



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

December, 1990

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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 it 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,

