



A descriptive study of the health care needs of neurologically impaired children and family care providers residing in central and western Montana
by Darlene R S Gaughan

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University
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Abstract:

This exploratory study described the physical and psychosocial needs of rural-dwelling neurologically impaired children and their primary family care providers relating to information, emotional support, and respite care for the purpose of building an initial data base. Additionally, it described the primary family care provider's perspective of the overall impact that living in rural Montana has on neurologically impaired children and their families.

This descriptive study used a semi-structured interview schedule to collect data from 12 primary family care providers for neurologically impaired children between the ages of three and twelve living in rural central and western Montana. The sample was derived, based on preestablished criteria, from a random selection of the patients of Dr.

M. Guggenheim, Montana's only pediatric neurologist. The interview schedule included demographic information questions about primary family care providers and their neurologically impaired children. Physical and psychosocial needs of neurologically impaired children and informational, emotional, and respite needs of primary family care providers and families were addressed. The interview schedule sought information about the impact of living in rural central and western Montana on the needs of neurologically impaired children and families.

Data were summarized narratively and with descriptive statistics where appropriate. Needs of neurologically impaired children and their providers as identified by informants were coded, categorized, and summarized. Frequency distributions were calculated for identified needs in each area and comments and quotes from participants were narratively summarized. Physical and psychosocial needs for neurologically impaired children and informational, emotional, and respite needs for the primary family care providers and families were identified. Findings from this study revealed that living in rural central and western Montana helped as well as hindered these families in meeting the needs of their neurologically impaired children. A major implication from this study is that primary family care providers need additional support from spouses, families, and communities. Further, federal law pertaining to the education of neurologically impaired children can cause major disruptions of family systems; more appropriate strategies to implement this law in rural areas should be developed. Additional research is needed to further describe the needs of families caring for neurologically impaired children, to assess rural nurses' knowledge of these needs, and to determine more appropriate special education services for neurologically impaired children in rural areas.

A DESCRIPTIVE STUDY OF THE HEALTH CARE NEEDS OF
NEUROLOGICALLY IMPAIRED CHILDREN AND FAMILY CARE PROVIDERS
RESIDING IN CENTRAL AND WESTERN MONTANA.

by

Darlene R. S. Gaughan

A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master of Nursing

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Bozeman, Montana

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VITA

Darlene R. S. Gaughan was born April 25, 1953, in Missoula, Montana, the daughter of Francis Swartz. She obtained an Associate of Arts from Miles Community College, Miles City, Montana, in 1977, and her Bachelor of Science in Nursing from Montana State University, Bozeman, Montana, in 1983.

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DRSG

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ABSTRACT

This exploratory study described the physical and psychosocial needs of rural-dwelling neurologically impaired children and their primary family care providers relating to information, emotional support, and respite care for the purpose of building an initial data base. Additionally, it described the primary family care provider's perspective of the overall impact that living in rural Montana has on neurologically impaired children and their families.

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CHAPTER 1

INTRODUCTION

Neurologically impaired children residing in rural Montana have complex health problems. Their families endure difficulties in coping with the long term sequela of their children's illness. They face problems in accessing and utilizing appropriate health care resources.

The incidence of neurologically impaired children in rural central and western Montana is approximately three in every thousand children (Vital Statistics, State of Montana, 1988). According to the Montana Department of Health and Environmental Sciences, in 1987, 673 low birth weight infants were born in Montana. It is estimated that up to 20% of these have some neurological impairment which will result in a lifelong dysfunction or disability. It is estimated that between 10 and 15% of all children have some type of chronic illness or disability (Mack, 1984; Whaley & Wong, 1983; Pless & Douglas, 1971). There are at present no accurate records to indicate the true number of neurologically impaired children in Montana. However, there is reason to believe that the number of neurologically impaired children is underreported. This is due in part to the lack of specific guidelines for reporting, the rural nature of Montana, and limited interaction between various health care providers.

Neurologically impaired children and their primary care providers are faced with a lifetime of disability. Most of these children are cared for in their home setting by a primary family care provider who is usually a parent. These care providers attend to the physical, emotional, social, and economic needs of the impaired children. The care

providers often require help and support from health care professionals in meeting the needs of these neurologically impaired children, including information and education about the neurological impairment conditions. The primary family care providers usually want and need to understand their children's underlying disease processes, disability, and care requirements. Some neurological impairments are common and the information and education about them is readily available. Others, however, are rare and information is limited or nonexistent.

Attitudes about health and illness play a role in the care provided to neurologically impaired children. The physical, psychosocial and educational needs of neurologically impaired children are influenced by the attitudes of their families, parents, siblings, extended families, and communities. These attitudes affect how health care needs are identified and met.

Special problems result when neurologically impaired children reside in rural areas of Montana. Distance and isolation can interfere with the availability and promptness of delivery of services which are required by these children and their families. Available care may be limited because of long distances to medical facilities, requiring extended miles of travel in all types of weather for health care and rehabilitation services.

In addition, it may be difficult for neurologically impaired children to receive the care they need because professional specialty care in neurology is available only in the larger cities of Montana. Currently, Montana has only one pediatric neurologist, based in its capital city. With such limited specialty resources available to these children and their families, home and community based care is particularly important. However, rural community health nursing support is limited. One nurse may provide care to many small communities with hundreds of people. Limited supplies and equipment also hinder efforts to provide adequate health care in rural areas.

The following case study typifies the plight of neurologically impaired children and their families living in Montana.

Sally is 11 years old. She has severe neurological impairments. Her diagnoses include: hyperactivity, moderate retardation, primary microcephaly, and complex seizure activity. Born 11 weeks premature, Sally spent the first two months of life on a ventilator. Her seizure activity was noted soon after birth, as well as a cardiac condition that has resulted in two major corrective surgeries over the past six years. Seizure activity was well controlled by medication up until age 10. At that time, she began having right facial and generalized seizure activity, causing weakness to the right side of her body. Her seizures were characterized by momentary loss of attention and slight myoclonic jerks of her hands. She was sometimes confused and seemed sleepy when having a flurry of seizure activity.

At age 11, Sally was evaluated by a team of specialists from the University of Utah and determined to have generalized type epilepsy. She was placed on two additional anti-convulsive medications in an attempt to achieve some level of seizure control while minimizing lethargy. Because of Sally's hypermetabolism, the anti-convulsive drug dosage that she was given was able to achieve only a sub-therapeutic, non-effective drug level, even though the dose was two to three times the normal therapeutic dosage.

Recently, Sally's seizure activity has increased and her behavior is becoming progressively more uncontrollable. On several occasions she has been unresponsive to the point where she was unable to swallow. She demonstrates a mixture of lethargy and intermittent minor motor seizures with staring spells, eye blinking, drop spells where her legs buckle, and brief myoclonic jerks. Electroencephalogram and CT scans show a definite diffuse change in the brain. Both ventricles and the subarachnoid space

appear to be atrophying. There is no explanation for this atrophy. The result is a slow, progressive atrophic process leading to death.

The present plan of care is only supportive, attempting to balance medications to minimize lethargy and still achieve reasonable seizure control. Sally lives in rural central Montana with her parents and a younger sibling. Her mother is the primary family care provider. Sally's family is economically supported by the father's wages as a blue collar worker. The family has always maintained frequent contact with their family physician and, following Sally's birth, several neurological specialty physicians.

Sally's problems are numerous. She is faced with a physical decline leading to death. Her care needs during this process will increase, placing more and more demands on her family. Physical care needs and requirements for resources, information, respite, and daily care will increase as this family faces the slow progress of their child's disease, finally ending in death.

Problem Statement

Through her work as a pediatric nurse, the author has found that the rural nature of Montana complicates the numerous problems faced by neurologically impaired children and their families, and that these additional problems have not been adequately studied. Neurologically impaired children are faced with long term disabilities over an extended period of time. Physical determinants influence the type and severity of the neurological impairment. In addition to birth trauma such as oxygen deprivation, chromosomal abnormalities including microcephaly and alterations in anatomy and physiology which cause dysmorphic features can be responsible for the underlying disability. The effects of one or more of these determinants is injury to the brain or central nervous system,

resulting in a degree of permanent neurological damage. These impairments result in lifelong disability. The type and severity of the determinant directly correlates with the magnitude of the impairment, and recovery from a neurological impairment is usually minimal.

The physical care of neurologically impaired children is demanding. Treatments, hygiene, administration of medication, safety, and other needs usually become the responsibility of the primary family care provider. Neurologically impaired children and their care providers are faced with disability, chronic illness, prolonged rehabilitation, and a lifetime of adjustment.

Health costs for the care and treatment of neurologically impaired children are staggering to their families and communities. Neurological testing, specialty care, rehabilitation equipment, supplies, and medications contribute to the cost of caring for these children. Distances and travel times caused by the rural nature of Montana also increase costs. In addition, seeking health care is often compounded by weather and other problems such as quality of roads and availability of transportation.

Health care costs, health seeking behaviors, and daily living routines of families and communities are affected by neurologically impaired children. Health care professionals are often unaware of the special needs of neurologically impaired children and their families. Rural patients and families may have great difficulty explaining their added problems and special needs to health care providers.

There is inadequate data about the care requirements of neurologically impaired children and their families who reside in Montana. There is a need to describe the health requirements of these children and their families. To date, there has not been an adequate descriptive study of health care needs from the perspective of primary family care providers. Such a study with specific information about care requirements can assist in providing health care professionals with a clearer understanding of the care needs of neurologically impaired children and their families who reside in rural areas.

Purpose

The purpose of this study is to describe, from the perspective of primary family care providers, the special health care needs of neurologically impaired children and their families who reside in rural central and western Montana.

The specific aims of this study are to: (1) describe, from the primary family care provider's perspective, the physical and psychosocial needs of rural-dwelling neurologically impaired children, (2) describe, from the perspective of the rural-dwelling family care provider, the need for informational, emotional support and respite care for families with neurologically impaired children, and (3) describe, from the primary family care provider's perspective, the overall impact that living in rural Montana has on neurologically impaired children and their families.

This study will contribute to a better understanding of the health care needs of rural-dwelling neurologically impaired children and their families. Specifically, the results will provide information on the nursing care needs of these children and their families. The information gained from this descriptive study will enable health care providers to better understand and meet the health care needs of neurologically impaired children and their primary family care providers. This study will contribute to the understanding of problems faced by rural primary family care providers, as well as the resources which they require in order to care for their neurologically impaired children. The information gained from the study will form a data base on needed public health services for neurologically impaired children in rural Montana.

Operational Definitions

1. Neurologically Impaired Children - For the purpose of this study, a neurologically impaired child is a child between the ages of 3 and 12 years who was diagnosed by the age of 3 as having a disorder of the nervous system as a result of accidental trauma, birth trauma, or genetic disorder. Diagnoses which may result from these etiologies are Downs Syndrome, Cerebral Palsy, and seizure disorders. For

this study the neurologically impaired child will reside in central or western Montana and be a current patient of Dr. M. Guggenheim, Pediatric Neurologist, or have been a patient of St. Peters Community Hospital, Pediatric/Adolescent Unit, between April, 1988, and April, 1990, where neurological specialty care is provided for neurologically impaired children.

2. Family - For the purpose of this study, family is defined as all those persons residing within the same immediate household and related to the neurologically impaired child by blood or marriage (eg. mother, stepfather, grandmother, sibling).
3. Primary Family Care Provider - For the purpose of this study the primary family care provider is the person who, on a daily basis, has the main responsibility for providing the physical and psychosocial care to the neurologically impaired child. This family member will be the person who usually provides treatments, hygiene, medications, safety, and coordination of health care for this child. For the purpose of this study, any primary family care provider who has had formal health care preparation, such as a physician, professional or practical nurse, or physical or respiratory therapist, will be excluded.
4. Health Care Needs - For the purpose of this study, health care needs are defined as the physical and psychosocial needs of the neurologically impaired child, and the emotional, informational, and respite needs of the family, as identified by the primary family care provider in response to structured interview questions.
5. Rural central and western Montana - For the purpose of this study, the area included is that part of Montana lying west of a line running roughly north and south through Cascade County. This includes the counties of Flathead, Missoula, Lewis & Clark, Lincoln, Glacier, Toole, Pondera, Teton, Lake, Sanders, Mineral, Ravalli, Powell, Granite, Deerlodge, Cascade, Jefferson, Silver Bow, Beaverhead, Madison, and Broadwater. Excluded are any areas within a 30 mile radius of a city of 20,000 population or greater.

CHAPTER 2

LITERATURE REVIEW

Background

There are no absolute criteria or specific definitions for a neurologically impaired child. This is because the impairment can be caused by damage to the brain, other parts of the central nervous system, or peripheral nerves. Neurological impairment can result from trauma or genetic disorders. Identifying the special needs of neurologically impaired children and their families was the focus of this literature review. Included were categories related to the neurologically impaired children's needs, the special needs of families caring for neurologically impaired children, and rural health care and nursing.

Neurologically Impaired Children's Needs

D. Jackson (1982) studied sixteen profoundly handicapped children, aged four to fifteen. Developmental levels of these children ranged from one week to thirteen months. Eighty percent of the children were functioning at a level less than three months developmentally, although the average chronological age was seven. Ninety percent suffered from epilepsy. These children showed distress by crying, facial expressions, aggression, and gross motor activity. During a 180 day period only 40 reports of distress were recorded, well below that expected for normal children. The suspected cause of the distress included pain, attention seeking, dislike, post seizure state, being left alone and unknown. Results indicated that impaired, low functioning children appear to react only

to extremes and that at the lowest functioning developmental level, children were never observed to be reactive to their environment.

Dixon's (1983) case study of adrenoleukodystrophy, a genetic inherited disorder, illustrated the physical care required for neurologically impaired children. Motor problems included vision defects, decreased hearing, seizures, and spastic or flaccid limbs. Care was predominantly related to safety measures to prevent injury. Physical therapy was offered for positioning of the often paralyzed limbs, and for insuring proper alignment with flexation of the hands and feet. Treatment was basically supportive.

Darbyshire (1980) indicated that play was essential for all neurologically impaired children to develop to their maximum potential. Nurses used play as a tool to maintain and improve levels of functioning. Appropriate positioning increased normal movement and facilitated play. Toys were placed so the child was encouraged to reach. Water was a good medium for exercise, particularly when suitable toys and activity boards were used to enhance development. Energetic rough-and-tumble play and physical fun was very important to handicapped children. Children who were unable to be involved in active play could be entertained with mobiles or music boxes. In caring for blind or deaf children, the sensation of touching assumed more importance than sight or sound. Severely neurologically impaired children had no understanding of language; the tone of voice was more important than what was being said. Voice variations from loud to soft, whispering and funny or singing voices, facial expressions, gestures, smiles, frowns, and laughing all helped neurologically impaired children to respond.

Leyser (1988), in a study of the education of handicapped children, points out the policy of participation in the federal Education Act For All Handicapped Children of 1975 (Public Law 94-142) requiring parents of exceptional children to be involved in the educational decision making and the planning of these children's special education programs. The basis of this law is the belief that such involvement would benefit these children and would have positive parental outcomes such as reduced stress, increased

family coping, and improved relationships between parents and families of the handicapped children. The research involved 338 parents of handicapped children living in two rural counties. Thirty-three percent of these parents met with their children's educational staff at least once a month. Ten percent of these parents reported having once-a-year contact or no contact at all with teachers or other school professionals. Three possible reasons identified for this low parent participation were the timing of meetings, transportation, and the difficulty in obtaining a baby sitter. Parents who attended school conferences regularly indicated that these contacts provided them with a better grasp and understanding of their children's academic progress. On the other hand, remarks made by parents who maintained limited communication with schools suggested that these experiences did not fulfill their expectations. They were unhappy with the information provided, or they felt left out of the decision making process. These parents expressed concern about their children's future as well as about issues of grading and placement, academic progress, and behavior.

Families Caring for Neurologically Impaired Children

Emotional and Psychosocial

Freitag-Koontz (1988) stated that the birth of infants with severe neurological impairments was devastating to the hopes and expectations of the parents. When the diagnosis of neurological impairment was made, the parents faced the loss of the "idealized" infant they had anticipated. The process of attachment between the parents and children was hindered by the children's limited ability to participate in interactions important to the establishment of strong loving bonds. The primary reaction of the parents to children born with neurological impairments was a grief response, which was defined as the movement through the mourning process to the acceptance of their new role as care providers. Thus, psychological concerns were not only for the neurologically

impaired children, but also for the primary family care providers, families, and communities.

Olshansky (1982) stated that parents proceed through grief at different rates and had different degrees of completion of the grief process. Parents were never completely free of the care and responsibilities for their "less than perfect" child until they or the child died.

P. L. Jackson (1985) described the rage of sorrow and the pervasive nature of grief. Parents of neurologically impaired children continued to hope that the cause of the impairment was transient and would decrease or go away completely. However, when these parents faced the reality of the children's disability and the long term prognosis, they often felt guilt, a sense of failure, or inadequacy and a biological and emotional responsibility for the helpless children, which invaded every facet of their day-to-day living. For families of neurologically impaired children, life revolved around the children's neurological impairments. When neurologically impaired children died, feelings of guilt progressed to grief and life became more normal. However, in families with a surviving neurologically impaired child, chronic grief continued; intensity of sorrow lessened but concern about the future was ever present.

Steinhauer, Mushin, and Rae-Grant (1974) stated, "Faced with the diagnosis of severe and chronic illness, the entire family is confronted with a series of stresses and demands that will tax relationships within and beyond the family unit." The more debilitating the illness and the sooner the prognosis, the greater the stress: Illnesses that were congenital intensified parental feelings of guilt and responsibility. If diagnosis was made at birth, these families never experienced or expected their children to be normal. If the diagnosis was made later in the children's life, the families had time to think of the children as normal and experienced a greater sense of loss and depression.

Steinhauer et al. (1974) studied chronic illness and indicated that the nature of the illness and treatment programs often caused cranky, irritable, unpleasant, or demanding

children. Additionally, they state, "These traits [in the children] will present additional pressures, evoke feelings of resentment, guilt and inadequacy in the parents, especially the mother." Home management and constraints on family life, demanding programs, and restrictions were resented and resisted by the child and family. The children's resistance to necessary treatments resulted in additional work and emotional strain for parents, becoming daily battlegrounds. Resentment and guilt in both parents and child occurred and spread to contaminate whole family relationships. Emotional responses of the family, including denial, anxiety, feelings of guilt, depression, and resentment, were reactions to their disappointment of not having a normal child, and were converted into bitterness directed toward each other, family, friends, physicians, community, or the child himself. "The child may be overtly or covertly rejected" (Steinhauer et al., 1974).

Horner and Rawlins's (1987) study revealed that parents with children who were chronically ill or disabled placed demands on the nursing profession. Deinstitutionalization has increased the number of children with chronic conditions who remain in the primary family. Strass and Munton (1985) studied disabled children; they reported that many young children with multiple physical and cognitive disabilities lived with their families, requiring a "broad spectrum of health service to meet physical and emotional needs." Therefore, health care providers had increasing demands placed on them to help families meet the needs of these children.

A study of societal reactions to physical disabilities by Smith (1971) stressed that the relationship of parents with each other was affected by the birth of a neurologically impaired child. Parenting a neurologically impaired child was much more stressful and complex than parenting a normal child. Couples who openly communicated and freely shared their feelings were better able to cope with this crisis and provide support to each other.

Klug (1968) revealed that families with neurologically impaired children were at risk for developing problems related to stress. The child with the impairment required

more of the parent's attention, energy, and time, so less attention was available for other children. Parents were often faced with social isolation, financial burden, a sense of loss of control, and a lack of confidence in their parenting abilities. The ability to cope with neurologically impaired children depended on the parents' ability to understand their children's developmental abilities and the reactions of families and communities. A study by Steinhauer et al. (1974) reported that the ideal for optimal health and well being was to allow the chronically ill child dependence during acute phases and encourage independence whenever possible.

Garrard and Richmond (1963) indicated that inadequacy and distress in the families of neurologically impaired children could be exacerbated by the presence of other healthy children. Siblings were jealous and resented the child who drew so much of the attention and energy from the parents. Siblings of the neurologically impaired child often appeared to be emotionally deprived. Hostility and resentment, if not outwardly expressed by the siblings and family, were exhibited as underachievement, behavior problems, or disorders. The community also had reactions of shame or embarrassment leading it's citizens to decreased interest and involvement in the family. Alienation and bitterness toward the relatives, family, and friends of the neurologically impaired child sometimes occurred.

Gartner and Riessman (1977) revealed that families of a neurologically impaired child promoted and received support by joining people who shared common problems, discussed feelings, and explored options in learning to cope. Gartner and Riessman stated, "Those who help are helped the most. The more intimate the involvement of the person in the helping process, the greater the positive effect." Halper (1984) also stated "Self-help groups are innovative and therapeutic modalities for individuals of families suffering from chronic illness." Horner and Rawlins's (1987) study reported, "Support groups consisting of other parents with similar needs are another valuable resource. These groups can provide emotional reinforcement as well as a forum for sharing firsthand

experiences and information." Support groups were found to be an invaluable source of help to the primary family care providers and family of the neurologically impaired child.

There was a significant absence of literature on the financial cost of caring for a neurologically impaired child, and when discussed, it was linked to the emotional aspect of care. Freitag-Koontz (1988) indicated that the cost of meeting medical and daily care needs of a neurologically impaired child placed emotional and financial burdens on families. Family financial status was influenced by care responsibilities for the child. Often the birth of a child requiring special care meant that one parent gave up his or her job to care for the infant, resulting in a loss of income for the family unit. Even "good" health care coverage did not cover the cost of the many supplies and services needed by the neurologically impaired child (Freitag-Koontz, 1988).

Informational Needs

Clausen's (1978) study revealed that communication problems existed between families of neurologically impaired children and health care professionals. Communication between families of neurologically impaired children and health care professionals formed a continuum with the family at one end and the health care provider at the other. At times, the communication between health professionals and families was clear and appropriate, however at other times their communication was unclear. Some family members had enough technical understanding to communicate with health care professionals in a meaningful, clear, and concise manner; unfortunately, others were unable to understand given information or did not know how to ask for needed information.

An article by Dean (1982) explained that families lacked knowledge about care of their handicapped child and were often too proud to seek information. Parents needed the ability to express hopes as well as fears. Shanley and Gagliardi (1988) depicted the nursing role as that of liaison between the interdisciplinary team and family members,

keeping lines of communication open for the benefit of the child. Medical reports were interpreted for parents, teachers, family and friends by the nurse. Ritchie and Trotter's (1984) assessment of neurodevelopment in high risk infants indicated that one nursing function was to act as an intermediary by arranging meetings to exchange information between the health care teams involved in providing direct services to the children and the children's families. Awareness by nurse case coordinators of individual health care team members' contributions and the translation of this information to family members was viewed as being important, as was nurses' knowledge of community resources.

Power (1978) stated, "Families often indicate by their questions that they want more information and advice. They are often left to fend for themselves without receiving pertinent information. Families turn to uninformed friends and relatives or read unscientific materials." Health care professionals who looked for cues to the family's response about readiness to accept information were better able to provide relevant information about the child. Gold (1981) indicated that the nurse can be a significant element in dispelling incorrect information about these children's conditions given by well meaning families and friends. It was found that better acceptance of these neurologically impaired children's disabilities by families and friends was achieved if nurses supplied accurate information in an open, sensitive fashion.

Rural Health Care and Nursing

No current literature specifically addressed the health care needs of neurologically impaired children in rural areas. Less specific general information about the health care needs and preferences of rural dwellers, however, was deemed relevant to this study.

Weinert and Long (1987), in an article summarizing ethnographic studies by graduate nursing students, demonstrated that health for rural Montanans was defined as the ability to work or be productive. Ill health was defined as the inability to work. Pain was tolerated if it did not interfere with the ability to work. The cosmetic, comfort, and

life-prolonging aspects of health were rarely viewed as important. These definitions of health and patterns of health seeking were considered to be distinct from those usually found among urban and suburban populations.

Moon and Graybird (1982) found that rural Montana people believed strongly in self-responsibility for health. Health service providers working with rural people were advised to address self-responsibility, rather than providing professional assistance only. Weinert and Long (1987) indicated that self reliance made it difficult for rural persons to seek mental health care; instead, they denied or covered up problems. Lack of trust, unavailability of help, and social stigma prevented rural Montanans from seeking mental health services. Therefore, self help and self reliance were viewed as basic strategies of rural populations for coping with health problems.

Scharff (1987), in a study of rural nursing, found that rural people used informal resources for help and support. Rural health care was community-based with family and friends providing care for each other. Swehla (1986), in a rural health study, found that most long-term health care was provided by friends or relatives rather than nurses or other formal providers. Weinert and Long (1987) reported that formal health care providers supplemented the rural, informal system. Snyder (1981) revealed that rural families with chronically ill members developed networks with other families in similar situations for support, exchange of information, and equipment. If help was sought, it was from trusted sources: the "old doc," family, relatives, or friends. Health care information came from relatives and families with a low reliance on formal sources. Rural families usually did not choose professional providers and formal health care services.

Long and Weinert (1989) indicated that rural Montana people were wary of health care providers who do not know them or their community. "Rural persons prefer a known and trusted, although possibly non-expert health care provider over an unfamiliar specialist or expert." Direct contact from health care professionals was often unwanted and unwelcome. These authors also indicated that distance orientation for rural people in

Montana was unique. A neighbor three miles away was perceived as close. An average of 23 miles was travelled without complaint for emergency care, and 57 miles for routine health care. Deterrents to seeking health care were road conditions, weather, and work demands. Rural ranching and farming occupations did not provide health insurance nor sick days, and health care was sought only when necessary, as in cases of severe accident or injury.

Conceptual Framework

The concept of chronic grief and concepts relating to the ability of families of neurologically impaired children to adapt and cope, have been used to form the conceptual framework for this research. Chronic grief theory involves recurring grief themes, concepts, stages of grief, and patterns in the adaptation and adjustment process of patients and their families when faced with chronic impairments such as the birth of neurologically impaired children. Chronic grief theory indicates that the grief of parents persists beyond the normal period of two or three months and often lasts for the lifetime of a chronically ill child. Intense feelings of shock, guilt, and bitterness never disappear. Parents never fully resolve the complexity of feelings about their children's disabilities and on numerous occasions, intense grief feelings are reawakened. Chronic impairments result in mourning that is cyclic and recurrent. Sorrow becomes the underlying pattern of life. Parents of chronically ill children grieve for the desired normal child, for the loss of a normal relationship with the child, and for the loss of companionship, health, money, energy, sleep, self-esteem, and control of their lives. The grief occurs at birth and/or at diagnosis and recurs at the time of developmental milestones for normal children such as walking and talking, and at the time of normal social milestones such as school entry and graduation. Parents are expected by others to mourn in a time-lined process following the crisis of diagnosis. Chronic grief stages for families of multiple handicapped children are problematic and ambiguous. Frequently there is a lack of delineated stages of grief and a

final stage of resolution. Suppression of sorrow and taking on a heroic, dedicated caretaker role are admired and encouraged by society. The family is expected to invest its energies in physical and psychological caretaking. Our culture provides no rightful place for the delivery of a living child with severe and lasting disabilities or for the recurrent grief of family members.

During disabled children's lifetimes, they require more physical, emotional, and supportive care than other normal children in families. The grief process for parents of a chronically ill child who dies after an extended period of care is intensified because of the long and often difficult course and the increasing amounts of parental energy that have gone into caring for the child.

A positive response by parents accompanying or following chronic grief requires specific kinds of adaptation and adjustment. Positive adaptation can lead the neurologically impaired child and his/her family to healthier states. Adaptation and adjustment for these parents is a three phase process. The first stage is that of initial crisis response. It is characterized by shock, denial, disbelief, and demolition of the expectations of a normal child. The second stage of continued sad feelings and responses entails emotional disorganization where extreme feelings of guilt, anger, and low self esteem are evident. There is decreased interest in the child and the attachment process is complicated and delayed. The third stage is adaptation and adjustment, characterized by the parents' acceptance of the child and the reality of the disability. In addition, there is the parents' acceptance of others' reactions to the disability. Parents need varying time to deal with the issues of each specific stage. Movement from one stage to another is characterized by changing parental reactions.

Nursing care of chronically ill children and their families requires alertness in observing and evaluating changes. For neurologically impaired children, mental and physical conditions, the environment, and relationships with family and community must be assessed and monitored. It is equally important for the nurse to assess the parents' stage

of adaptation. Family adaptation can be facilitated by support from health care professionals. Nurses can promote adaptation by making effective referrals, mobilizing resources as appropriate, and helping to establish goals which actively involve the family. Support services can enhance adaptation and aid primary family care providers in coping with the needs of their neurologically impaired children. These services relate to physical, psychosocial, informational, and respite needs. As problems with needs, adaptation, and coping occur, nursing plays an intercessionary role. Nurses, through use of the nursing process, can assess new impairments, identify service gaps, gather information, and plan and implement interventions collaboratively with the families of neurologically impaired children.

CHAPTER 3

METHODOLOGY

Introduction

This study was an exploratory descriptive survey focused on identifying the special health needs of neurologically impaired children from the perspective of their primary family care provider. The aims of this study were to: (1) describe, from the primary family care provider's perspective, the physical and psychosocial needs of rural-dwelling neurologically impaired children, (2) describe, from the perspective of the rural-dwelling family care provider, the need for information, emotional support and respite care for families with neurologically impaired children, and (3) describe, from the primary family care provider's perspective, the overall impact that living in rural Montana has on neurologically impaired children and their families.

Design

An exploratory, descriptive design was used in order to develop a data base regarding the needs of neurologically impaired children and their families. At the time of the study, these needs had not been adequately addressed through research, and no substantive literature existed with regard to neurologically impaired children residing in rural areas.

Sample

The target population for this study was neurologically impaired children and their families residing in rural areas. A purposive, convenience sample was used. Sample criteria were developed by the investigator in order to maximize subject's ability to describe the special needs of neurologically impaired children and their families.

Study subjects were persons who, on a daily basis, had the primary responsibility for providing physical and psychosocial care for a neurologically impaired child. These informants (termed primary family care providers) were viewed as specialists in their role as care providers. They were believed to be knowledgeable about the needs of neurologically impaired children because of their active involvement in the provision of care. The sample consisted of primary family care providers of neurologically impaired children in Montana who met the following criteria: (1) their neurologically impaired child had a confirmed diagnosis of neurological impairment before the age of three, (2) their child was between the ages of three and twelve years at the time of the study, (3) their child had been served by Dr. M. Guggenheim, pediatric neurologist, or their child had been a patient in the Pediatric/Adolescent unit of St. Peter's Community Hospital in Helena, Montana, with a neurological diagnosis during the time period from April, 1988, to April, 1990, and (4) their family resided in the rural area of Montana designated for the study.

Seventy nine neurologically impaired children met the criteria for inclusion and their primary family care providers were listed as prospective participants. A random number was assigned to each name from a random number table (Nachmias & Nachmias, 1987). The names were ranked numerically and the lowest 30 numbers were selected to be sent study information, including informed consent materials (see Appendix A). Additionally, a follow-up letter was sent 10 days after the original letter to those primary family care providers who had not responded. A response rate of approximately

50 - 75% was anticipated based on norms for response to solicited interview participation among families with health care problems (Woods & Catanzaro, 1988). A total of 14 primary family care providers responded, resulting in a response rate of 47%. The first 12 primary family care providers who responded within 14 days of mailing the letter of consent were included in the sample. This purposive, convenience sample of 12 families was deemed appropriate for this descriptive, exploratory study since the purpose was to develop a beginning data base on the health care needs of neurologically impaired children in rural areas.

Data Collection

Procedure

The first 12 primary family care providers who signed and returned the letter of consent within 14 days of mailing were contacted by the investigator and an interview time was arranged. Other family care providers who responded later were informed that an adequate number of respondents for the study had been achieved, and they were thanked for their interest.

Data were collected using a semi-structured interview format (Appendix B). Personal interviews with primary family care providers of neurologically impaired children were conducted in their homes during the Spring of 1990. An effort was made to conduct the interview at a time and in an area of the home with maximum privacy and minimum distractions.

Interview Guide

The semi structured interview guide was formulated based on the review of literature regarding rural nursing and the physical and psychosocial needs of neurologically impaired children and their families, and on the researcher's experience as a pediatric nurse providing care for neurologically impaired children, primary family care providers of

these children, and their families. A review of the interview guide by nursing experts addressed content validity. Sarah Fox, RN BSN, supervisor of the Pediatric/ Adolescent Unit at St. Peter's Community Hospital in Helena Montana; Jan Donaldson, RN BSN, clinical nurse specialist in neurology; and Joyce Hendricks, RN MSN, instructor of Maternal Child Nursing at Montana State University, College of Nursing, Billings Extended Campus all reviewed the guide. One of the concerns expressed by these experts was the extended length of the guide. This was addressed by decreasing the length of the physical and informational sections to include only questions deemed relevant by all reviewers. A second concern was insuring that the questions included all areas that were relevant to the needs of neurologically impaired children residing in rural Montana. This issue was addressed by revisions of the interview guide so that question selection was based on input from nurses with expertise in rural practice. The final concern raised by reviewers was language usage and the need to ensure that the participants would fully understand the questions. This was addressed by revisions based on suggestions from the expert reviewers.

The categories within the revised interview guide were deemed relevant and comprehensive to the study of health care needs of neurological impaired children and their primary family care providers by the three experienced practitioners. This interview guide was developed because no other tool for acquiring the necessary data was available.

Structured demographic questions about these children's ages, genders, and neurological impairments and about the rural family care providers' relationships to the children, marital status, and ages were included to provide baseline data about the subjects and participants of this study. Questions on the interview guide (see Appendix B) were grouped into physical and psychosocial needs of the neurologically impaired child; informational, emotional, and respite care needs of the primary family care provider and family; and needs specifically related to living in a rural area. If needs were indicated, a rating scale was applied with 1 being not important, 2 important, and 3 very important.

The guide also allowed the researcher to record comments, quotes, and anecdotal notes. The open-ended format of questions allowed for the generation of data. The first section described the physical needs of the neurologically impaired child. The psychosocial section described the social and developmental needs of the child. The informational section investigated the needs and resources of the primary family care provider in caring for the neurologically impaired child. The emotional section of the guide described, from the perspective of the primary family care provider, emotional support needs required for themselves and their families. The respite section described the respite care needs of the primary family care provider. The final section, rural, describes the impact that living in rural Montana has on neurologically impaired children and their families.

Analysis

Descriptive statistics were used to analyze demographic data about the sample. Needs identified by caregivers were coded, categorized, and summarized in relation to each area of interest: physical care needs of the child, psychosocial needs of the child, informational needs of the family, emotional support needs of the family, respite care needs of the family, and special needs related to residing in a rural area. Frequency distributions were calculated for the identified needs in each area. Comments from the participants were narratively summarized by the researcher, including services desired and suggested types of services, as well as additional relevant quotes, comments, and anecdotal notes.

Protection of Human Subjects

Both the Department of Administration of St. Peter's Community Hospital and Dr. M. Guggenheim received a written explanation of the study and a sample consent statement. The same materials were presented to the Bioethics Committee of St. Peter's Community Hospital, which reviewed and approved the study. The research proposal was

also reviewed and approved by the Montana State University College of Nursing, Human Subjects Review Committee.

Primary family care providers whose child met the criteria listed above were contacted by the investigator through a written letter of explanation asking them if they would consider participating in the study. They also received a letter of consent. Those who chose to participate, signed and returned the tear-off portion of the letter of consent to the researcher (See Appendix A for sample). All participation was voluntary. Prospective subjects were assured that subsequent medical and health care for their child would not be affected by either their refusal or consent to participate in the study. Participants were informed that they could refuse to answer any question, or could withdraw from the study at any time without penalty. At the time of interview, each participant again received a verbal explanation of the study and an assurance regarding voluntary participation and confidentiality.

CHAPTER 4

FINDINGS

The purpose of this study was to determine the needs of neurologically impaired children and their primary family care providers residing in rural Montana. This study focused on the physical and psychosocial needs of neurologically impaired children; the informational, emotional, and respite care needs of the primary family care providers; and the impact that living in rural central and western Montana has on the needs of these children and their primary family care providers. Semi-structured interviews with the primary family care providers of neurologically impaired children were conducted to obtain data.

Seventy-nine children in rural central and western Montana met the criteria for inclusion in the study. A random sample of 30 subjects was selected using a random number table. The researcher sent letters of consent to the primary family care providers for these subjects. Fourteen primary family care providers responded, a response rate of 47%, however only 12 interviews were conducted. One respondent could not be reached to set up an interview, despite repeated attempts, and another respondent's letter of consent was not received by the researcher until 14 days after the deadline. These two respondents were sent letters stating that the research interviews had been completed, however they would be considered if any further research was conducted. Of those who responded, 11 met all of the study criteria. The twelfth subject, who was over the age set by the criteria by two months, was included in the study because of the unique opportunity to acquire information about the needs related to this subject's rare degenerative neurological disease. All but one interview were conducted in informants' homes. The

one interview that was not conducted at the informant's home was completed in a location preferred by the informant, a restaurant. The lower than expected response rate in this study may relate to the emotional difficulty associated with recalling the needs of a neurologically impaired child and the burden of having to take additional time out of an already hectic and overloaded schedule to meet with a researcher. Selection bias may be relevant in that families with the greatest burdens of care may have been less likely to participate. This aspect is considered in discussing the study's conclusions. The intent of the study was to establish a data base on a heretofore unstudied population, thus the sample size was deemed appropriate.

The data collected from the 12 interviews was organized in the following manner: Demographic data of the respondents and their children is presented. This is followed by the types and causes of neurological impairments, the physical and psychosocial care needs of children, the services that primary family care providers indicated were needed. The informational, emotional, and respite care needs of the primary family care providers is then presented. Finally, what has been the impact of living in rural Montana on the primary family care providers and their neurologically impaired children is considered.

Demographic Data

The primary family care provider for the neurologically impaired children in this study was usually the mother, however in three families this responsibility was shared by both parents. In these instances, both parents served as respondents. The demographic data relevant to this study is presented in Table 1. Listed are the age and gender of each neurologically impaired child, his or her county of residence and nearest town, the distance to the nearest town with health care, the distance to specialist care, and the age and gender of the primary family care provider(s).

Table 1. Demographic data on children and informants

Respondent number	Child's age/gender	County	Nearest Town	Nearest medical care city and distance	Nearest neurological care specialist	Age of primary family care provider(s)
1	9 / F	Lewis & Clark	Helena	Helena / 30 miles	30 miles	mother - 26
2	4 / F	Toole	Ledger	Conrad / 50 miles	170 miles	mother - 36
3	4 / M	Cascade	Dutton	Great Falls / 36 miles	126 miles	mother - 39, father - 44
4	3 / M	Gallatin	Belgrade	Bozeman / 20 miles	110 miles	mother - 31
5	6 / M	Park	Gardner	Livingston / 55 miles	179 miles	mother - 42
6	8 / M	Missoula	Missoula	Missoula / 28 miles	114 miles	mother - 38
7	11 / M	Park	Livingston	Livingston / 6 miles	110 miles	mother - 37, father - 42
8	6 / F	Flathead	Columbia Falls	Kalispell / 17 miles	197 miles	mother - 32
9	13 / F	Lincoln	Troy	Libby / 18 miles	335 miles	mother - 47
10	2 / M	Gallatin	Belgrade	Belgrade / 3 miles	110 miles	mother - 25
11	11 / F	Beaverhead	Dillon	Dillon / 6 miles	120 miles	mother - 36, father - 38
12	10 / M	Lewis & Clark	Helena	Helena / 16 miles	16 miles	mother - 34

Types of Neurological Impairment

The following are types and definitions of the neurological impairments as reported by the primary family care providers during the interviews:

- Petit mal - a mild form of epileptic attack.
- Cerebral Palsy - an inability to control voluntary muscles due to damage to some portion of the brain.
- Complex seizure disorder - complex abnormal brain waves with severe clinical symptoms and seizure activity.
- Aphasia (motor) - inability to coordinate muscles controlling speech; inability to control saliva.
- Attention disability, learning disability, and hyperactivity - the inability to focus on some phase of consciousness; excessive or above normal activity.
- Tourett's syndrome - abnormal brain waves resulting in tics, abnormal vocalization, decreased saliva control, and decreased concentration.
- Neurofibromatoses - spontaneous mutation of bone structure of the skull.
- Rett's syndrome - characterized in female children as non-ambulatory, non-verbal, having poor circulation, scoliosis, and seizure activity; progressive to death.
- Hypertonia - loss of muscle tone; slowed or loss of mobility.
- Grand mal seizures - epileptic attack with loss of consciousness.
- Mental retardation - mental deficiency with severe IQ of less than 50.
- Developed delay - physical or intellectual growth slowed or not at standard.

Causes of Neurological Impairment

There were various causes for the children's neurological impairments as reported by primary family care providers. One of the neurologically impaired children had cerebral palsy which was reportedly caused by Cytomegalovirus (CMV). One child's Rett's syndrome was the result of an abnormal X chromosome. Another child's Tourett's syndrome was attributed to a genetic disorder. Cerebral palsy in another child was reported by the primary family care provider as being caused by birth trauma or an in-

utero accident. The remaining eight primary family care providers were unable to give specific causes for their children's neurological impairments.

Physical Care Needs of Neurologically Impaired Children

Physical care needs of neurologically impaired children as identified in this study were related to physical growth, treatments, safety, medications, feeding, elimination, skin care, rest, hygiene, immunizations, dental care, vision care, in-home nursing, physical complications, and controlling seizure activity.

Four primary family care providers expressed concern that their neurologically impaired children were below the fortieth percentile in height and weight on standard growth charts. One aspect of all of these children's neurological impairments was their inability to digest food and utilize nutrients well.

Five respondents described specific needs related to treatments for cast and brace care, mobility, and respite services. Safety needs were identified by three respondents. There were needs for safety helmets, child-proof electrical outlets, and door latches. Two of these respondents said that their children were hyperactive and "constantly into everything." They reported being afraid that their children would be injured or would injure themselves.

Medication administration assistance related to seizure prevention was a need indicated by four primary family care providers. One respondent said that a mid-day medication administration was necessary, but personnel at the child's school refused to help. The primary family care provider felt that school cooperation was needed. Another respondent stated that in order to give medications to the hyperactive neurologically impaired child, the primary family care provider and spouse found that on a regular basis is was necessary to "...hold the child down and force feed [the medications]". Two primary family care providers noted that help with diet planning and diet restrictions were needs because of their children's difficulty in digesting any food or absorbing nutrients. One of

these providers stated that, "[The child] eats everything, but does not gain weight." Assistance with chronic constipation and an elimination routine for their children was identified as a need by two respondents. One primary family care provider, whose child had constipation, stated that, "[The child] has chronic constipation... there has to be a better way than an enema every three days."

One respondent, whose child had neurofibromatosis which affects the skin pigmentation, described skin protection as a need for the child and discussed the great care that was given to covering the child's skin from the sun. Obtaining adequate sleep and rest was a need reported for four hyperactive children. The following examples were given by four primary family care providers in relation to this need:

"[We] were told by a psychologist to set limits and make the child sleep in his own bed."

"With the new house, [the child's] sleep hours went from nine per night to six."

"If [the child] doesn't get enough rest, seizures increase."

"After the last surgery [the child] was to sleep on the unaffected side for at least two months. [The child] slept with me during that time while dad slept in her bed. We never got a full night's rest."

Four respondents expressed the need for assistance with checkups for dental and vision care. One primary family care provider said that the child did not have the capability to follow commands, so dentists have to "...put [the child] to sleep to clean his teeth." Another told about recurrent and painful abscessed teeth caused by excessive drooling because the child had motor aphasia, and explained that the child became anxious and hyperactive during dental checkups. Eight primary family care providers noted that their children, who ranged in age from 3 to 12, had never received any dental or vision care. The providers did not see this as a priority; their time and energy was consumed by daily care. One primary family care provider identified needing help measuring the child's ability to hear and see. The child was microcephalic and his vision was undeterminable.

This concerned the parent because the child was also profoundly deaf, and touching him was the only sure way of communicating.

Independent mobility for their children despite physical handicaps was identified as a need by five primary family care providers. One child's physical disabilities included inward rotation of the feet, requiring braces costing \$750 per pair. These needed to be replaced about every six months and the family's insurance did not cover this cost. Another respondent, who's child was in a scoliosis brace, described the pushing, pulling, turning, and lifting required in toileting, providing hygiene, and visiting the doctor. This respondent said, "We invented the car call. It's like a house call, but the doctor comes out to the car to examine [the child] so I don't have to lug [the child] into the office."

Help controlling their children's physical activity level was a need indicated by all primary family care providers. Three primary family care providers said they needed help supporting their children's hypertonia while four respondents needed help controlling their children's spasticity. Measures were needed to reduce their children's hyperactivity. One primary family care provider noted that the more hyperactive the child was, the more likely the child was to have increased seizures. Another primary family care provider indicated that his child's seizures had lasted up to 45 minutes. One primary care provider stated that "[The child] had as many as 42 seizures in 12 hours.... no medication on the market helps." Currently this child was taking an experimental anticonvulsant drug not yet approved by the FDA. "We had to have our Congressman get it for us."

Table 2 summarizes the physical care needs of the neurologically impaired children as reported by their primary family care providers. Listed are the basic physical needs and the percentage of family care providers who indicated they required help in meeting these needs for their children. Table 2 shows that, considered as a group, the family care providers studied were reported as requiring help with every basic physical need for their children except hygiene, grooming, and immunizations. Fifty percent indicated needing help with management of their children's hyperactivity. Additionally, 41% of these

providers were reported as needing help with treatments and mobility. Thirty-three percent of these primary family care providers were cited as needing help with problems related to physical growth, medication administration, adequate sleep, dental and vision care, and spasticity. Finally, 25% of these primary family care providers reported needing help with maintaining safety and with seizure management.

Table 2. Summary of physical needs of neurologically impaired children as reported by family care providers

	family care providers needing help		family care providers not needing help	
	no.	%	no.	%
PHYSICAL CARE				
physical growth	4	33	8	66
treatments	5	41	7	58
safety	3	25	12	75
medications	4	33	8	66
diet or feeding	2	16	10	83
elimination	2	16	10	83
skin	1	8	11	92
sleep	4	33	8	66
hygiene	0	0	12	100
grooming	0	0	12	100
immunization	0	0	12	100
dental/vision	4	33	8	66
in-home nursing	0	0	12	100
COMPLICATIONS				
blind or vision	1	8	11	91
mobility	5	41	7	59
hearing	1	8	11	91
SEIZURE				
hypertonia	3	25	9	75
spasticity	4	33	8	66
hyperactivity	6	50	6	50

Psychosocial Needs of Neurologically Impaired Children

The psychosocial needs of neurologically impaired children in this study were related to playing with other children, getting along with family members, attending school and learning, exercise, behavior, and the ability to express wants or needs to others.

Three primary family care providers indicated that having their children be accepted by other children was an important need. One parent stated that "[The child] does not play with other children because, they make fun of him [because of his tics]." Instead, the child spends play time with siblings, parents, or grandparents. Another care provider indicated wanting other children to accept and play with the child. Instead, "They tease him and make fun of him."

Two respondents told about their children's problems getting along with other family members and also expressed a need for help with their children's behavior in public. The parent of a child with Rett's syndrome described how her child had, when younger, frequently lost control in public. The child had uncontrollable seizures, bit, and exhibited other wild physical behavior. Another primary family care provider described how the child with cerebral palsy had a fear of any stranger, and would often cry and hide behind the parent when approached in public.

Three primary family care providers voiced concerns about acquiring appropriate special education for their children's learning needs. One care provider, whose child had neurofibromatosis, stated that "...up to 50% of all children with neurofibromatosis have learning disabilities." She was very concerned about the child's learning ability since the child was to start school in two months. All of the children in this study who attended school were either reported to be in a self-contained classroom or special education classes for the majority of each school day. "Mainstreaming" in school was done only for lunch, recess, and in some cases for physical education. Two of the informants disclosed that home schooling or tutoring was continued by the care providers during the summer so the child did not "lose ground" during these months. One family care provider wished that the child would go to school all year round because, "...I just need the break."

Providing safe and appropriate exercise despite the neurologically impaired children's physical and cognitive limitations was a need expressed by four of the respondents. The majority of occupational and physical therapy treatments were done by

family care providers themselves in order to prevent contractures which could cause deformity and immobility. Additionally, two care providers said that in conjunction with their efforts, occupational therapists also came to their homes to assist.

Three care providers said that providing physical comfort to their children was a special need. Touching, holding, and reassuring the children helped these children to relax and regain control. The care provider of the child with Tourett's syndrome stated, "...holding [the child] does not quiet the tics but it comforts [the child]." One child with cerebral palsy was hyperactive and was very busy climbing on chairs and running in the house during the first part of the interview. This child was quieted by sitting in the care provider's lap and soon fell asleep for the remainder of the interview.

Two primary care providers indicated a need to better understand their children's ways of communicating which included using sounds or gestures. However, another respondent whose child was age 11 and profoundly neurologically impaired, stated, "I know every want by now." A fourth care provider's child was nonvocal, and the child was reported to touch or point to what was wanted.

Identifying possible options for the children's futures was a need expressed by seven of the twelve participants. Informants became tearful when asked about what would happen to their children in the future, and some of their responses were:

"We don't know..."

"...live minute by minute."

"...unsure, we take it one day at a time... can't see past that."

"We hope for new technology to help."

"We just get along day by day."

Four of these care providers talked about the long term future of their children. One commented on the need for "a good group home or an autistic school." Another expressed uncertainty by saying "We are unsure if [the child] will be able to get married, take care of herself or have children. We don't know if she can drive, have a career, or if

she will pass this [seizures] along to her children". A third parent stated, "I hope to outlive [the child] because I don't know who will take care of her." A fourth expressed the realization about the child's neurological impairment and said, "This is for life."

When the researcher asked the primary family care providers about additional possible psychosocial needs, one indicated clearly that family support was very important and that she would go to family members for help before seeking help from a doctor. The respondent also said that her child, who was profoundly impaired and had complex medical problems, had not seen a doctor in over a year.

Table 3 summarizes the psychosocial needs of the children in the study as seen by their primary care providers. Listed are the psychosocial needs and the percentages of family care providers who needed help in meeting these needs for their children. Table 3 shows that, taken as a group, the primary family care providers studied were reported as needing help with every psychosocial need listed. Fifty-eight percent of the primary family care providers noted needing assistance in planning for their children's futures. Additionally, 33% were cited as needing help with exercise. Twenty-five percent of these providers reported needing help with their children's play and comfort needs. Finally, despite all the spontaneous comments that were made by the care providers relating to their children's education, only one respondent specifically identified needing help with school and learning needs when questioned in the formal interview process.

Table 3. Summary of psychosocial needs of neurologically impaired children as reported by family care providers

	family care providers needing help		family care providers not needing help	
	no.	%	no.	%
PSYCHOSOCIAL				
play	3	25	9	75
getting along with family	2	16	10	84
behavior in public	2	16	10	84
school/learning	1	8	11	92
exercise	4	33	8	67
comfort	3	25	9	75
verbalization	2	16	10	84
future	7	58	5	42

Informational Needs of the Primary Family Care Provider

Family care providers expressed a need for more information in relation to their children's illnesses and disabilities, management of their children's conditions, therapy techniques, care available from specialists, communication with health care providers, community resources, and out-of-home placements.

Five primary family care providers said that they did not have a clear understanding of their children's neurological impairments. Six stated that they needed help in obtaining reading materials about their children's conditions. Four family care providers reported that obtaining more information about their children's neurological impairments was a need. Eight of the twelve respondents stated that they had obtained most information about their children's condition on their own. In order to keep current on conditions, treatments, and therapies for their children, four of these families were members of national neurological associations; two belonged to the National Epilepsy Foundation, one belonged to the National Tourett's Association, and another to the Rett's Association. All of these providers revealed that they had researched every accessible informational source. Three care providers stated that they were "experts" about their children's neurological impairments and often knew "more than the doctors." One family

care provider had been writing to the National Epilepsy Foundation and receiving pamphlets on her child's condition for years and had distributed them to the local doctors' offices and the local hospital in order to "help other people." The one pediatric neurologist in Montana was mentioned by all the primary family care providers. They expressed appreciation for this individual's willingness to share information relating to their children's conditions.

Confirmation of a diagnosis for their children was a need discussed by seven family care providers. These respondents also wanted help solving problems of daily living that their neurologically impaired children had, and help obtaining appropriate medication and medical treatments. These care providers reported numerous visits to local physicians seeking help, but they felt they had not received appropriate information or assistance. After repeated attempts at problem resolution with local doctors and frustration with unanswered questions, several care providers had their children referred to large medical facilities. One family was referred to Los Angeles while another was referred to Denver three times, and then on to Baltimore. All respondents felt they had been treated poorly at these large medical centers and felt that medical residents "practiced" on their children. One family care provider said that he felt that he was "...being jerked around a lot..." that questions were never answered, and the child "...never saw a doctor in three days, and they did \$9,000 of tests." One care provider was discouraged by the lack of personal care at the large hospitals and wanted answers to questions, but never got any. Finally the care provider returned home, saying, "We had enough, packed our bags, and left."

Training for care providers by occupational therapists and physical therapists, habilitation and in-home management techniques was a need identified by seven primary family care providers. These needs were for hands-on, structured lessons with their neurologically impaired children in speech and occupational therapy, diet instruction, general habilitation, and sign language.

Six respondents indicated that having locally based pediatric neurologists, nurses, laboratory technicians, and general practitioners trained in neurology was a need. One family had moved from their rural home to a larger city to be closer to medical care because their child had seizures daily and many medical emergencies. This same care provider reported no longer taking the information received from physicians, nurses, or laboratory technicians as "gospel" because of all the misinformation, bad advice, and bad experiences in the past. This family care provider also stated that when the child had medical emergencies, the care provider was the one who took control of the emergency care given to the child and also stated, "We [the parents] tell them what to do." Additionally, he described two separate incidents where the child was having a seizure and was mistakenly thought to be having a cardiac arrest, resulting in unnecessary and dangerous chest massage and defibrillation.

Communication with and getting questions answered by health care professionals was a need indicated by four primary family care providers. One respondent often did not get direct answers when asking specific questions and was "...used to getting the run around." Another care provider told about the extensive miles travelled for doctors' appointments, often without getting questions answered. The respondent stated, "We have had such bad luck.... All we really want is straight answers." A third family care provider stated, "If they tell you to do something and after a few days it doesn't work go back and tell them and get another thing to do. You have to be persistent." Most respondents indicated that, once a diagnosis was made, a primary physician established, and a pediatric neurologist consulted, getting answers to questions was much easier. However, this process often took many years and a great deal of parental effort.

When asked about any other informational needs related to the child's care, one respondent reported frustration with the child's primary physician. This care provider was angry that there had not been a confirmed diagnosis and that the child had not been referred to a specialist. The care provider became frustrated and, without referral, sought

out and was seen by the only pediatric neurologist in the state. Another care provider was very dissatisfied with the care that the child had received from the local physician. This physician reportedly had not provided the desired information. One care provider said that the school system would not provide special training for the teachers who instructed neurologically impaired children. In order to correct this, this family care provider had actually paid the tuition for the child's special education teachers to attend a series of workshops on neurologically impaired children.

Community resources to assist with financial needs, respite care, and emotional support for the family were needs identified by four primary family care providers. Two informants discussed their association with statewide support groups for the families of children with a specific neurological impairment. Others indicated that there were few or no support groups for parents of neurologically impaired children in their small communities. Local family service outreach programs, respite, day care, and medical supplies were seen as valuable but often unavailable to the primary family care providers. One respondent recounted the community's support with the financial burden of the child's last surgery. A fund raising function was held to help cover the costs. Another family care provider and spouse discussed seeking legal counsel from the Montana Advocacy Program in order to force the local school system to provide the necessary educational services to which their child was entitled by law. This was seen as partially successful because the school district put the child into special education, but failed to provide a teacher that understood the child's special educational needs.

Only one of the primary family care providers discussed the need for out-of-home placement for their child who was profoundly neurologically impaired, severely mentally retarded, non-ambulatory, non-visual, and non-vocal. As the child grew older and larger, providing physical care became increasingly more difficult. The care provider discussed a growing concern for the diminishing ability to care for the child and the need for a good long term out-of-home placement. This care provider stated that finding group homes was

very difficult and that often a child's name was on the waiting list for "years and years" before placement.

Table 4 summarizes the informational needs of primary family care providers in relation to caring for their neurologically impaired children. Listed are the informational needs and the percentages of respondents stating that they desired or did not desire help with these needs. Table 4 shows that the primary family care providers studied, as a group, reported needing help with all of the informational needs listed. Fifty-eight percent indicated needing help managing their children's care and obtaining in-home therapy. Additionally, 50% of these care providers needed reading material on their children's disabilities and help obtaining specialty care. Forty-one percent of these care providers cited needing help with understanding their children's disabilities. Finally, 33% of these primary family care providers reported needing help with understanding their children's illnesses, communication, and obtaining community resources.

Table 4. Summary of informational needs of the primary family care provider

	family care providers needing help		family care providers not needing help	
	no.	%	no.	%
INFORMATIONAL				
understanding illness	4	33	8	67
understanding disability	5	41	7	59
reading material	6	50	6	50
managing care	7	58	5	42
in-home therapy	7	58	5	42
specialty care	6	50	6	50
communication	4	33	8	67
questions	1	8	11	92
community resources	4	33	8	67
placement	1	8	11	92

Emotional Needs of the Primary Family Care Provider

Emotional needs of the primary family care providers that were identified in this study related to needing help with their marital relationships; communication; time

constraints; effects on the family system; energy and money implications; hostility or resentment; extended family and community relations; and feelings of grief, loss, guilt, and hope. Issues related to individual or family counseling were also discussed by informants.

Four primary care providers said that after the birth of their neurologically impaired children, dealing with feelings of isolation from their marital partners was a special concern. One care provider identified that communication and intimacy between herself and her spouse "...were not so good." Another respondent stated that "[Her spouse] worked long hours so he wouldn't have to deal with us [sibling, child, and wife]." Another respondent stated that she "felt sorry" for her husband because he did not have a normal son, and that was why she handled all care for the child. One care provider indicated that the child had "caused strain" in the marriage and family. Another respondent and spouse described themselves as "a working couple..there's no romance." indicating that all of their time and energy was spent caring for the neurologically impaired child, and there was no time for each other. Only one care provider, whose neurologically impaired child had petit mal seizures, a less severe neurological impairment, said there was no change in their marital relationship after the child was born.

Five family care providers expressed a need for help communicating with their partners, families, friends, and communities about their children. One care provider was grateful for the many ways the spouse helped care for the child. Another respondent expressed hurt that her in-laws were more accepting of the child than her own parents, who had asked, "He won't have fits, will he?" "It's the same baby as yesterday..." one respondent said when referring to the child, indicating that the neurological impairment was not important and did not make her love the child less. Communication with others, spiritual resources, and support from families and church were cited as the most helpful coping techniques for several of the primary family care providers.

Seven of the primary family care providers indicated a need for help with feelings of drained energy and time. For one care provider who worked three days a week,

arranging for the child's day care was mentioned as a serious problem. Another working care provider said that she was often tired and the responsibilities of the neurologically impaired child, her full time job, spouse, a new six week old baby and the constant stress "wears me down." One family care provider expressed concern that the neurologically impaired child would "always be a baby," with constant infantile needs that drained the family. Several other primary family care providers stated that they were helped by their spouses, parents, grandparents, churches, and communities, and that if they had not received this support, the drain would have been much worse.

Six primary family care providers stated that promoting independence in their children was a special problem. One respondent admitted to "hovering" and indicated that the child's therapist pushed the child toward independence more than she did. The parent stated, "I watch too close," and told the child, "don't fall," and "wear your helmet." This care provider was very anxious when the child took adaptive swim lessons and enrolled in a dance class. Two care providers explained that promoting independence was something they never did. They said they felt no need to, because the children would never get better or progress, only deteriorate, and eventually die.

Eight respondents discussed their children's effects on the family system. One family care provider said that their neurologically impaired child "runs the whole family" and that the child's needs were always first. Family projects, outings, or vacations were often delayed or cancelled in order to meet the neurologically impaired child's needs. All primary family care providers indicated that the needs of siblings and parents always came second to those of the neurologically impaired children. One respondent discussed feelings of confinement, lack of freedom, and limited choices stating, "We don't go out." and "We never leave [the child] alone."

Nine primary family care providers revealed that time, energy, and money taken away from the family in order to care for the neurologically impaired children was a major concern. Caring for a neurologically impaired child was reported to be very expensive and

one informant stated, "We have big bills [for medication and emergency services]."

Another told of two separate incidents where the child had grand mal seizures that could not be stopped and was flown by air ambulance to Great Falls. Insurance did not cover these costs. Another respondent explained that the family had health insurance, but the insurance company considered the neurologically impaired child's condition pre-existing, and would not cover any of the surgical care. This family care provider had calculated it would take \$600 every month for 30 years in order to pay for the child's current surgical and medical bills. Two care providers said they were lucky to have insurance that covered their children's medical costs. Three respondents indicated that they had received financial assistance from medical services or medical waivers and that this had been very helpful to them.

Only three primary family care providers said that coping with hostility or resentment was an issue for them. They noted however, that their neurologically impaired children had changed their lives, had confined their life style, added stress, and caused money problems and that they were angry about this. One respondent was frustrated by the way other children and adults treated the child, usually reacting by staring and laughing. Two participants said that they couldn't be angry at their child because it "wasn't [the child's] fault." Another respondent said, referring to the child's disease, "...it's so rare... it's not her fault."

Three primary family care providers expressed a need for help in dealing with their feelings about family and community reactions to their children. One informant stated having "big resentments" about the way others reacted to the child. Another respondent said that when the child was in foot braces, people would ask who had hurt the child, and one person was told by a stranger that the primary family care provider shouldn't "cause child abuse." One respondent, who's child had a speech impairment, recounted how people would ask the child to repeat words over and over and finally give up and walk away in disgust. One informant expressed concern about the child's inability to learn and

his hyperactivity and emotional ups and downs. This same informant said, "[The child] appears so normal... I feel bad for all the things [the child] will have to go through."

Another respondent and spouse told about how uncooperative the school system was in meeting the special needs of their child and how they obtained assistance from an advocate in the Office of Public Instruction after the school principal told them that the child was "only acting out." Another care provider explained that people were curious about the child's looks, would stare, and were afraid to touch or talk to him. In the past this bothered the care provider, but she said that over the years she had grown accustomed to it. Two participants acknowledged support they had received from community and church and expressed gratitude for this. These respondents described their children as "special."

Finding and attending appropriate counseling was a need expressed by three primary family care providers. One respondent, based on the recommendations made by the school system, had sent the child to psychotherapy. The child spent "useless months" in therapy without any change in behavior or help in confirming a diagnosis. A family care provider reported seeing a counselor on a regular basis, and had started counseling because of a 60 pound weight gain. This was attributed to the stress of not knowing what would happen to the child and the lack of spousal support. A family care provider reported seeing a counselor for six sessions. This was during a time when the care provider had a feeling of providing all physical and emotional support to the family and believed she was "taking care of everyone." This care provider's spouse was present at the final counseling session and the counselor reportedly had helped the spouse understand the provider's needs. The respondent indicated that since that time "things have been better." Finally, two respondents stated that they had not sought counseling and did not feel a need for it.

Four primary family care providers related that help in dealing with their feelings about extended family and community response to their children was a need. One of

these described her in-laws as "...so stupid. They're on some religious kick and want to do faith healing on my child. I won't let [the child] stay with them."

Dealing with grief or prolonged loss was a need expressed by all of the primary family care providers. One said that "it was such a loss [when she realized the child was not normal], but I'm better now." Another respondent stated that there was a lot of guilt and grief until another normal child was born in the family. One respondent said there was a need to maintain strength and therefore the spouse had denied any loss related to having a neurologically impaired child. Three primary family care providers stated that they felt that their lives were being controlled by their children's needs. For example, one indicated that she and her spouse would "...never be able to build our home because of the medical bills."

Dealing with guilt was an issue noted by only one informant, and this was directly related to a time when her physician suggested that she might have done something during her pregnancy to cause the neurological impairment. The respondent stated she had gone over every detail of the pregnancy again and again trying to think about what could have caused the child's impairments. The respondent said, "I can't think about [the child] before I go to sleep at night or I have nightmares."

Feelings of joy or hope were noted by all but two primary family care providers. Parental comments about the joy and hope for their neurologically impaired children are as follows:

"He is so normal in so many ways, it's hard to see the disability."

"My child is a challenge."

"There was such a relief after the genetic tests were done and I knew our next child would be O.K."

"There is no one to blame."

"... very hopeful."

"It's the way it is, and life goes on."

Table 5 summarizes the emotional care needs of primary family care providers. Listed are the emotional needs and the percentages of respondents stating that they needed help or did not need help with these needs. Table 5 shows that the primary family care providers studied, as a group, reported needing help with every emotional need listed except counseling. Seventy-five percent needed help with the drain of money and time related to caring for the child, and 66% stated they needed help with emotions in the family system. Additionally, 58% needed help managing the drain of energy relate to caring for the child. and 50% noted needing help with gaining and maintaining independence from the child. Forty-one percent needed help with communication with spouse, family, and community about the child, and 33% cited needing help with feelings about their partner in relation to dealing with the neurologically impaired child. Finally, 25% of these primary family care providers reported needing help managing hostility from family and community, community reaction, and control of their emotions.

Table 5. Summary of emotional needs of the primary family care provider

	family care providers needing help		family care providers not needing help	
	no.	%	no.	%
EMOTIONAL				
feelings about partner	4	33	8	67
communication	5	41	5	41
drain of energy	7	58	5	42
independence	6	50	6	50
family system	8	66	4	44
drain of money and time	9	75	3	25
hostility	3	25	9	75
community reaction	3	25	9	75
counseling	0	0	12	100
grief and loss	12	100	0	0
control	3	25	9	75
guilt	1	8	11	92
joy	2	16	10	84

Respite Needs of the Primary Family Care Providers

The respite needs of the primary family care providers in this study were related to desiring "breaks" from their children, a person to come into the home to help, child care while at work or for leisure time, support groups, money for child care, and/or obtaining money to cover medical costs.

Three primary family care providers revealed needing a "break" from caring for their neurologically impaired children. One respondent indicated knowing it was time for a break when her husband told her she was "crabby." Another participant said she "always needed a break" from the neurologically impaired child, indicating that the responsibility was often too much. Another primary family care provider said that for the first time in six years the family was able to take a vacation. This would be during the time that the child was in the Shriner's Hospital having surgery. The primary family care provider for a child with Tourett's Syndrome related that for the first time in many years, the couple was able to join a square dance group. One respondent felt that she and her husband were no different than any other family; they needed a "break from the kids."

Two informants explained that finding someone who could be trusted to come into the household to help was a serious problem. One of these families was being provided with services available from a family outreach program. Their child was hyperactive and had multiple seizures daily. The primary family care provider's main concern was having someone that was knowledgeable about neurological impairments and was willing to care for the child. Informants who had respite support available stated that these respite workers, whether they were trained volunteers, grandparents, a brother or sister, or neighbors, were "godsend." One respondent who was receiving respite services from a family outreach program said that through this service, two local families provided overnight respite twice and three evening "time outs" each month. One participant's neurologically impaired child was to attend school in the fall. She saw child care as a need because she planned to return to work and needed safe after-school care for the child.

Another care provider reported that the neurologically impaired child was taken to day care or a private baby sitter. Four respondents noted that there was little leisure time with the responsibilities of caring for their children, and finding child care to allow for leisure time away from the children was a major need. In general, persons reported to be used as baby sitters were siblings, grandparents, families, and respite workers.

Three primary family care providers indicated that having someone to come in and help with household chores would be very helpful. However all three stated that lack of money was a main reason they did not have this help. In contrast, two informants stated that they did not want anyone to come in to clean their house. They felt that it was an invasion of their privacy.

One respondent indicated that finding and attending a support group was a need. However, eight other participants reported that they disliked support groups and that attending a support group "...would be admitting that something was wrong." Travel time to and from support groups was a problem for two care providers. Both had a one and one half hour commute each way to attend the closest available support group. Two others reported they knew of no support groups for primary family care providers of neurologically impaired children. One participant had attended a support group twice, but "...everyone was so negative and depressed" that the care provider didn't go back because of feeling worse after going than before the respondent went.

Money to help with the cost of caring for the children was a need reported by four of the twelve primary family care providers. Several informants indicated that medications and personal care items like diapers were very expensive. One respondent stated to having "learned the system well" in order to maximize the financial support available for the child's needs. Four care providers noted that medical insurance coverage was a need. Two of these had children who were not covered by medical insurance because of the designation of pre-existing conditions. Three families had some coverage for their children, but the coverage did not include anything associated with the neurological

impairment. One care provider talked about insurance claims being rejected and the ongoing battles with the insurance provider over getting these paid. Two providers had children who qualified for help from the Shriners organization, two had Medicaid waivers, and two had insurance that covered the medical care costs for their children. One participant said, "We took out insurance before the child was born, and it was the best move we ever made," indicating that most of the child's medical care costs were covered by insurance. A respondent said, "I make good money and we have insurance, but it doesn't help with travel or lodging costs when we have to go to see a specialist in Denver or Helena."

Table 6 summarizes the respite care needs of the primary family care providers in caring for their neurologically impaired children. Listed are the respite needs and the percentages of respondents needing and not needing help with these needs. Table 6 shows that the primary family care providers studied, as a group, were reported as needing help with every respite care need. Thirty-three percent cited needing help with child care for their leisure activity, money for respite care, and adequate medical coverage for the child. Twenty-five percent of these care providers reported needing a "break" from the child.

Table 6. Summary of respite needs of the primary family care provider

	family care providers needing help		family care providers not needing help	
	no.	%	no.	%
RESPITE				
break	3	25	9	75
household help	2	16	10	84
child care for work	1	8	11	92
child care for leisure	4	33	8	67
support group	1	8	11	92
money	4	33	8	67
medical coverage	4	33	8	67

Impact Of Rural Area On The Neurologically Impaired Child
and Primary Family Care Providers

The interviews specifically addressed the impact of living in a rural area on obtaining health care, obtaining support in the community, and obtaining emergency medical care. Informants were asked to identify the ways that living in Montana had helped or hindered them in caring for their neurologically impaired children.

Obtaining health care locally was reported as a problem for only one primary family care provider. This respondent lived over 50 miles away from the nearest town on a gravel road. The town had only one doctor and a county public health nurse who provided care to the individuals within 50 miles. Three other care providers said that obtaining money from any source to care for their neurologically impaired children was a problem, and indicated that travel money and better insurance were needs. Greater emotional support from family friends and community in the rural setting was a need expressed by three primary family care providers.

None of the primary family care providers indicated that travel to emergency care was a problem. However, one informant said that travel to the family doctor was a problem and it was cumbersome transporting the non-ambulatory children who was in foot and spine braces. Travel to the neurology specialist was reported as a problem for three primary family care providers. They often missed a day of work and the travelling was tiresome. They commented, "It's a long day" and "...takes a whole day away from work."

When asked about how living in rural Montana may have hindered care for their neurologically impaired children, primary family care providers had the following comments:

"...less specialist care, less technology."

"Doctors won't tell you what's going on or won't refer you."

"Specialty care is far away."

"The cost of travel is a problem."

"It takes six weeks to get an appointment with a specialist."

"If we were in a bigger place [my child] may have been diagnosed sooner. If we were in a bigger place we might have more information."

"If it was a bigger school system [the child] might have more opportunities and less problems with school."

When primary family care providers were asked how they thought living in rural Montana may have helped their neurologically impaired children they responded with the following comments,

"In rural areas there are a few good people who care and help."

"The relaxed lifestyle helps."

"There are friends, church, and community to help."

"...treated well."

"...socially helped. People are more accepting."

"...no difference on rural health care."

"People get to know the child. Family support and the rural lifestyle helps."

Table 7 summarizes the specific needs of the primary family care provider in relation to the rural area in which they live. Listed are the rural needs and the percentages of respondents reporting they have or do not have these needs. Table 7 shows that primary family care providers studied, as a group, reported needing help with all the listed rural needs except emergency travel. In particular, thirty-three percent of the primary family care providers were reported as needing help in obtaining health care.

Table 7. Summary of the impact of rural residence on the neurologically impaired child and the primary family care provider

	family care providers needing help		family care providers not needing help	
	no.	%	no.	%
RURAL ISSUE				
obtain health care	4	33	8	66
obtain "support"	3	24	4	33
emergency travel	0	0	5	42
travel to family doctor	1	8	5	42
travel to specialist	3	24	5	42

In summary, there were many specific needs expressed by the primary family care providers. The following areas were mentioned by 40% or more of the respondents: treatments, mobility, hyperactivity, the child's future, understanding of the disability, reading material about the diagnosis, managing care, in-home therapy, specialty care, communication, energy, independence, family systems functioning, drain of money and time, and dealing with grief and loss. Needs in relation to rural residence were specifically for help in obtaining health care, particularly travel for specialist care.

CHAPTER 5

CONCLUSIONS AND IMPLICATIONS

Conclusions

Review of the literature pertaining to neurologically impaired children revealed that these children had many needs which affected all aspects of their care. This study examined the health care needs of neurologically impaired children in rural central and western Montana. The study focused on the responses given by primary family care providers who, on a daily basis, provided care for neurologically impaired children. The research described the primary family care providers' perceptions of the physical and psychosocial needs of their children and their own informational, emotional, and respite needs related to providing care. This study also looked at the effects that living in rural Montana had on the health care needs and resources of neurologically impaired children and their primary family care providers. No studies were found which specifically examined the relationship of these needs to rural residence. This chapter summarizes the findings and also discusses the implications and recommendations for future research.

Neurologically impaired children and primary family care providers have multiple needs. The data obtained in this study demonstrate the magnitude of the needs faced daily by these children and their care providers. As reported by the primary family care providers, neurologically impaired children have physical disabilities requiring complex care. The care providers expressed a need for increased physical, occupational, and habilitation services for their children. However, all 12 of the family care providers in the study expressed a strong mistrust of the medical community based on past experiences. Several stated that they refused to seek care from physicians or other formal providers

until absolutely necessary. These family care providers reported frustration with their local physicians because of the physicians' inability to diagnose their children's conditions and refusal to refer the children for special assessment or treatment. Additional dissatisfaction was expressed by family care providers when their children had been referred to large urban medical centers, often at great distances from the family's home. Due to the children's impairments, transporting these children including the use of adaptive equipment for health status assessments and treatments was reported as very cumbersome. Such things as routine dental checkups were often impossible without the use of general anesthesia. The primary family care providers felt that their children were not seen as people, but rather as "diseases" or "numbers" at many health care facilities.

The major physical needs of neurologically impaired children as seen by the care providers were for maintenance of exercise, play, and learning. Darbyshire (1980) indicated that play was essential in order for developmentally delayed children to obtain their maximum potential. Exercise for neurologically impaired children requires special considerations including safety, special equipment, and supervision. Neurologically impaired children often do not have the social, physical, and/or intellectual skills needed to be able to play with other children in a normal manner.

Primary care providers discussed the major psychosocial needs of their neurologically impaired children in relation to school and learning. These children have learning disabilities which require special provisions for basic education. Current Federal law (Public Law 94-142), as discussed in Leyser's (1988) study on the education of handicapped children, requires that neurologically impaired children be educated in the least restrictive environment. To comply with this law, many rural families endure adverse effects such as relocation, long distance commuting, changing jobs, or selling family farms. Moving and commuting were sacrifices endured by the families studied and the family care providers reported feeling discouraged and disappointed with the law because they felt it forced them to give up their homes and communities, and because school systems were

often unsympathetic and uncooperative in meeting these children's and families' needs. Two families in this study were forced to move closer to urban schools because special education was not provided at their rural schools. Another care provider commuted 100 miles each day with the child because it was felt that the bus attendant would not give the child adequate supervision for the two hours needed on the school bus each day. Finally, family care providers felt there was inadequate equipment and inadequate funding overall to meet the requirements of neurologically impaired children and inadequate training of school personnel in relation to understanding and meeting neurologically impaired children's special needs.

The primary family care providers also expressed their needs for help in administering treatments, maintaining mobility, giving medications, and controlling activity for their neurologically impaired children. These expressed needs support Dixon's (1983) case study on the physical care requirements of neurologically impaired children.

The family care providers stated they may at times have incorrect, inaccurate, or outdated information or training related to the physical and psychosocial needs of their children. Thus, the care providers studied vary in their abilities to adapt to the chronic nature of their children's impairments. Primary family care providers reported a need for more accessible and understandable information. All family care providers reported having obtained information on their own about their children's neurological impairments. They had requested much of this information from university libraries or from specific national disease foundations or associations. Several admitted that they did not understand all of the information, while others considered themselves experts on their children's disease processes.

The care providers expressed their emotional needs relating to caring for their neurologically impaired children. Responses from family care providers to questions about emotional needs indicated that the major need was for more support from spouses. Respondents saw more and better communication with families, friends, and communities

as the second major need. Steinhauer et al. (1974), Klug (1968), Smith (1971), and Garrard and Richmond (1963) all discussed the emotional problems that families of neurologically impaired children were at risk for developing. The data collected from this research supports the writing of these authors. The providers studied reported feeling drained of energy and having no time for themselves while caring for their neurologically impaired children. Worries about insufficient money, poor insurance, high medication costs, and inadequate medical care placed additional emotional burdens on these families. Neurologically impaired children were described as affecting the whole family system because they made significant demands on the family care provider, spouse, siblings, grandparents, and community.

Most respondents discussed the chronic nature of their children's conditions. The majority of family care providers agreed that planning for their children's futures was a major emotional need. P. L. Jackson (1985) described the rage of sorrow and the pervasive nature of grief for parents of neurologically impaired children and explained how the long term prognosis evoked feelings of grief, guilt, and failure and an ever-present concern about the child's future. Most respondents cried and became upset when asked about their children's futures and each expressed uncertainty about this aspect. Although they were at different stages in the chronic grief process, dealing with grief and prolonged loss was a need expressed by all parents. The primary family care providers were all dealing with special emotional needs related to caring for their neurologically impaired children.

This study's conceptual framework of chronic grief, adaptation, and coping for families of neurologically impaired children is supported in the findings. However, despite the clear presence of chronic grief, only three of the twelve family care providers identified a need for professional counseling or other formal emotional support measures. Four family care providers specifically stated that they had no need for professional counseling services and would turn to friends or family instead for emotional support.

Weinert and Long (1987) and Snyder (1981) have found that health care assistance and information for rural Montanans comes from relatives or family members rather than professional sources.

Family care providers expressed the need for respite care and support groups. Most care providers stated that they did not get a break from their children often enough. When questioned about respite care, these primary family care providers indicated that being able to take a break from the responsibilities of caring for the neurologically impaired child was a major need. Freitag-Koontz (1988) indicated that the cost of meeting medical and daily maintenance requirements of neurologically impaired children placed emotional and financial burdens on these children's families. This study found that there were two main obstacles to having time away from the responsibility of caring for the child. The first of these was identifying someone that the provider trusted to come into the home and give adequate care. Neighbors, friends, extended family, church members, and family outreach programs were cited as providing occasional respite services for a small number of families. The second obstacle to seeking respite care services was lack of financial resources. The cost of providing physical care, medications, treatments, and supplies left little money for baby sitters or for family recreational activities. A support group was identified as providing emotional respite for one of the primary family care providers. However, travel to and from support groups was seen as a problem for two respondents and another respondent stated that these groups were negative and depressing.

The rural nature of Montana and the isolation of farms and ranches compound the problems of care provision and access to health care. Weinert and Long (1987), Moon and Graybird (1982), Scharff (1987), Swehla (1986), and Snyder (1981) all found that living in rural areas affects the ways in which people adapt and adjust to chronic illness. The findings from this research indicate that living in rural central and western Montana did affect these primary family care providers and their neurologically impaired children.

The greatest effects were identified as difficulty in obtaining qualified health care and adequate educational services locally for neurologically impaired children. Distance and weather were concerns because the needed services of a pediatric neurologist were a day's travel time away for over half of the respondents.

The rural respondents studied can and do cope, despite the magnitude of problems they face, including the limited formal sources of support, a single pediatric neurologist to provide services to an area that reaches beyond the borders of Montana, limited specialists and other care providers, poor funding, and an inadequate number of rural nurses. Snyder (1981) indicated that health care information for rural Montana people comes from friends or relatives and that there is less reliance on professional providers and formal health care services. Additionally, Weinert and Long (1987) found that self-help and self-reliance were basic strategies of rural Montana populations for coping with health problems and that nurses served to supplement and support informal rural systems. The rural families in this study tended not to utilize formal sources of support as demonstrated by infrequent use of routine dental and vision checkups and formal counseling.

The 47% response rate in this study raised concern about self-selection bias among respondents. The investigator may have interviewed primary family care providers who were better able to meet the needs of their neurologically impaired children and had the time and energy to participate in the study. It may be that the sickest, most needy children and care providers were unable or unwilling to participate or had moved to larger urban centers to obtain needed help and were no longer living within the rural areas targeted for study. Thus, while the findings from this study suggest diverse and serious needs among neurologically impaired children and their family care providers in Montana, these findings may actually underestimate the extent and severity of these needs.

In summary, the specific services desired by the primary family care providers in meeting the neurologically impaired children's care needs were for special discounts on medicine and supplies; better medical coverage; qualified respite help; day care assistance

for neurologically impaired children; travel money; increased family outreach programs; increased school funding for adaptive equipment, supplies, and additional specialized training for teachers; and additional help from spouse and family. This study identified specific needs of the neurologically impaired children and their family care providers, as well as the hindrances involved in meeting these needs in rural central and western Montana. As such, it provides an initial data base for the planning of needed health care, education, and social services for this unique group.

Implications

Implications for Nursing in Rural Settings

Nurses have a wide spectrum of knowledge related to health care, available resources, and funding sources. The role of the rural nurse providing care to neurologically impaired children and their primary family care providers is one of coordinating physical care, establishing support networks, providing respite, referring when necessary, increasing public awareness, and educating public school administrators, teachers, and community officials. Rural nurses applying the nursing process have the opportunity to assess the physical, psychosocial, informational, emotional, and respite care needs of neurologically impaired children and families. The nurse who is familiar with the implications of a neurological impairment diagnosis, complications of the impairment, complex therapies, long term prognosis, and survival rate is in a unique position to provide the needed services in a cost effective manner, especially in rural areas. This is because nurses are able to assess the physical and psychosocial status of the child and care provider, provide therapies, deliver treatments, supply information to families, and give emotional support. No other specialty field in health care provides this wide spectrum of needed services. The rural nurse can provide services within the context of a therapeutic relationship with the neurologically impaired child and family care provider.

Nurses can enhance physical and emotional support for neurologically impaired children, primary family care providers, spouses, and families. They can provide support by educating the primary family care provider in methods of medication administration and daily management. Nurses can also teach primary family care providers mobility and transfer techniques in order to transport their children in ways that will not be harmful. Nurses can assist primary family care providers in clothing selection for neurologically impaired children in order to obtain optimal individual mobility for the children. Rural nurses can instruct the care providers in safety practices that parallel each individual child's intellectual and mobility level. These include the use of fenced yards, gate locks, colorful soft toys, and appropriate outdoor play equipment. Nurses can assist in modifying homes, classrooms, schools, or day-care centers with ramps, rails, and accessibility features to meet the special needs of these children. Rural nurses can educate primary family care providers about the need for regular medical, visual, and dental checkups for neurologically impaired children to aid in the early detection of problems and avoidance of serious complications. Nurses are knowledgeable about family dynamics and can provide emotional support to families with neurologically impaired children who are dealing with chronic grief and the impact these children have on the total family systems. Nurses can teach the spouses of primary family care providers ways of providing emotional support such as active listening. This teaching can be offered in a variety of ways and settings including one-to-one individual instruction, hands-on practical demonstrations, or in groups or classroom settings.

Neurologically impaired children have complex care needs and the more profound the neurological impairment, the more complex the care requirements. Nurses can be role models in the provision of care by providing clear directions to primary family care providers, families, and communities about the care neurologically impaired children require. Nurses and other health care professionals must be aware of the importance of their actions as they become sources of support for neurologically impaired children,

primary family care providers, families, and communities. Effective and sustained communication between family care providers and nurses is essential in order to help parents achieve a balance between effective support and independence in dealing with these children's chronic illnesses. Nurses must be responsive to the unique abilities and limitations of these children and the need for effective referrals so that families can receive additional information and assistance.

Support networks, parenting groups, and respite services can be arranged by rural nurses. Nurses can help provide support to the neurologically impaired child and primary family care provider through group socialization. Planned activities with other families and friends can provide the environment for social and emotional support in dealing with the chronic grief of these primary family care providers and other family members. These groups, whether related to educational or psychosocial needs, are generally few in number in rural areas and nurses can help encourage the development of more of these. Support groups can reduce feelings of isolation and seclusion by offering an environment of acceptance and a sharing of common problems and solutions. Rural nurses can help primary family care providers find hope and joy in their neurologically impaired children by helping to establish and recognize small goals. Rural nurses can convey a sense of joy and support to these families through a sharing of time and self.

Public Law 94-142 requires that neurologically impaired children be educated in the least restrictive environment. The primary family care providers in this study indicated that local rural schools did not have adequately trained teachers or appropriate classroom facilities to provide for the needs of these children. Rural nurses can collaborate with teachers in rural areas to develop ways to provide education to these children who have both limited and unique physical and intellectual abilities. Alterations of the classroom environment and special training related to each individual child's special needs may be required. Many local rural schools are unable to provide the required education for neurologically impaired children. The primary family care providers are then forced to

either transport their children long distances for education or relocate their entire family to meet the requirements of this law. This is a sacrifice and presents difficulties for these families. Rural nurses can provide emotional support to these families and educate primary family care providers and school personnel, including school bus drivers, about the special individual needs of these children. Nurses can inform teachers about chronic grief and help them realize that there may be no final solutions for neurologically impaired children's special needs. The education of these children may be a process of accommodating and making changes as necessary to meet the current circumstances.

Often rural communities have only one neurologically impaired child but many other children requiring education and related services. The majority of public education funds is spent providing services to the majority of children. Thus, rural nurses may need to supplement available resources for neurologically impaired children by seeking private and public funding sources, helping to obtain services such as family outreach and respite, and assisting with grant applications to secure funding for rural families, schools, and communities. Through collaboration with local merchants, pharmaceutical companies, and corporations, rural nurses can seek funding for specialized training in neurological nursing. Rural nurses can help shape community responses to neurologically impaired children. They can educate community members and increase public awareness about the specific needs and capabilities of these children. Nurses can be advocates for these children, rallying support for the child and care provider in the community.

Many neurologically impaired children remain in the home setting. The parents of these children are forced to provide long term care in spite of personal expense, time, and energy. Many of these children will outlive their parents, and these parents are unsure of what will happen to their neurologically impaired children in the future. One option is to secure placement for the child in a group home. However, there are only a few group homes in Montana for neurologically impaired children and the waiting list for placement is long. The child may wait years for placement. Nurses can seek available sources of

placement for these children, advise parents on available options, and aid in decision making for long term, out-of-home placement.

In summary, the nursing implications of this study are that rural nurses need to be able to assess, evaluate, and plan for the complex needs of neurologically impaired children, their care providers, and their families living in rural areas. This process can be enhanced by observing the child and listening to the needs expressed by the family care provider, family, teacher, and community. Nurses can serve as resource persons and can take an active role in establishing liaisons with other helping resources. Rural nurses become advocates for neurologically impaired children by assisting their families in program coordination, by providing support, and by seeking appropriate referrals and funding.

Future Studies

A process for identifying the needs of neurologically impaired children and their primary family care providers has been developed. Future studies, especially those targeting the unique needs associated with rural living, are needed. A larger study utilizing a random sample could serve to confirm or refute findings from the current study. In addition, a longitudinal study using the same sample could provide a better understanding of the continuing needs of neurologically impaired children and their families, revealing how these children move through various developmental phases. A study contrasting the perceptions of rural nurses or physicians with those of family care providers could provide insight about provider/client discrepancies that may affect health care seeking behavior and health care service delivery. A study assessing the current knowledge and skills of rural nurses in the area of neurological impairments could be used as a base line to determine educational needs for nurses who provide services to neurologically impaired children. In addition, research focusing on the assessment of current special education services offered to neurologically impaired children in rural areas

could provide guidance for rural school districts which are attempting to improve services to meet the needs expressed by the families of neurologically impaired children.

This study provided an initial data base on neurologically impaired children living in a rural area. Continuing research should be done to provide additional data and to increase the information available to rural nurses and other health care professionals. This study provided data which can be helpful in relation to planning relevant, feasible, and cost effective services to meet the unique needs of neurologically impaired children and their families who live in rural areas.

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APPENDICES

APPENDIX A
INFORMED CONSENT MATERIALS

May 30, 1990

Name
Address
City, MT 5xxxx

Dear (name),

I am a Registered Nurse attending Graduate School at the Montana State University College of Nursing. I have worked in rural Montana as a Registered Nurse for 12 years. Currently, I am the nurse manager of a Pediatric Unit which serves neurologically impaired children. I am conducting a research study to determine the health care needs of these children and their family care providers. You are being asked to participate in this research study.

Information is being gathered from persons who are primary family care providers of neurologically impaired children. The study seeks information on the physical, psychological, and emotional needs of families of neurologically impaired children in rural areas. Study participants are being sought from families residing in rural central and western Montana.

You are being contacted because your child is a current patient of Dr. M. Guggenheim or has been a patient at St. Peter's Community Hospital's Pediatric / Adolescent Unit from April 1988 to April 1990. This study is not being conducted by St. Peter's Community Hospital, but rather by myself, an MSU Graduate Student, as partial fulfillment of the requirements for a Master's degree. You are under no obligation to participate in this study. The care your child receives at St. Peter's Community Hospital or from Dr. Guggenheim will in no way in the future be affected by your decision to participate or not to participate.

Your ideas and experiences as a primary family care provider can be important in helping health care providers identify and assist in providing care to neurologically impaired children and their primary family care providers. The benefits of this research may be a better understanding of neurologically impaired children's care needs, both in and out of the hospital setting. The only possible risk may be remembering stressful events, treatments, or care issues related to the child. Should this occur, you will be referred to the thesis chair for this study.

June 13, 1990

Name
Address
City, MT 5xxxx

Dear (name),

Three weeks ago I sent you a letter inviting you to participate in a research project involving neurologically impaired children. If you have lost or misplaced the letter and are interested in participating in the study, please complete and return the tear-off section of this letter and return it to me by (date) in the enclosed envelope. If you have any questions, or would like additional information or a second copy of the research project letter, please feel free to call me at 458-9604.

Thank you for your consideration and time in this matter.

Sincerely,

Darlene Gaughan RN, BSN
8783 Douglas Circle
Helena, Montana 59601

----- remove and return this stub -----

I have read the informational letter regarding the study on the health care needs of neurologically impaired children residing in rural central and western Montana. By signing this form and returning it in the self addressed, stamped envelope, I, _____,

the

(Please Print)

primary family care provider for _____,

(Please Print)

a neurologically impaired child, am agreeing to participate in the study.

Phone: (home) _____

(Signature of Participant)

(work) _____

Best time to call: _____

Date: _____

August 12, 1990

Name
Address
City, MT 5xxxx

Dear (name),

I would like to thank you for offering to participate in the research project on neurologically impaired children. Limitations of time and resources prevented the inclusion of all persons who were willing to participate. The research interviews have now been completed. If, at a later date, further research on neurologically impaired children is conducted, you may be contacted again. If you have any questions, please feel free to contact me at 458-9604.

Thank you for your consideration and time in this matter.

Sincerely,

Darlene Gaughan RN, BSN
8783 Douglas Circle
Helena, Montana 59601

APPENDIX B
INTERVIEW GUIDE

DEMOGRAPHIC INFORMATION

First, I would like to ask you some questions about your child:

1) What is the child's:

A) Age: _____

B) Gender: M F

C) Neurological impairment: _____

D) When was the child diagnosed: _____

E) What is the cause of the child's neurological impairment: _____

F) What are the major symptoms, features of the neurological impairment: _____

Next I would like to ask you some questions about yourself:

2) What is your relationship to the child:

A) Are you the child's:

Mother

Father

Grandparent

Other: _____

Maternal Paternal

B) Are you: married single widowed divorced

C) How many people are in this household: ____

D) What is your age: _____

PHYSICAL CARE NEEDS OF NEUROLOGICALLY IMPAIRED CHILD

3) Now I'd like to ask you some questions about what do you or don't you need help with in regard to the child's physical care. Are these needs related to:

PHYSICAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
A) Physical growth.								
B) Providing specific treatment.								
C) Providing safety.								
D) Administering medications.								
E) Providing a diet or diet restrictions and methods of feeding.								
F) Elimination, either assisted, independent, or incontinent. (urinary or bowel)								
G) Caring for the child's skin.								
H) Providing sleep and rest for the child.								
I) Providing hygiene, bath, teeth.								
J) Providing grooming, hair, nails.								
K) Maintaining current immunizations.								
L) Attending to routine health care, dental, vision.								
M) Obtaining in-home nursing care.								

PHYSICAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not imp 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
N) Helping the child with physical complications.								
1) blind or vision impairments.								
2) mobility.								
3) hearing.								
O) Understanding or controlling seizure activity.								
1) Hypertonia.								
2) Spasticity.								
3) Hyperactivity.								

4) Are there any other physical needs or anything else about the care of the child's physical condition that you would like to mention?

PSYCHOSOCIAL NEEDS OF NEUROLOGICALLY IMPAIRED CHILD

5) This next section of questions deals with some of the social and developmental needs of the child. Are there needs related to:

PSYCHOSOCIAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
A) The child's play with other children.								
B) The child's getting along with family members.								
C) The child's behavior in public.								
D) The child in school / learning needs.								
E) Providing exercise/play.								
F) Providing physical comfort by helping regain or maintain controlled behavior by holding to quiet or comfort the child.								
G) Understanding the child's needs as expressed by verbalization, such as talking, grunts/noises, nods/gestures, or expressions.								
H) Planning for the child's future.								

6) From your perspective, are there any other psychosocial needs of the child?

INFORMATIONAL NEEDS OF THE PRIMARY FAMILY CARE PROVIDER

7) This section deals with you having enough information to help you take care of the child. Are there needs related to:

INFORMATIONAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
A) Understanding of child's illness/disease.								
B) Understanding child's disability.								
C) Obtaining reading materials about the child's condition.								
D) Instructions on managing the child's condition.								
E) Training for in-home therapy techniques, ie: respiratory therapy, physical therapy.								
F) Seeking specialty care or treatments.								
G) Communication with health care providers. Getting questions answered.								
H) Help getting questions answered between clinic appointments								
I) Identifying your community resources.								
J) Information on out-of-home placement.								

8) Are there any other kinds of informational needs you have in caring for the child?

EMOTIONAL NEEDS OF THE PRIMARY FAMILY CARE PROVIDER

9) This section deals with some of the emotional support needs for yourself and family. Are there needs related to:

EMOTIONAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
A) Feelings about your partner after the birth of the child								
B) Open communications to partner, family, friends, and community.								
C) Feelings of the constant drain of your attention, energy, and time in caring for the child.								
D) Feeling of promoting independence or dependency in the child.								
E) Feeling of how the child affects the family system, additional work, and emotional strain.								
F) Feeling how the impaired child draws time, energy, and money away from other family members.								
G) Feelings of hostility and resentment toward the child.								
H) Feelings about how the extended family and community react to the child.								

EMOTIONAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
I) Finding/ attending family or individual counseling. - behavior problems - under achievement								
J) Personal feelings about responses from extended family and community.								
K) Feelings of grief.								
L) Feelings of prolonged loss of your dream child or life.								
M) Feelings that your life is controlled by the needs of the child.								
N) Feelings of guilt or failure.								
O) Feelings of joy or hope about the child's future.								

RESPITE CARE NEEDS OF THE PRIMARY FAMILY CARE PROVIDER

10) This section of questions deals with what gives you a break for yourself and family.

RESPITE Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
A) How do you identify when you need a break from caring for the child.								
B) Identifying persons to come in to help with household.								
C) Getting someone to come in to help with household chores, cleaning, laundry, cooking.								
D) Child care while you work.								
E) Child care for your leisure time.								
F) Finding or attending a parent support group.								
G) Providing money to cover the costs of caring for the child.								
H) Obtaining and using resources to cover the expenses of medical care.								

11) Who, if anyone, comes to your home and helps care for the child?

RURAL NEEDS

12) This final section deals with your perspective about the impact of living in rural Montana has on care needs for your family and the neurologically impaired child. Do you have needs related to:

RURAL Questions	Need Help	Don't Need Help	How Managing		Services Desired		Scale 1 not 2 imp 3 very imp	Comments, Quotes, Anecdotes, & Non-verbal
			Alone	With Help	If "Need Help" what type needed	If "Not Need Help", Suggest Additional Services		
A) Obtaining the health care you need locally - clinics - hospitals, in-patient, out-patient - money								
B) Obtaining the "support" emotional help you need in your rural community. - money - mental health care, who do you see or supports you								
C) Travel to nearest help in case of emergency.								
D) Travel to the family doctor.								
E) Travel to the specialist.								

13) In what other ways do you believe you have been helped or hindered in caring for the neurologically impaired child because of living in rural Montana?

14) Is there anything that you feel is important that you would like to discuss that you have not shared?

APPENDIX C

CORRESPONDENCE

March 31, 1990

Jean Simpson, RN
Vice President Patient Care Services
St. Peter's Community Hospital
2475 Broadway
Helena, Montana 59601

Dear Ms. Simpson,

As a registered nurse attending Graduate School at the Montana State University College of Nursing, I am conducting a research project involving the description of the health care needs of neurologically impaired children residing in rural Montana. The population for this study is the primary family care providers for these children.

This letter is a request for your permission to access the patient logs of the Pediatric / Adolescent Unit of St. Peter's Community Hospital from April 1988 to April 1990 to obtain the names of neurologically impaired children and their primary family care providers. The primary family care providers will be invited to participate in the study and, if willing, will agree by signing a letter of consent. The interviews will be conducted during the Spring of 1990 in the neurologically impaired children's homes at the convenience of their primary family care providers.

Enclosed is a copy of my proposal for human subjects committee review. This study is also being reviewed by the MSU College of Nursing, Human Subjects Review Committee. A similar letter has been written to Dr. M. Guggenheim requesting her consent as well.

Please send me a letter with your response to this request. Should you have additional comments or questions, please feel free to contact me at 458-9604.

Thank you for your time in this matter.

Sincerely,

Darlene R. S. Gaughan
8783 Douglas Circle
Helena, MT 59601

March 31, 1990

Dr. M. Guggenheim
St. Peter's Community Hospital
2475 Broadway
Helena, Montana 59601

Dear Dr. Guggenheim,

As a registered nurse attending Graduate School at the Montana State University College of Nursing, I am conducting a research project involving the description of the health care needs of neurologically impaired children residing in rural Montana. The population for this study is the primary family care providers for these children.

This letter is a request for your permission to access the patient logs of the Pediatric / Adolescent Unit of St. Peter's Community Hospital from April 1988 to April 1990 to obtain the names of neurologically impaired children and their primary family care providers. The primary family care providers will be invited to participate in the study and, if willing, will agree by signing a letter of consent. The interviews will be conducted during the Spring of 1990 in the neurologically impaired children's homes at the convenience of their primary family care providers.

Enclosed is a copy of my proposal for human subjects committee review. This study is also being reviewed by the MSU College of Nursing, Human Subjects Review Committee. A similar letter has been written to Jean Simpson, Vice President Patient Care Services, requesting her consent as well.

Please send me a letter with your response to this request. Should you have additional comments or questions, please feel free to contact me at 458-9604.

Thank you for your time in this matter.

Sincerely,

Darlene R. S. Gaughan
8783 Douglas Circle
Helena, MT 59601

May 6, 1990

Dr. M. Guggenheim
St. Peter's Community Hospital
2475 Broadway
Helena, Montana 59601

Dear Dr. Guggenheim,

This letter is to clarify that the interviews for my research project involving the description of health care needs of neurologically impaired children residing in rural Montana will be conducted with the family member who, on a daily basis, has the main responsibility for providing the physical and psychosocial care for the child.

The Human Subjects Review Committee has requested that I clarify this with you, and that I obtain from you a written response indicating that this question has been clarified.

Should you have additional comments or questions, please feel free to contact me at 458-9604.

Thank you for your time in this matter.

Sincerely,

Darlene R. S. Gaughan
8783 Douglas Circle
Helena, MT 59601



(406) 442-2480 • 2475 Broadway, Helena, Montana 59601

M E M O

DATE: April 17, 1990

TO: Darlene Gaughan

FROM: Jean Simpson, Vice President *J.S.*

SUBJECT: Research Proposal

Your request to conduct your research by accessing the patient logs of the Pediatric/Adolescent Unit of St. Peter's Community Hospital from April 1988 to April 1990, to obtain the names of neurologically impaired children and their primary family care providers, is approved with the following requirements:

1. That you obtain Dr. Mary Anne Guggenheim's approval;
2. That the primary family care providers, who are invited to participate in the study, are clearly advised of the voluntary nature of participating in the study; and,
3. That it be made very clear to the participants that this is not a St. Peter's Community Hospital study, but rather a study conducted by an MSU student as a research project for a Master's thesis.

PEDIATRIC NEUROLOGY SERVICES
2475 Broadway
Helena, Montana 59601
(406) 444-2288
Fax # 406-444-2153

Mary Anne Guggenheim, M.D.
Board Certified in
Pediatric Neurology

Jan Donaldson, RN, BSN

Darlene R. S. Gaughan
8783 Douglas Circle
Helena, MT 59601

Dear Darlene,

I am happy to grant you permission to access my records to obtain names and other demographic information of children who would be appropriate subjects for the study you have proposed. The only thing that is not clear to me is whether you are interviewing the families of the neurologically handicapped children or whether you are interviewing their primary care provider, i.e., family practice physician or pediatrician. I gather it is the latter. I wonder if you indeed will get the expected degree of cooperation in view of the time of the interview which many physicians might be resistant to. At any rate, you have my permission to access patient files and I wish you good luck.

Sincerely,



Mary Anne Guggenheim, M. D.

MAG/jp

PEDIATRIC NEUROLOGY SERVICES
2475 Broadway
Helena, Montana 59601
(406) 444-2288
Fax #: 406-444-2163

Mary Anne Guggenheim, M.D.
Board Certified in
Pediatric Neurology

Jan Donaldson, RN, BSN

May 16, 1990

Darlene R. S. Gaughan
8783 Douglas Circle
Helena, MT 59601

Dear Darlene,

Let me formally acknowledge your letter of May 6, 1990 which satisfactorily clarifies for me your proposed research plan. I hope things go well.

Sincerely


Mary Anne Guggenheim, M.D.

MAG:at

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