved in the child's care, and adults who had to take time off work is not statistically significant for PCGs. A possible explanation could be that PCGs

traveling a far distance are displaced from their normal environment and spend large amounts of time at the hospital. PCGs who travel closer distances may still be able to run errands and check back home, and therefore do not spend as much overall time at the hospital, even though the same number are involved in the child's care. There are fewer other family members involved in the child's care from the far category compared to the other 2 categories; however, they spend more hours caring for the child.

CHAPTER 6

DISCUSSION

6.1 Introduction

This chapter is divided into 2 sections. The first, discusses critical aspects of the literature regarding the familial impact of childhood chronic conditions. The second, highlights the key findings concerning the significance of distance to hospital and relates these findings to the subjective and objective adoption and harmonization of families with a child with a chronic condition.

An in-depth analysis of the items composing the FFFS factors and the QRS scales is used to determine why only some of the factors and scales are affected by distance. The objective measures of the direct and indirect costs to the family are also examined to determine why only some of the costs demonstrate distance differences among the near, medium and far categories. Comparisons are also made between the results of this thesis and 2 other studies of the direct and indirect costs associated with childhood chronic conditions. The chapter concludes with a discussion of the findings of the thesis and relates them to the cumulative effects of other caregiving challenges that affect families with a child with a chronic condition.

6.2 Reviewing The Literature

6.2.1 Support For Using A Non-Categorical Approach For Classifying Childhood Chronic Conditions

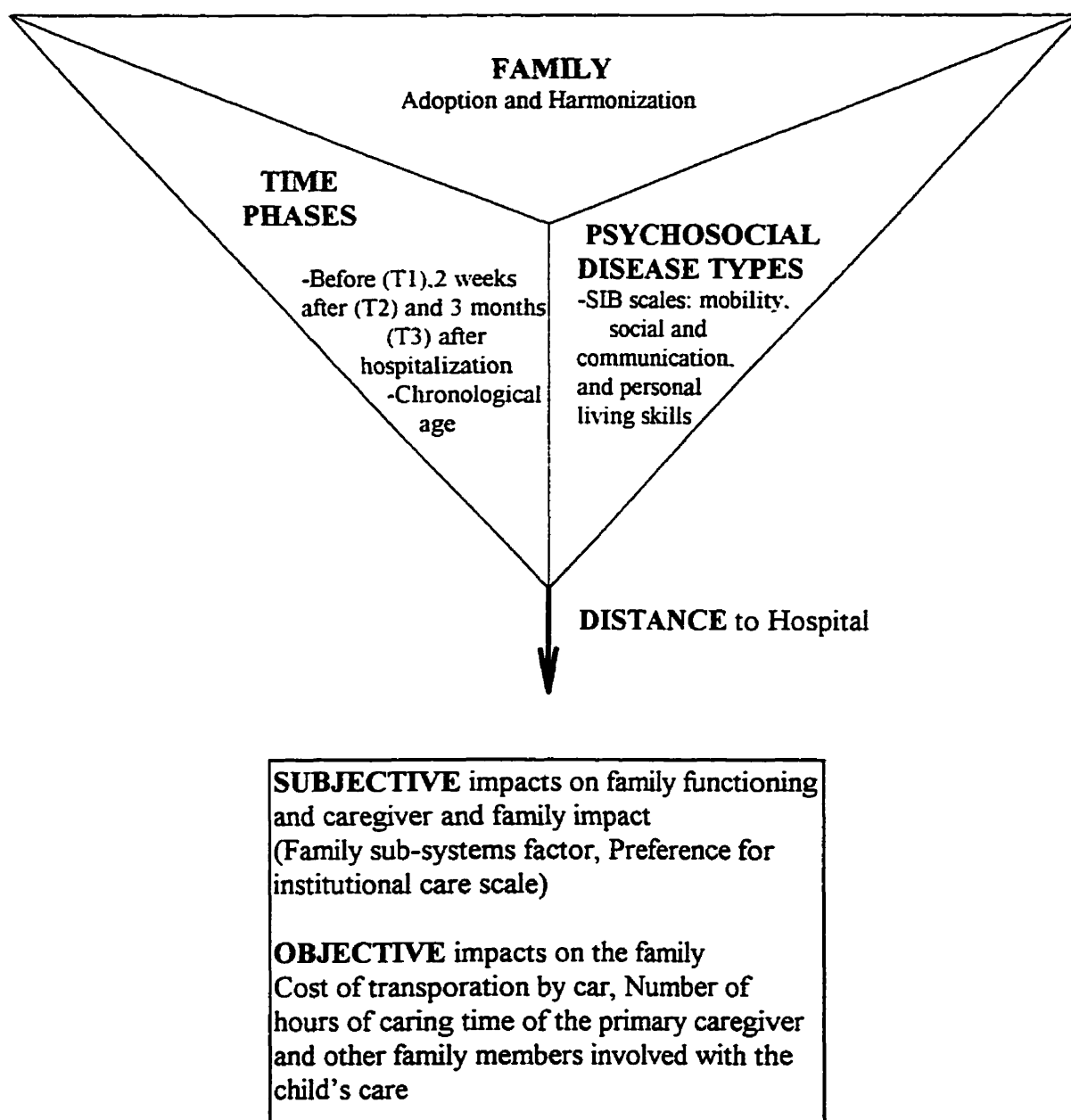
The low counts for particular diagnosis groups from the HALS 1991 Disability Index, support the use of a non-categorical approach for classifying childhood chronic conditions. The Scales of Independent Behaviour, by including the child's motor skills, social and communication skills, and personal living skills, provides a multi-faceted method for categorizing childhood chronic conditions. Including the child's chronological age, as part of the SIB scale scores and total score emphasizes age appropriate activity. This facilitates moving away from stereotyping and predicting the abilities of children with chronic conditions, and concentrates on the abilities rather than the disabilities of these children. A non-categorical approach for classifying childhood chronic conditions is essential, as it recognizes many of the challenges, such as financial concerns that families face, while at the same time providing a mechanism to include some of the different challenges such as, the child's developmental level, or the child's chronological age.

6.2.2 The Usefulness Of Rolland's Conceptual Framework

The intertwining of the illness, individual, and family lifecycles, identified in Rolland's (1987) conceptual framework for studying the familial impacts of chronic conditions has proved useful for conceptualizing the familial impact of childhood chronic conditions. However, the limitations of the data set such as, not including the time of

illness, and the extreme importance of the family as emphasized throughout this thesis have led to a revision of Figure 2.2 and a new model (Figure 6.1)

Figure 6.1. A Conceptual Framework For Exploring The Impacts Of Distance To Hospital On Families Caring For Children With Chronic Conditions



The framework, by considering the family lifecycle, embraces the various coping and lifestyle changes which help the family minimize as much as possible the impacts on family life. The inclusion of the SIB through the psychosocial disease types, provides a means for a non-categorical classification of childhood chronic conditions. Collecting the FFFS and QRS data both before (T1) and after (T3) hospitalization is critical for examining the impacts of distance to hospital on families caring for children with chronic conditions. Use of T1 data provides a benchmark for family functioning and caregiver and family impact before hospitalization. By subtracting T1 data from T3 data the change in family functioning and caregiver and family impact after hospitalization can be examined. Collecting the direct and indirect cost data 2 weeks after hospitalization (T2) rather than at T3, helps the family remember the details such as, how much money was spent, and how much caregiving time was required while the child was hospitalized. The intertwining of the various lifecycles provides an holistic conceptual framework for exploring the impacts of distance to hospital on families caring for children with chronic conditions.

6.2.3 The Differences Between Subjective And Objective Adoption And Harmonization

The importance of differentiating between subjective and objective adoption and harmonization has been clearly shown. These types of impact have distinct “correlates” and “an understanding of the causes and consequences of subjective burden does not necessarily accompany an understanding of the causes and consequences of objective burden” (Montgomery, Gonyea and Hooyman 1985, pg. 24). It is for this reason that

both subjective and objective impact are explored in this thesis, as not examining both would limit a study of the impacts of distance to hospital on these families. However, the potential for each type of impact to have varying associations with distance necessitates the separate study of subjective and objective adoption and harmonization. Therefore, the remainder of the discussion is separated into 2 parts. The first examines the impacts of distance on subjective adoption and harmonization, and the second discusses the impacts of distance on objective adoption and harmonization.

6.3 The Significance Of Distance To The Subjective Adoption And Harmonization Of Family Functioning And Caregiver And Family Impact

While there is evidence of subjective adoption and harmonization for various FFFS factors and total score and QRS scales and total score, the significance of the impacts depends on their individual composition. Examining the individual items that compose each factor and scale is helpful in determining possible reasons why there are distance differences with some factors and scales ((1)FFFS- individual relationships factor, family sub-systems factor, and the overall score (2) QRS- preference for institutional care, lack of personal reward, and total score).

The family problems factor, which is not affected by distance, is composed of only 3 items; these include problems with children, time that the respondent is ill, and time that their spouse misses work. Perhaps items such as the number of problems with children are not as likely to vary with changes in distance. The other FFFS factors consist of a larger number of items, and concentrate on questions concerning the amount of time that the

respondent spends on certain activities such as, time spent alone with their spouse, time spent with neighbors, and the amount of help with family tasks received from the spouse, other relatives, and friends. This may support the premise that families caring for children with chronic conditions have higher caregiving time demands than those with healthy children, and traveling far distances to a hospital further stretches their time resources.

The family sub-systems factor, which concentrates on issues regarding the amount of help and communication with both neighbors and friends, is the only FFFS factor significantly related to distance. These types of issues may be of more concern for families that need to travel far distances to access some necessary aspects of health care.

The preference for institutional care scale is the only QRS scale significantly related to distance. This scale focuses mainly on issues concerning the future care of the child, such as, considering the possibility that the child will not be able to stay in the family's house much longer, that the child is better off in the family home, and concerns regarding the attention, affection and care of the child if they go somewhere else to live. It may be that these types of concerns are more prevalent if the family has to travel a far distance to access some necessary aspects of health care.

One of the main problems with exploring the subjective caregiving experience is the lack of policy impact and relevance associated with the concept of caregiver distress. Braithwaite (1992) states that, "in the caregiving context, burden, as distress, is not useful directly in guiding public policy" (pg. 11). However, she does note that because of cuts in health care, 'burden' is relevant when it is associated with family decisions regarding

institutional care. The findings have shown that longer travel distance to hospital is associated with more heightened family concerns regarding this decision.

It appears that the parent-respondent (usually the mother) of those families traveling a further distance for hospitalization is more concerned about the problems that the family face, and the effects of caring for the child on both the individual parent and family. There seems to be some distance differences in the total QRS score between those living near hospitals and those living far from hospitals. However, these must be treated with caution because of the inconsistent results for those families classified as living a medium distance from a hospital.

Both the FFFS and QRS are mainly measures of subjective adoption and harmonization, as they ask questions about feelings, attitudes and emotions regarding the caregiving experience. Distance may not be as significant a factor because families adopt and harmonize the impact of hospitalization. This is demonstrated by ANOVA results showing that both the number of hospitalizations in a child's lifetime, and the number of weeks a child has been hospitalized in his or her lifetime are not significantly related to the total FFFS clinical differences, or the total QRS hospitalization effects. Significant relationships would demonstrate that increased hospitalization has a negative impact on subjective experience.

These results differ from Burke and Kauffmann's study (1990), which found that approximately 50% of the parents reported that lengthy outpatient and/ or hospitalization visits had a slightly to a very negative personal impact. However, the majority of their measures explored objective impact such as, determining the practical difficulties involved

in traveling to a health sciences center for comprehensive health care. The use of subjective and objective measures may help account for the differences. Thus, families caring for children with chronic conditions normalize the hospitalization experience, including the distance traveled, which enables minimization of the social effects of living with the condition, concentration on the 'normal' aspects of life, a lessening of the focus on limitations, and examination of the family's circumstances in the context of difficulties that can affect people's lives (Thorne 1993). This does not obviate research which shows the negative impacts of hospitalization on families, but instead highlights the tremendous strength, courage and determination of these children and their families.

6.4 The Significance Of Distance To The Objective Adoption And Harmonization Of Direct And Indirect Family Costs

Similar to the subjective impact discussion, there is some evidence of objective adoption and harmonization for some of the direct and indirect costs; however, the significance depends on the type of cost being explored. For the direct costs to the family, the cost of transportation by car is the only variable having a statistically significant association with distance. Families traveling a far distance have significantly greater car transportation costs than families in the near category, and higher although not significantly higher than those in the medium distance category. This cost is calculated based on the distance per 1-way trip * the number of one way trips* a set reimbursement rate. Even though people in the far distance category made significantly less 1-way trips than people in the near category, the cost differences remain.

Besides transportation by car there were other direct costs which show some distance differences, although these are not statistically significant. Accommodation costs are difficult to analyze due to the large number of parents who stayed in the child's hospital room, consequently few families reported expenses resulting from accommodation. Over 50% of families from all distance categories stayed in the child's hospital room; however, the percentage increases as distance increases, with 62.5% of families from the far category staying in the child's hospital room. No economic costs resulting from staying with the child are reported; however, non-economic costs such as, a poor nights sleep due to staff monitoring the child, ward noises, not sleeping in their own bed, and inability to be with the rest of the family including other children, spouse or partner are not considered in the Burke et al. (1994 to 1996) study. Difficulties also arise when considering accommodation costs from hotels/rotels/hostels, due to a lack of observations in the near category and very small counts in the medium category. However, a larger number of families from the far distance category reported costs for hotels/rotels/hostels than families traveling a medium distance.

The distance differences in accommodation type should be noted. There are fewer distance differences with staying in the child's hospital room compared to staying in an hotel/rotel/hostel. If a child is insecure, afraid, or quite ill a family member will stay with the child regardless of the distance from their residence. However, it is not sensible for families who are in the near or even some in the medium distance category to pay for a room.

Costs reported for meals and telephone calls show a general trend of the costs increasing as distance increases. More families traveling a far distance reported telephone costs than families from the other distance categories. Although some of these calls may be local calls, a majority are likely long distance calls to family and friends.

Approximately 15 families have total expenditures for a single hospitalization in excess of \$100.00. The total expenditure for families increases as distance increases as demonstrated by both the mean cost (near = \$393.34, medium = \$436.99, far = \$605.98) and the median cost (near = \$212.45, medium = \$331.00, far = \$401.35). The median total expenditure calculated by Harrison et al. (1998) for direct costs to families in the Burke et al. (1994 to 1996) study is \$317.00. In the near distance category approximately 33% of families have total expenses greater than \$317, approximately 50% of families traveling a medium distance have expenses greater than \$317, and approximately 67% of families traveling a far distance have total expenses greater than \$317. The above percentages show that families in the far category have higher total expenditures.

The analysis of direct costs by distance can be difficult. Although there may be no significant cost difference, there is a much higher percentage of families in the far distance category reporting costs such as those for hotel/rotel/hostel and telephone calls. There are many other factors such as, the inability to sleep in unfamiliar surroundings and the separation of family members which have value, but are difficult to measure in economic terms. There needs to be some way to measure the effects of these type of phenomena that affect families.

For costs such as, miscellaneous items and meals, distance may not be as critical a factor because all families will purchase the item when their child is in hospital. If a child wants a toy or snack the item will likely be purchased regardless of the distance from the residence. Similarly, if a PCG, who is staying with the child is hungry they will purchase a meal, regardless if they have traveled a near, medium or far distance.

Lansky et al. (1979) in a study of family costs associated with childhood cancer treatment, Houts et al. (1984) in a study of costs to patients and their families associated with outpatient chemotherapy, and the results of this thesis depict transportation and meals as considerable expenses for families. However, the first two studies did not mention child care (or family care) as a major cost, and the results of this thesis show child care to be the largest expense for families from all distance categories. Several reasons may exist for this difference among the studies: (1) the previous studies explored weekly expenses, and this study explores expenses arising from a single hospitalization; and (2) the previous studies explored costs associated with outpatient cancer treatment, while this thesis has explored a single hospitalization experience. Outpatient treatment likely involves shorter but more frequent trips compared to inpatient hospitalization which has a mean LOS of 6.1 days. It may be easier and less expensive to arrange child care for shorter time frames than for longer continuous periods.

Multiple regression analyses in the Lansky et al. (1979) study and the Houts et al. (1984) study show that distance to treatment center is significantly related to total out-of-pocket expenses. The multiple regression results of this thesis do not show distance to the health center as a significant factor in total expenditure. However, the distance differences

for total expenditure are evident from the descriptive statistics of mean, median and percentiles. Similar to the differences in child care, one reason for the difference in multiple regression analyses regarding distance may be that the previous studies were for outpatient cancer treatment, which likely involves shorter, more frequent visits. These shorter visits would likely have fewer expenses such as miscellaneous items, telephone costs, and meals, which in this thesis did not show significant distance differences. An increased number of 1-way trips, would lessen the significant difference as shown in this thesis between the number of 1-way trips for the near and far category, and increase the transportation costs for families traveling a far distance for outpatient therapy. Whereas, when a child is hospitalized families may have similar expenses, such as miscellaneous items, and families traveling a far distance make fewer 1-way trips. The combination of these factors could decrease the distance differences for total expenditures.

The indirect costs of families caring for a child with a chronic condition are divided into costs due to PCG time, and costs due to other family member's time. There appears to be 2 conflicting results for the PCG time. There are no significant distance differences for the number of PCGs who spent extra time caring for the child, but there are significant distance differences regarding the amount of hours that the PCG spent caring for the child. It is possible that those in the near or even some in the medium distance category may be close enough to their home, working and recreation environment that they are able to continue with some of their regular daily activities. When the child is sleeping or at a recreation room, the PCG may be able to leave the hospital and attend appointments, carry out errands, or return to the place of residence. This allows the PCG to have a rest period

or break, and be able to continue with some semblance of regular daily life, which in turn may decrease stress related to the inability to carry out errands, attend appointments and help with household activities. However, PCGs traveling a far distance may be unable to continue with some activities because they are removed from their everyday environment. Instead of leaving the hospital, PCGs in the far category may remain at the hospital for longer, continuous time periods.

Measuring the caregiving time of other family members involved in the child's care needs to be approached with caution, as it automatically assumes that family members are around to help with the child. Extended family dynamics, responsibilities such as, caring for young children or employment, lack of other family members (for example the parent is a single child whose parents have both died), and distance separating extended families, may make it difficult for other family members to be involved in caregiving activities while the child is hospitalized. These factors may help explain the larger number of other family members involved in caregiving in the medium distance category, compared to the smaller percentage involved in caregiving in the far distance category. However, this inequality levels out as family members from the far distance category spend more caregiving hours than families in the near and medium categories. This increase in caregiving hours may help compensate for the smaller number of other family members in the far category involved in caring for the child in hospital. It is important to remember that the distance category may not represent the distance from the other family member's residence to the hospital, it represents the distance from the child's residence to the hospital. Therefore, more family members from the medium distance category may live close to the child and

their family, and other family members listed in the far category may actually live even further away from the hospital than the actual distance recorded.

Lansky et al. (1979) and Houts et al. (1984) examined wages lost to determine indirect costs to families. The problem with this as emphasized by Hodgson and Meiners (1982) is that the value of life is measured in terms of employment earnings. Using time measured as hours spent caring for the child, allows analysis of time lost from all activities including work and leisure, whereas, analysis of wages lost focuses only on work. Also focusing on the number of PCGs and other family members involved in the child's care, and the number of caregiving hours that they spend avoids undervaluing the contributions of women, minority groups, and very young or older adults who are often in lower paying jobs.

6.5 Summary

Since distance does not affect all FFFS factors, QRS scales, and all direct and indirect costs there must be other factors which are mitigating the impact of distance. Parents will often do whatever it takes to help their child, which in this case involves taking the child to the hospital that will provide the best level of care. As part of subjective and objective adoption and harmonization the family will travel as far as necessary to access the level of care needed; it may not matter if they are 2 kilometers or 220 kilometers away from the hospital. Yet, even with the coping and lifestyle changes that are facilitated by adoption and harmonization there is still evidence of a geographical dimension to the family impact of childhood chronic conditions.

Despite the overwhelming parental objective to access the best level of care, there are significant distance differences with the FFFS family sub-systems factor, the QRS preference for institutional care scale, the transportation by car direct cost, and the number of hours that the PCG and other family members spend caring for the child while the child is hospitalized. There are also some general trends that demonstrate the impact of distance on families: the negative impacts increasing as distance increases for the FFFS independent relationships factor and total score, and the QRS lack of personal rewards scale and total score; the direct cost categories of meals and total expenditure increasing as distance increases; and the indirect cost of other family members taking more time off work as distance increases. Thus, it can be seen that distance to hospital is an important factor when exploring the impact of childhood chronic conditions on the family.

This thesis has shown the significance of distance to various aspects of subjective and objective family impact. In examining the impacts of distance to hospital on families with a child with a chronic condition the psychosocial, direct and indirect costs have all been explored. However, it is important to realize that the total impact of distance to hospital on families is not a sum of all the individual impacts. There is a synergistic effect from combining the different impacts. If a family is concerned about providing lifetime care for a child, "The combination of financial strain may be especially devastating" (Hodgson and Meiners 1982, pg. 435).

The impacts on the family could also be considered in terms of 'a tipping factor'. There may be a certain threshold which individual families can manage, which is affected by the ability of a family to adopt and harmonize the combined challenges. Daily

caregiving responsibilities, emotions such as sorrow and guilt, unknown future outcomes, concerns regarding the quality of the child's life, and out-of-pocket expenses are examples of the numerous challenges that families caring for children with chronic conditions must face. In some instances coping with the added challenge of traveling a far distance for health care may be the 'tipping' factor that topples the family over threshold that they can manage. Any factor that enhances or increases the familial impacts of childhood chronic conditions must be explored. The results and analyses of this thesis have demonstrated the influence that distance exerts on many of the subjective and objective impacts of families caring for children with chronic conditions.

CHAPTER 7

CONCLUSION

7.1 Introduction

This thesis examined the geographical dimension of the familial impact of childhood chronic conditions, and has demonstrated the critical role of distance in terms of family functioning, family and caregiver impact, and direct and indirect costs. The concluding chapter highlights some of the key results, and examines some of the limitations of the data and methodology. The broader implications resulting from the findings of the thesis are discussed in terms of interventions to help families cope with hospitalization experiences, and policies to help mitigate the impacts on families caring for a child with a chronic condition.

7.2 Highlighting Key Results

The primary goals were to demonstrate the impacts of distance to hospital on both subjective and objective measures of family impact, and to determine which areas of family functioning and family and caregiver impact, and which direct and indirect costs are most affected. Reconceptualizing burden as adoption and harmonization changes the focus from the negative aspects of caregiving, to the coping and changes in lifestyle that families make to accommodate, and minimize disruption to family life. This emphasis on the proactive rather than the reactive responses to the caregiving experience, addresses the second research goal of highlighting the tremendous strength and courage of children and their families who are dealing and coping with childhood chronic conditions.

Statistical analyses demonstrated the significance of distance for a limited number of items regarding family concerns about the amount of social support from both neighbours and friends, and institutional care. Significant distance difference regarding the costs of car transportation and the amount of caregiving time that primary caregivers and other family members spent while the child was hospitalized were also shown.

The statistically insignificant results concerning the role of distance on many of the measures of subjective and objective impact of families caring for a child with a chronic condition cannot, however, be ignored or discounted. Findings that several of the factors of the FFFS, scales of the QRS, and direct and indirect costs do not appear to be affected by distance means that distance must be considered in a more nuanced fashion. Just as families use adoption and harmonization to minimize the effects of living with a chronic condition, they may also find ways of rationalizing the negative impacts of traveling to comprehensive health services.

The difference in number of one way trips among families traveling a near, medium or far distance can have important implications for the impacts on families caring for a child with a chronic condition. The Burke et. al (1994 to 1996) data did not provide a mechanism to explore the time and space patterns of families. For example, with the removal of extreme outliers, families from the near, medium and far distance groups report using the same number of child care hours. However, the composition of the total number of hours is not known. Since families in the near category are making more one-way trips they may be using fewer hours of child care, but at a more frequent rate. Families in the medium and far distance categories may be using longer, continuous hours of child care.

Although approximately the same number of primary caregivers, and other family members from all distance categories spent extra caring time with the child in hospital, the total number of hours spent by those in the near distance category was significantly less than those in the far distance group. It would be helpful to have a daily record of when the PCG and other family member visited the child, and the duration of each visit. This would help determine if the frequency and duration of hospital visits varies with distance.

The ability of families at a closer distance to go back and forth from their place of residence to the hospital is important. Primary caregivers and other family members living within a near, or even some in the medium distance category may be able to participate in some of their regular home, work, recreation and leisure activities. It may be possible for them to keep appointments, run errands, return home to do a load of laundry, or spend time with their other children. Carrying out these tasks maintains some sense of routine for the family, and may also decrease stress from feeling overwhelmed at the number of tasks that remain unfinished. With all the other challenges that families caring for children with chronic conditions face, anything that can be completed and which lessens anxiety or stress is beneficial. The above suggestions indicate that space and time are mediated by a complex array of factors which need to be taken into account in any future research on children with chronic conditions and the impacts on their families.

7.3 Limitations Of The Data And Methodology

The Repeated Hospitalization Study (1994 to 1996) data are rich given the difficulties of collecting family information of a private and sometimes sensitive and

uncomfortable nature, and the lack of general studies of the family impact of childhood chronic conditions. However, there are some limitations resulting from the data set and methodology. The use of three health care centers in Ontario as study sites limits the geographical scope, and restricts the number of children and families that were involved. Although 140 children began the study, only 115 completed it, and of the 115 only 113 families answered the question determining distance from their home. Thus, a limited number of observations was available for analysis.

The other difficulty with the data is the short time frame between time T1, 2 weeks before hospitalization and time T3, 3 months after hospitalization. Although 3 months has been noted as the period where the acute effects of hospitalization dissipate and the chronic effects remain, it is a short time to analyze the impacts of distance to hospital on the family. Also the data set provided a single hospitalization experience to examine. It would be beneficial to examine more than 1 hospitalization to increase the robustness of the results and subsequent analysis.

It would also be useful to examine the impacts of distance to hospital on families, over several hospitalization experiences and for varying time periods. This would increase the scope of the study, providing the ability to determine if distance differences of family impact exist for numerous hospitalizations. The interaction effect between distance and number of hospitalizations could be investigated, to determine if a critical threshold exists, where the impacts of distance to hospital on family functioning and economic and time costs are more pronounced.

Another limitation is the use of 3 particular distance categories to explore the impacts of distance on families. The nominal nature of the FFFS and QRS data, and the non-normal distributions for some of the direct and indirect costs data limited the statistical analyses that could be used. Distance was at first categorized into 2 groups to maintain consistency with previous study methodologies which differentiated between those living near to and at a distance from the hospital. However, the number of observations in the near category was much greater than the far category, and a decision to use 3 distance categories (near, medium, far) was made after examining the frequency distribution of the distance variable. The limited range of the distance data (0 to 220 kilometers), due to a maximum distance allowing personal interviewing, also limits the geographical analyses. Some families travel further than 220 kilometers, and the impacts on their situation have not been explored. It would be beneficial for another study to repeat the analysis, with other distance categories to make sure that the results are not a function of the distance categories, but that the impacts are a reflection of the actual distance that families travel.

7.4 Policy Implications

Despite these limitations, this thesis is an important contribution to the caregiving literature, helps remedy the lack of geographical research of the caregiving experience of families with a child with a chronic condition, and responds to the “relative neglect of the problem of childhood chronic illness” (Perrin 1985a, pg xii).

Studies and interventions have been implemented to help families cope with the hospitalization of a child with a chronic condition. In examining profiles of children and families most likely to benefit from interventions such as, Stress-Point Intervention By Nurses (SPIN) a range of factors have been explored including, the sex, chronological age, and chronic condition of the child, the length of stay of the hospitalization, the lifetime admissions and total number of weeks spent in hospital, the education of the parents, income of the family, number of adults in the home, and number of adults involved in the child's care (Burke et al. 1998a; 1998b).

However, distance to hospital from the child's home has not been considered as a possible factor in how children and families respond to intervention. The results of this thesis have demonstrated that distance should be considered in future examinations of the impacts of hospitalization, and types of interventions useful in mitigating the effects of hospitalization. Families who are traveling a far distance for hospitalization should be considered at higher risk for having difficulties with various subjective and objective impacts.

Traveling to the hospital for the purpose of hospitalization is not the only geographical dimension to the caregiving experience of families dealing with childhood chronic conditions. For some families traveling to the hospital for appointments at outpatient clinics is also a reality. This often means arranging child care, transportation, making school and work arrangements, meal costs, and sometimes accommodation expenses. In fact many of the issues surrounding traveling to the hospital to stay as an inpatient, are similar to issues regarding traveling to the hospital for appointments at

specialty outpatient clinics. Therefore, policies and research should also consider the impacts of distance to hospital on families traveling to outpatient clinics. Combining the results of this thesis concerning travel to hospital for inpatient care, and results of other studies regarding travel to hospital for outpatient care would demonstrate the impact of distance to access all required health services on families caring for a child with a chronic condition.

Health Canada, in a paper on the principles of child and youth health states that, “[F]or optimal development, children need to grow up in a nurturing atmosphere of support, happiness, love and understanding. Support for the family...is the single most important way that society can optimize the development of children and youth”. (Health Canada 1993, as cited in National Advisory Council on Aging March 1996, pg. 1). In another guide for families, policy makers, and program developers on respite care, it states, “that the best place to care for a child with a disability is in the child’s home and community” (National Respite Guidelines, as cited in National Advisory Council on Aging March 1996, pg. 3).

With the cuts to health care, and decisions regarding the closing and restructuring of health care facilities, government policy needs to consider the impacts of traveling distance to hospital on families caring for children with chronic conditions. Of particular concern is the impact of distance on family decisions regarding the preference for institutional care. The closing of chronic care facilities and changes in health care facilities may increase the distance that families travel, further heightening their concerns regarding institutional care, and many other subjective and objective impacts. In order to maintain

their mandate of supporting all children and families, the federal and provincial governments must include distance to health services as a factor when researching and implementing guidelines and policies to help mitigate the subjective and objective impacts on families caring for children with chronic conditions.

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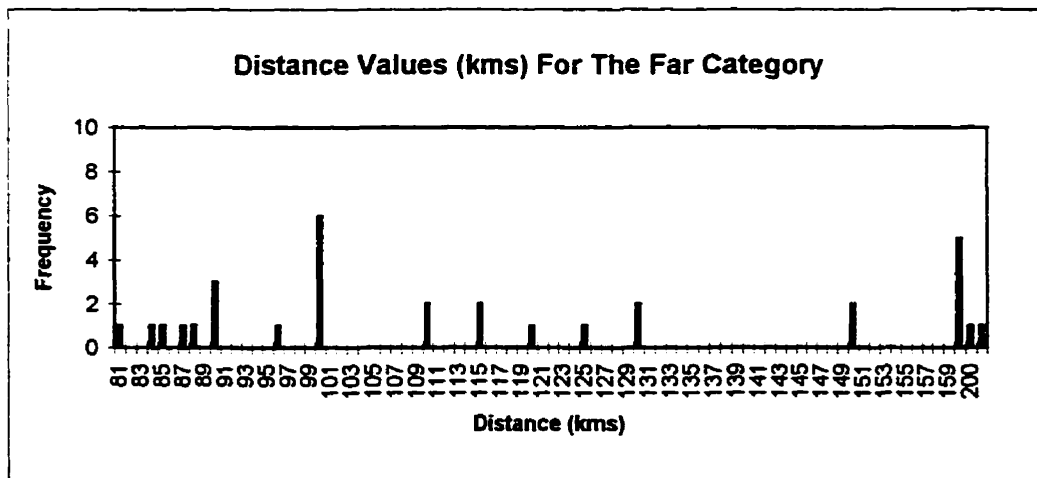
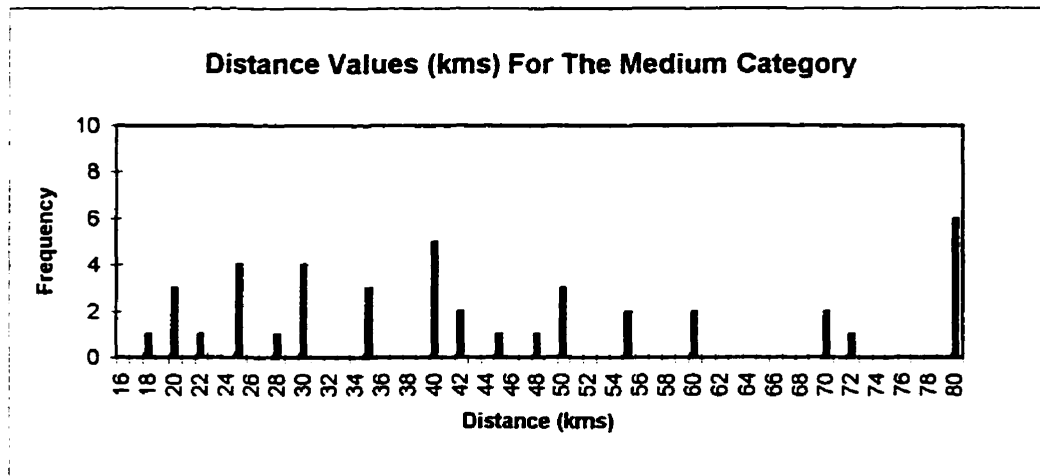
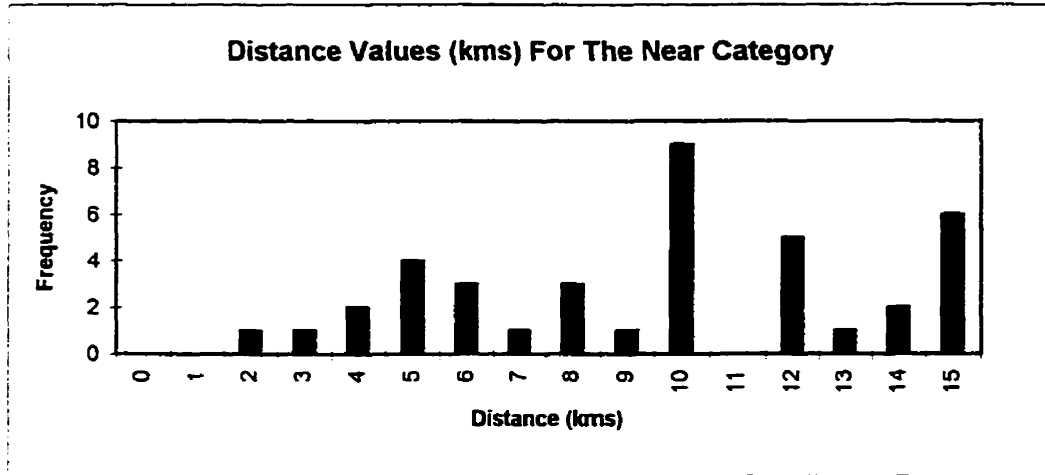
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**APPENDIX A. GRAPHS SHOWING DISTANCE VALUES (kms)
FOR EACH DISTANCE CATEGORY**



APPENDIX B. COMPOSITION OF THE SUBJECTIVE MEASURES OF FAMILY IMPACT

B-1 Items Composing The Feetham Family Functioning Survey (FFFS)

Family Problems Factor

The number of problems with your child(ren).

The amount of time you are ill.

The amount of time your spouse misses work (including housework).

Individual Relationships Factor

The amount of time you spend alone with your spouse.

The amount of discussion of your concerns and problems with your spouse.

The amount of help from your spouse with family tasks such as care of the children, house repairs, household chores, etc.

The amount of time you spend with your child(ren).

The number of disagreements with your spouse.

The amount of emotional support from your spouse.

The amount of satisfaction with your marriage.

The amount of satisfaction with the sexual relations with your spouse.

Family Sub-Systems Factor

The amount of discussions with your relatives regarding your concerns and problems (do not include your spouse).

The amount of time you spend with neighbours.

The amount of help from relatives with family tasks such as care of children, house repairs, household chores, etc. (do not include spouse).

The amount of help from your friends with family tasks such as care of children, house repairs, household chores, etc.

The amount of time you spend doing housework (cooking, cleaning, washing, yard work, etc.)

The amount of emotional support from friends.

The amount of emotional support from relatives.

B-2 Items Composing The Questionnaire On Resources And Stress (QRS)

The name Jill is used as an example of how the questions were asked, the interviewer would insert each child's name where the name *Jill* is currently inserted. Based on the intention of the question either a false or a true answer is counted as 1.

Personal Burden Of The Respondent

Jill is cared for equally by all members of our family. (False =1)

A doctor or therapist or nurse sees *Jill* at least once a month. (True = 1)

Most of *Jill's* care falls on me. (True = 1)

Preference For Institutional Care

- The doctor sees *Jill* at least once a year. (True = 1)
- I would not want the family to go on vacation and leave *Jill* at home. (False = 1)
- There is no way we can possibly keep *Jill* in our house much longer. (True = 1)
- We take *Jill* along when we go out. (False = 1)
- I am afraid *Jill* will not get the individual attention, affection, and care that *she* is used to if *she* goes somewhere else to live. (False = 1)
- Jill* is better off in our home than somewhere else. (False = 1)

Lack Of Personal Reward

- People who don't have the problems we have don't have the rewards either. (False = 1)
- We enjoy *Jill* more and more as a person. (False = 1)
- Having to care for *Jill* has enriched our family life. (False = 1)
- Caring for *Jill* gives one a feeling of worth. (False = 1)
- I have become more understanding in my relationships with people as a result of *Jill*. (False = 1)
- I am pleased when others see my care of *Jill* is important. (False = 1)

Limits On Family Opportunities

- Other member of the family have to do without things because of *Jill*. (True = 1)
- The constant demands for care for *Jill* limit growth and development of someone else in our family. (True = 1)
- I have given up things I have really wanted to do in order to care for *Jill*. (True = 1)
- Caring for *Jill* has been a financial burden for our family. (True = 1)
- One of us has had to pass up a chance for a job because *Jill* could not be left without someone to watch *her*. (True = 1)
- Outside activities would be easier without *Jill*. (True = 1)

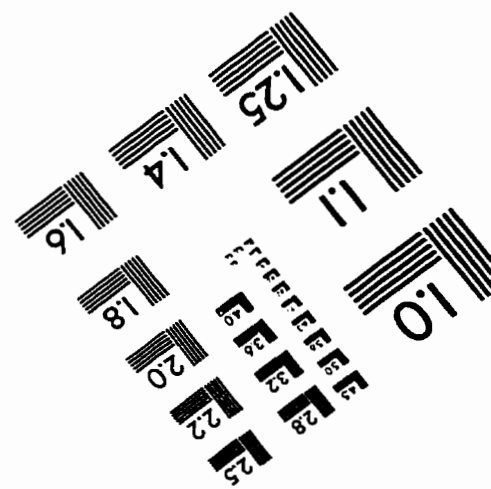
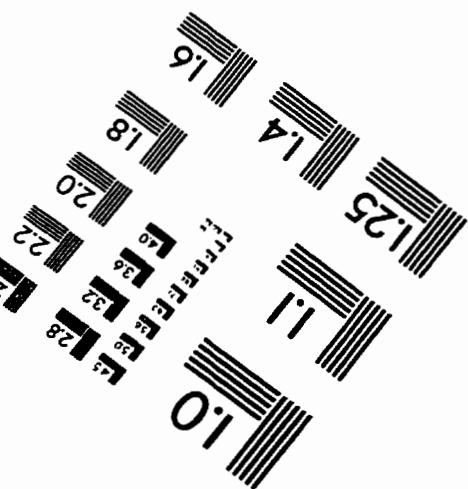
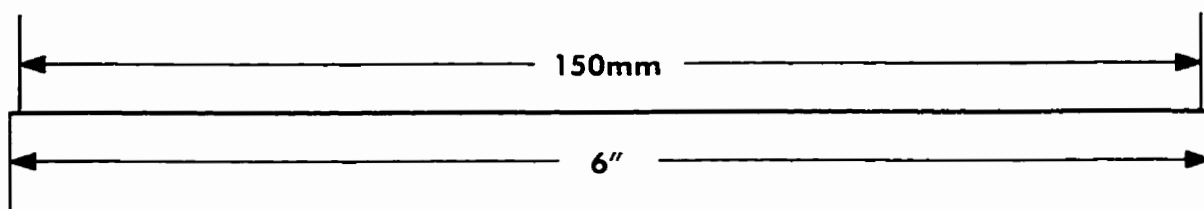
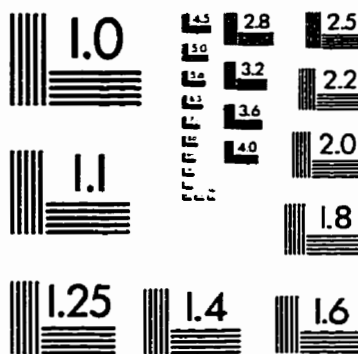
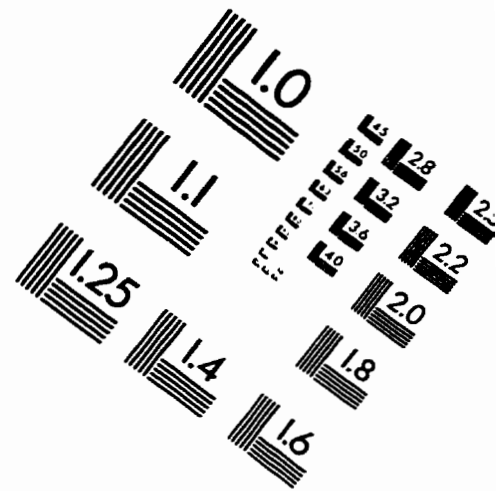
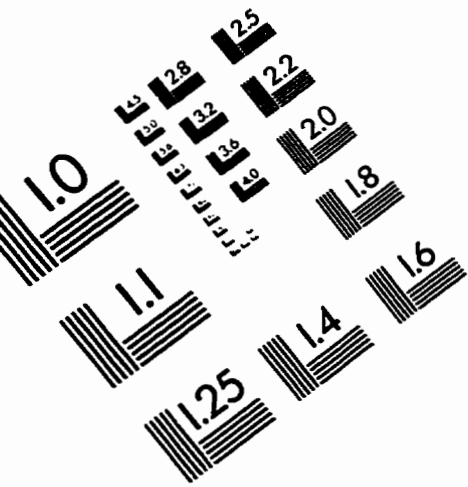
Terminal Illness Stress

- I don't worry too much about *Jill's* health. (False = 1)
- As the time passes I think it will take more and more to care for *Jill*. (True = 1)
- I worry that *Jill* may sense that *she* does not have long to live. (True = 1)
- I worry about how our family will adjust after *Jill* is no longer with us. (True = 1)
- In the future *Jill* will be able to help *herself*. (False = 1)
- Jill* cannot get any better. (True = 1)

Life Span Care

- I worry about what will happen to *Jill* when I can no longer take care of *her*. (True = 1)
- Jill* is limited in the kind of work *she* can do to make a living. (True = 1)
- Jill* spends time at a special day center or in special classes at school. (True = 1)
- The part that worries me most about *Jill's* going on *her* own is *her* ability to make a living. (True = 1)
- I worry about what will be done with *Jill* when *she* gets older. (True = 1)
- It bothers me that *Jill* will always be this way. (True = 1)

IMAGE EVALUATION TEST TARGET (QA-3)



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