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PSYCHOSOCIAL PROBLEMS FACING PARENTS OF CHILDREN WITH NEUROLOGICAL DISORDERS

BY

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Psychosocial Problems Facing Parents of Children with Neurological Disorders: A Study at Korle-Bu Teaching Hospital, Ghana.

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Supervisor

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Declaration

I declare that except for reference to other people works which have been duly acknowledged, this dissertation is the outcome of my own original research and that it should neither be presented in whole or in part for any certificate.

………………………………………………

Peace Delali Nyasor

Declaration by the Dissertation Supervisor

This is to certify that Dr Florence Naab has supervised the Masters' dissertation of Peace Delali Nyasor and have found that it is complete and satisfactory in all respect.

INTEGRI PROCEDAMUS

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Dr Florence Naab

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Dedication

These words are dedicated to the Nursing Profession. The Nursing profession is increasingly involved in the development of a scientific body of knowledge relating to its practice. Not all nurses will engage in research projects of their own, but there is a need for all nurses to be able to critically appraise research reports. Also it is my expectation that nurses – especially those in clinical practice – will conduct research and utilize the results of scientific studies as a basis for making decisions in their work.

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I started with the premises that it takes a campus to teach a writer. It is also the case that it takes a community to write a dissertation; as such dissertation work usually requires the involvement of a lot of people. Therefore, I take this chance to express my special acknowledgement to my supervisor: Dr Florence Naab. Her patience, guidance, suggestions and unending support and encouragement made my work complete. Also my special thanks goes to Mr. Fakor Agakpe not only share his astute reflections on teaching and writing but also gave me valuable classroom materials to use as I saw it fit.

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Abstract

Chronic neurological conditions impose psychosocial problems on caregivers. The objective of this study was to survey and describe caregivers' psychosocial experiences; beliefs and effects neurological illness have on the family and social life. A purposive sample of 160 parents enrolled using a standard questionnaire to obtain socio-demographic information, beliefs and psychosocial experiences. Data analysis demonstrated that mean stress reported by the caregivers was 69.7 and standard deviation of stress was 2.45. This implies that all parents reported moderately high level of stress (69.7). In addition, results obtained from one sample t-Test Analysis confirm the fact that stress associated with caring for neurologically ill child is significantly high ($p < 0.5$). There is the need to provide caregivers with adequate information to prepare them well to leave with the disability with minimal stress. The level of stress experienced by caregivers calls for psychological support to carers and stress management interventions.

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CHAPTER ONE

1.0 BACKGROUND TO THE STUDY

Neurological illness restricts the child's normal function and activity; the disease is a strain on child-parent relation, family routines and also other siblings in the family. Apart from the direct involvement with the sick child the family's entire life is transformed. The support system is put on trial and test as long-term illness generates different demands for attention, supervision and care. The psychosocial impact of neurological illness on the child and the family's everyday life depends on several factors including the severity of the disease; the complexity of the clinical management; the meaning of the illness to the child, family, and society as a whole; restrictions in the child's and family's activities; the level of social support and extent of resources available to deal with the illness and the innate coping abilities of the child and family.

Successful management of these children and their complex health problems needs to be based on medical, social, psychological, economic, political and humanistic knowledge and skills, on clinical individual-based as well as population-based medicine, and on therapeutic as well as preventive and promotional aspects.

Jowi (2007) in his paper indicated that globally, neurological disorders account for about 11% of disease burden and over 80% of people living with epilepsy are in the developing countries. According to Jowi, epilepsy is a major global concern in neurology. Over 50,000,000 people are known to suffer one form of epileptic syndrome or another. Also, it is estimated that 80 – 90% of people living with epilepsy do not get appropriate treatment.

Both genetic and environmental influences play a role in childhood illnesses. Chronic childhood diseases not caused by infections are still common in children. About one child in hundred is born with a serious physical or neurological disorder such as spina bifida, cerebral palsy, autism spectrum disorder, epilepsy and multiple sclerosis. According to Hirtz, Thurman,

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Gwinn-Hardy, Mohamed, Chaudhuri, and Zalutsky (2007) for some disorders, prevalence is a better descriptor of impact, for others, incidence is preferable per 1,000 children. Estimated prevalence was 2.4 for cerebral palsy, 5.8 autism spectrum disorders, and prevalence of Attention Deficit Hyperactive Disorders (ADHD) ranges from 4% to 12% in the general population of 6 – 12-year olds (Biederman, 2003). In the general population per 1,000 the one-year prevalence of migraine headache was 121, 7.1 for epilepsy, and 0.9 for multiple sclerosis (Hirtz et al. 2007). For diseases best described by annual incidence per 100, 000, the rate for major traumatic brain injury was 101, 4.5 for spinal cord injury. A similar number of babies are born with defects that cause chronic ill health such as diseases or tumors of the spinal cord or brain. Convulsive disorders constituted 3% of cases of acute or recurrent illness in children referred to the Korle-Bu Teaching Hospital (KBTH) (Commey, 1995). Two to four percent of children have seizures during childhood, with an incidence of one per 1,000 (Ball & Bindler, 2003). Myasthenia gravis and muscular dystrophies also contribute to the existence of chronic neurological disorders. Other neurological conditions caused by infections and environmental factors include cerebral malaria, untreated neonatal jaundice and meningitis. Hydrocephalus and trauma to the nervous system also produce neurological deficit. Of all cases, 70% appear before five years of age (Ball &Bindler, 2003).

Many children with neurologically based motor impairment do not have only movement problems without impairment to other functions controlled by the brain. Having obvious neurological injury, however, does increase the likelihood that other areas of the brain have also been injured. Auditory processing problems, cortical visual impairment and mental retardation are examples of other neurologically based problems that may occur. Hypersensitivity to stimuli (increased sensitivity to touch, sound, rapidly changing visual input), attention and/or activity

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problems, difficulty regulating arousal (including sleep problems), seizures, speech problems, and various learning difficulties are among the most common symptoms reported for children with early brain injury. These non-motor symptoms associated with brain injury can emerge in children with normal or near normal motor development, but are more common in prematurely born children who also have motor problems.

Children born prematurely are more likely than full-term children to develop motor problems during infancy and about 10% of the smallest (1000grams) preterm infants will develop cerebral palsy (Carter, 2001). While developmental differences for most children born prematurely are benign and will eventually resolve, some of these differences can be associated with long-term problems. In some cases, long-term difficulties can be minimized by helping families and professionals to better understand the underlying conditions which influence the child’s development. When a child has a neurological disorder, it affects the entire family. It needs specialty healthcare which includes a partnership between the family and the medical team that allows the best understanding of the child’s difficulties and helps provide the best possible care. This includes a thorough evaluation of the child, diagnosis and carefully planned treatment to improve the child’s health and quality of life.

In Bruce (1993), the World Health Organization (WHO) launched a global initiative aimed at increasing public and professional awareness of the importance of neurological disorders which together affect hundreds of millions of people. The challenge is to draw attention to neurological illness to have them acknowledged as public health problems, and to emphasize the huge possibilities that exist for prevention. Although huge numbers of people suffer from one disorder or another, there is an acute global scarcity of neurologists to treat them.

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Jowi (2007) indicated in his paper “Provision of care to people living with epilepsy” that Kenya currently has 10 neurologists both in pediatric and adult medicine services; and this translates to a ratio of one neurologist to 3.3 million Kenyans in the population.

Neurological disorders are neglected in public health. The absence of these disorders from lists of the leading causes of death has contributed to their long-term neglect by both donors and policy makers in developing countries. As a result, 90% of people with epilepsy in developing countries are inadequately treated (Hyman, Chisholm, Kessler, Patel and Whiteford, 2006). The stigmatization and discrimination associated with these disorders also remain substantial obstacles to diagnosis and treatment. In addition, lack of transportation, lack of public knowledge about neurological disorders in children and inability to communicate effectively in the patient’s native language denies or delays specialty services.

In another WHO document, Saraceno (2003) indicated that throughout the history of the WHO neurological disorders or mental health program, the attention dedicated to children and adolescents has not been commensurate with that dedicated to adults. Yet from demographic and epidemiological perspective as well as from the burden of neurological disorders of children represents a key area of concern. The exact prevalence of many of them is unknown, as their real impact on society – their effects on families and their communities, the cost of care and treatment, are sheer waste of human potential. In another WHO document, “Disease Control Priorities Project” by Hyman *et al*, (2006) mental and neurologic disorders affect more than 450 million people globally, causing substantial disability rates and suffering, making major contributions to the world’s total disease burden. About 13 % of Disability Adjusted Life Years (DALYs), a measure of the amount of health lost due to a particular disease or condition is due to neurologic disorder (Hyman et al. 2006).

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These disorders bring significant physical and economic hardship not only to those who suffer from them, but also to their parents/caregivers – who are often the patient's family, given the lack of health resources often found in developing countries. The costs are devastating – the caregivers' loss of family income, the requirement for care giving, the cost of medication, and the need for other medical services, physical strain, stress, and anxiety associated with caring for neurologically ill child. Communicable diseases, maternal, perinatal and nutritional conditions account for 67% while noncommunicable diseases and injuries account for 33% of neurological disorders or mental illness (Franciosi, 2000).

Many neurological illnesses can be prevented. The world Atlas of Neurology depicts the four leading causes of epilepsy as head trauma, central nervous system infections, perinatal complications and cerebro-vascular accidents (Jowi, 2007).These are all preventable etiologies and with good primary health care policy, much can be achieved towards preventing epilepsy. The incidence of cerebral palsy, for example, could be reduced by improved ante-natal screening and better management of child birth, post natal, and childhood infections. Some conditions linked to infections such as malaria, meningitis, tuberculosis and trauma could be prevented by control measures against the diseases themselves. Where prevention is not possible, care and treatment for the neurologically ill children should be ensured.

Impairment may be congenital or acquired and may vary in duration and severity. Estimates of the prevalence of disabilities depend on the precise definitions used. This question is of particular importance given that children with chronic illnesses need more medical care than those who are healthy. It is not only the sheer number that makes these children so special, but it is a well-documented and widely accepted fact that families with children who have long-term

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illness or handicaps/disabilities are under greater strain and are more vulnerable than other families.

The strain can take many forms – physical, mental, economic and social. For these children and their families childhood is often a worrying time, with frequent hospitalizations and medical consultations, complicated and strenuous treatment, intrusions on private life, economic strain, uncertainty and anxiety for the child's future. Parents or caregivers of children with chronic neurological illness are intimately involved with their child's health care on a day to day basis because the majority of these children are normally cared for at home. The substantial effects of chronic diseases particularly neurological illness are perceptible on several planes. They are apparent on individual plane because the disease restricts the child's normal function and activity. Several studies have demonstrated a noticeable elevated incidence of behavioral disturbances among children with neurological disorders. The effects are noticeable on the family plane, because the disease is a strain on parent-child relations, on family routines, and also on other children in the family. The mere presence of a medical complaint leads to innumerable daily problems for the child and his or her family, regardless of secondary problems. Some children experience pain and suffering every day. Apart from direct involvement with the sick child, the family's entire life is transformed negatively.

Every day care demands greater consideration from other members of the family. Perhaps one of the parents has to give up working or change jobs in order to be able to look after the child or move closer to caring resources. To a great extent, mothers had been forced to interrupt their education and employment because of their disabled children, while fathers pursued a normal career. Kohler (1993) reported that children with disabilities used more health services than other children, both hospital and primary care, and usage increased by age. Also there was

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widespread discontent with the amount of information parents received about their children's disease from professionals and the way such information was delivered. Ordinary social activities like attendance at church, funeral, engagement, wedding, and birthday ceremonies, travels and socialization may have to be reorganized or abandoned. In a Norwegian study, for example, 74% of families with functionally impaired children reported that they felt inhibited as families. Certain neurological conditions such as seizures, tumors, and hydrocephalus may require demanding medical consultations and hospital care. Some of these intensive medical interventions can be planned in advance but others take the form of sudden crisis.

Siblings of children with neurological problems run the risk of psychosocial problems because frequently they are left outside the immediate focus of parental care and attention. Some studies suggest that the frequency of behavioral disturbances can be just as high among siblings as among the children with neurological problems themselves. It is clear that the change in the family situation affects the lives of the siblings. The consequences for the family seem to depend to a great extent on the nature of the disorder or disability. The social network is likely to be more destroyed in families who spent a lot of time in hospitals, and the lack of parental support is more pronounced in children that create anxiety and extensive daily care for their families.

Obviously, families are not identical simply because they happen to have a child with a neurological problem. The common differences found in society may be economical, social, and cultural which all play a part in determining the situation of the child and family either negatively or positively. There could be as much happiness and companionship with a child with neurological problem as with the one without such problems. There are also many examples of a child with neurological deficit bringing positive experiences to the parents and siblings which have led to a stronger family relationship. In these contexts, it seems suitable to remind ourselves

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that even in the most disabled child there is still a normal human being – thinking, feeling and reacting. It is a common belief that the frequency of family breakdowns, as reflected in the incidence of divorce is higher in families with handicapped children than in the general population. In the general population, divorces generally occur early in the marriage, while in families with handicap children, they occur later. Risk factors for family breakdown that seem to be common include previous conflicts in the family, low age of the mother and families who perceived the handicapped child as a heavy burden. In a Norwegian training centre study of families with disabled children of various diagnoses, the frequency of divorce was two and half times lower than in the general population, and the relationship between the spouses before the birth of the child shaped the relationship after the child was born (Kohler, 1993).

Effects are also apparent on the social plane, as handicap puts the support system on trial and tests the covering and function of the medical and social caring system in things both large and small. Consequently children with disabilities or other chronic complaints generate different demands for attention, supervision, and care from children with episodic or acute illness. Whilst there is a growing body of literature addressing interactions between parents and nurses, parents and the hospitalized child, and between nurses and children, there is paucity of literature exploring relationships with children with long term illness or disability (Ford & Turner, 2000). Within the literature, caring relationships are recognized as being problematic.

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1.1 Statement of the Problem

Most parents are extremely upset when their child is diagnosed with neurological disorder for instance epilepsy, cerebral palsy, head injury autism mainly because of the stigma and extra parental burden associated with such disorders. Typical parental responses are shock, devastation, sorrow, and depression.

Spangenberg, (2006) indicated that parents witnessing seizure for instance in a young child can be one of the most anxiety-provoking experience for a parent. He further pointed out that these experiences lead to feeling of helplessness, fear and often results in overprotection or overindulgence of the child.

Parents often fear divulging their child’s neurological problems to friends and relatives because they have experienced a sense of shame, self-blame and rejection. They may consequently withdraw from their relatives and social circle. Parents may fear that the child’s neurological problem(s) is due to neglect during pregnancy, labour and delivery. Feeling of guilt and inadequacy develop leading to further loss of self-esteem.

Parents and nurses have different perceptions or feelings of the experience of chronic illness particularly the effects neurological illness has on parents/caregivers, sufferers and their families. Parents of these children with special needs and or chronic illness are intimately involved with the children’s health care on day to day basis because the majority of these children are normally cared for at home. The families of children with special needs are under greater strain and are more vulnerable than other families. The strain can be physical, psychological, social or economic. There may be uncertainty and anxiety for the children’s future. The substantial effects of neurological illness are perceptible on individual, family and social planes.

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Ball and Bindler (2003) indicated that Central Nervous System (CNS) malformations accounts for approximately one third of all apparent congenital malformation in live infants, and 90% of these are neural tube defects. CNS defects are responsible for 40% of infant death in the first year of life (Ball &Bindler, 2003).

Personal observation in rural societies indicated that neurological conditions are thought and believed to be due to wrong behaviors such as breaking a taboo, witchcraft, or due to evil people or spirits. It is also generally believed that for these chronic neurological conditions, orthodox or western medicine has no cure or management. Rather cure is rooted in divine intervention. Also personal interaction with parents who have children with neurological disorders in rural communities and in practice indicated that neurological illness in children with unpredictable characteristics puts the family at risk for poor communication, poor cohesiveness and poor integration. The burden of care may fall more heavily on one member who is mostly the mother which may lead to resentment and increased family and social tension.

Large part of the morbidity and mortality from neurological problem seen in children are preventable. The reasons why these preventable diseases result in permanent disability in children are rooted in poverty, ignorance and tradition. In rural societies, neurological conditions are thought and believed to be as a result of wrong behaviors, breaking a taboo, witchcraft, or due to evil spirits. It is also generally believed that for these chronic neurological conditions orthodox or western medicine has no cure or management.

All families of neurologically ill children are under some stress, particularly the mother who may devote time to the child at the expense of other family members and her career.

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The question then is what are the psychosocial problems that families of neurologically ill children face particularly the mother, who may devote time to the child at the expense of other family members, education, and careers? What are the effects of long-term illness on family and social life? What are the parents' views regarding provision of adequate information on the management of neurological conditions of their children? What are the parents' beliefs about the causes and management of neurological disorders in children?

No literature was found on studies into psychosocial problems facing parents of children with neurological deficits in Ghana. Nevertheless, there is recognition of the crucial need to promote the awareness of the problems for better management of these neurological disorders in children which may reduce the burden on the parents and the family.

1.2 Purpose of the Study

The purpose of the study was to identify and describe the psychosocial problems of parents of children with neurological disorders in Ghana and to make recommendations for future health policy formulation, implementation, and future research in the area.

1.3 General Objective of the Study

The main objective is to examine the psychosocial problems that parents of children with neurological disorders at the Neurodevelopmental Clinic (NDC) at Korle-Bu Teaching Hospital (KBTH) in Ghana encounter.

1.3.1 Specific Objectives of the Study

1. To describe beliefs of parents/caregivers of children regarding causes and management of neurological disorders.
2. To describe the level of anxiety, stress and depression among parents/caregivers whose children have neurological disorders.

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3. To explore the impact of a child’s neurological illness on parents/caregivers, the family and their social life.
4. To describe the demographic characteristics of caregivers/parents whose children have neurological disorders.
5. To make recommendations for health care providers on management, education and prevention of neurological illness where applicable.

1.4 Research Questions

1. What are the beliefs of parents/caregivers of children regarding causes and management of neurological disorders?
2. What are the levels of anxiety, stress and depression among parents/caregivers whose children have neurological disorders?
3. What are the impacts of a child’s neurological illness on parents/caregivers, the family and their social life?
4. What are the demographic characteristics of caregivers/parents whose children have neurological disorders?

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1.5 Significance of the study

Psychosocial problems that parents of children with neurological disorders encounter at Korle-Bu Teaching Hospital (KBTH) and their relationship to specific variables such as gender, age, marital, and employment status, level of education, frequency of medical consultations and involvement in social activities will be explored. The outcome of this study will pave the way to further research on the psychosocial problems of parents of children with neurological problems.

Exploring these problems that parents of these children encounter may be a step in the right direction on which provision of care can be based in relation to patient management, education/teaching, and counseling towards the prevention of complications.

The relationship between parents' psychosocial problems and their demographic variables will be examined. Findings of this study will be relevant for health education of parents with neurological deficit children.

Also findings of this study may provide baseline data to the development of a collaborative effort in which nurses and parents/caregivers as well as other healthcare professionals work together in partnership to provide care for neurologically ill children.

1.6 Definition of Terms

- Neurological disorders – disease conditions that affect the nervous system that produce neurological deficit(s)
- Parents – any adult taking care of a child with neurological disorder(s). This includes biological or foster parents of both sexes.
- A child – any person within the age range of zero to thirteen years.

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CHAPTER TWO

2.0 REVIEW OF LITERATURE

The purpose of the literature review for this study was to explore the psychosocial problems of parents of children with neurological disorders.

Impairment may be congenital or acquired and may vary in duration and severity. Parents of children with neurological disorders / neurological illness are frequently confronted with various kinds of psychosocial and practical problems that sometimes cause high level of parental distress. These include emotional problems such as fear, depression and worry, reduce satisfaction in their marriage, practical and financial problems, problems related to educational task as well as reduced levels of self esteem and self confidence.

This is because the child who is developmentally limited and has difficulty performing basic skills of self care or performing in age appropriate task may be a source of worry for the parents especially the mother. Such a child may be singled out and treated as the cause of all the family problems. The reasons given for scapegoating may include difficult temperament different appearance disability of health status. Scapegoating may indicate a parent child mismatch or disappointment in the child who does not fulfill parental expectation. The parents must try to manage their personal, social and occupational activities whiles continuing to provide for their child’s needs. Sometimes one parent particularly the mother may have to end her employment outside the home to take care of the child. This may lead to a reduced income for the family and therefore the reduction in pleasurable activities.

Typical parental responses to the diagnosis of neurological illness are shock, devastation, anger, frustration, sorrow and depression. Parents may experience periods of fatigue, discomfort or immobility related to treatment regimes that necessitates modification in daily routines, social

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withdrawal, anxiety and embarrassment. The multiple stresses associated with neurological illness and parenting may intensify the family's vulnerability for child maltreatment. Some of the neurodevelopmental disorders require frequent medical visits, expensive medication, time consuming treatment and periodic hospitalization.

2.1 Psychosocial Problems of Parents

In their study Kausar and Powell (2005) examined the coping levels and psychological distress experienced by parents/care givers, in relation to the post-onset personality and physical changes in patients with neurological disorders. The participants of the study were 112 parents/caregivers (either a close relative or a friend) of patients. It was hypothesized that the distress levels experienced by the parents/caregivers would be in relation to the degree of personality changes, and that psychological distress in parents/caregivers would be predicted by the strategies they employ to cope with post-onset changes in the patient. Assessment of the parents/caregivers was carried out 4-18 months after the onset of neurological disorders in the patients. Coping was assessed using the "Ways of Coping Questionnaire". Psychological distress in parents/caregivers was measured in terms of the subjective burden, anxiety and depression they experience. The Leeds' scales for anxiety and depression, and a 10 point rating scale were used to measure subjective burden in parents/caregivers. Data were analyzed using t-test analysis, correlation and regression analyses. It was found that parents/caregivers experienced an enormous amount of psychological distress. Those parents/caregivers who were more dependent on emotion-focused coping styles reported greater distress as compared to those who depended more on problem-focused strategies. These findings have important implications for rehabilitation and community care. Sanjeev and Bindu (1999) undertook a study to ascertain psychological and economic problems among patients attending a tertiary referral centre for

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epilepsy in India. A structured questionnaire was administered to parents of 50 children aged between 5 – 10 years who had epilepsy for more than one year’s duration. Some 52% of the children had epilepsy whilst the remaining had generalized epilepsy. The majority of the patients (86%) were living in the villages and the family income was less than $1USD for 66% of the patients. A decline in social activities, after the onset of epilepsy in their children, was reported by 80%of the parents. Daily routines were significantly affected in over 75% of the parents. Parents had been experiencing frustration (52%) and hopelessness 76%, whilst 60% were in financial difficulties. The most important item of expenditure was cost of drugs or cost of travel to hospital for 54% and 36% parents respectively. Impaired emotional status and poor social adaptation were co-related with the severity of epilepsy (frequent seizures/generalized seizures/attention disorder) and low economic status of the parents.

The sample size was too small and the results cannot be generalized. The researcher used descriptive statistics. Inferential statistics would have made the results obtained from the study more likely to be real and replicable.

An essential component of quality nursing care is nurses’ ability to work with parents in the hospital care of their children. However, changes in the health care environment have presented nurses with many new challenges, including meeting family centered-care expectations particularly children and their families with special needs. Espezel and Canam (2002) in their study examined parents who interacted with nurses in hospital settings regarding the care of their children. A qualitative approach was employed to conduct in-depth audio taped interviews with eight parents representing seven families. Data collection was completed over a seven-month period. Findings indicated that parents related their experiences with nurses caring for their children in the form of interactions, and identified the elements of establishing rapport and

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sharing children's care as a key positive perception of the interaction. These elements were influenced by parental expectations of the nurse; changes in the nurses' approach were reported by the parents as the children's condition changed.

The study provided an in-depth perception of parents' experiences in the care of their children. However, their interactions with the nurses did not constitute collaborative relationships. A deeper understanding of these interactions may provoke new thinking about how to promote an agency's philosophy, and how nurses enact this philosophy in practice. The sample size was not large enough to be generalized.

Daoud, Dooley and Gordon (2004) examined depression, self-esteem, and mastery in the family caretakers of a group of males with Duchenne muscular dystrophy in comparison to a control group. A questionnaire based on the National Population Health Survey from Statistics Canada, a survey to collect information on the health of the Canadian population and related socio-demographic information, was conducted by telephone with 42 parents. The results were compared with the national data from the National Population Health Survey (1994 and 1999); matched for province of residence, number of children in the household, age, and marital status of the respondents. Parents of children with Duchenne muscular dystrophy had a higher probability of going through a major depressive episode and had significantly lower self-esteem and mastery scores than the national control group. None of the variables investigated (age, intelligence quotient, and ambulatory status of child or sex, age, and marital status of parent) could predict the depressive episode, with two exceptions. Parents without a partner had lower scores on the mastery scale, and parents of males older than 13 years of age were more likely to experience distress that interfered with life. It is incumbent on those caring for patients with

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Duchenne muscular dystrophy to counsel families regarding their potential to suffer a major depressive episode and to advise on appropriate therapy.

Chen and Clark (2007) investigated the relationships of child- and family-related variables with family function in families of children who had Duchenne muscular dystrophy. Child-related variables included level of disability (indicator: Barthel Index) and age at diagnosis. Family-related variables included caregiver health status (indicator: Duke Health Profile), family income and employment, family support (indicator: Family APGAR), family hardiness (indicator: Family Hardiness Index), and family functioning (indicator: Family Assessment Device). Family function displayed a significant correlation with age at diagnosis, but not with disability level. It was also significantly correlated with caregiver health status, and levels of family support, but not with income or employment variables. These findings highlight the need to assist families to cope with the presence of serious illness in their children.

In a study by Van den Borne,Van Hooren, Van Gestel, Rienmeijer, Fryns and Curfs (1999) into psychosocial problems, coping strategies and the need for information of parents of children with Prader-Willi syndrome and Angelman syndrome. The study results show that a number of parents are very concerned about the possible disappointment with which their child may be confronted in the future. The loneliness of their child and a worsening of the child’s disabilities. A comparison in the two parent groups shows a significant difference in these kind of concerns (t = -24430;P = 0.02). The Prader-Willi parent group has a higher concern about possible negative consequences for the child than the Angelman parent group. This was also found in an analysis based on only two parent families (t = -2581;P = 0.01).

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On the fear of negative consequences for the parent themselves, both groups have a lower level of fear as compared to fear for negative consequences for the child. Some parents expressed the fear of losing their patience with their child, fear of not being taken seriously when talking to others about their child, fear of needing to depend on other people because of their child's disability and fear of visiting other people with their child.

On the issue of loss of control, many parents feel a high level of loss of control indicated by feelings like their hands and feet are more tied, "not feeling able" to handle their affairs as before, thoughts that wonder to concerns about their child and more financial burden. A significant difference (t = 3164; P = 0.002) between both parent groups was found with parents of children with Angelman syndrome reporting more loss of control.

The difference remains significant for parents of families consisting of two parents only. The results also indicated a great need for information for parents with respect to many different aspects that may impact on the development of future prospects of their children. In another study by Sanjeev and Bindu (1999) psychosocial and economic problems of parents of children with epilepsy was studied. A structured questionnaire was administered to parents of 50 children aged between 5-10 years and having epilepsy for more than 1 year duration. Majority of the parents (86%) were living in villages, 80 of the parents reported a decline in social activities after the onset of epilepsy in their children. Daily routines were significantly affected in over (75%) of parents. Parents have been experiencing frustration (52%) hopelessness (76%) whiles (60%) were in financial difficulty. Impaired emotional status and poor social adaptation were correlated with the severity of epilepsy and low economic status of the parents

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In a paper by Ashum and Singhal (2005) on psychosocial support for families of children with autism. The paper drew attention to the stress level and coping strategies in the families of children with autism. The paper highlighted the importance as well as lack of providing psychosocial support to the families of children with autism. The paper indicated that the characteristics that are common among children with such disease condition contribute to parenting stress include scattered intellectual abilities or isolated skills and pervasive problem behavior such as self stimulatory behavior. It also pointed out that behavioral social and cognitive dimensions of the disorder re associated with stress in parents.

2.2 Nurse-Parent Relationships

Espezel and Canam (2003) stated that the parent-nurse relationship is considered to be a cornerstone of quality pediatric nursing care. This long standing view is manifest in the family-centered care philosophy embraced by most health care organizations on a global scale. However, while family-centered care is promoted philosophically by policy makers and nursing leaders, it is unclear as to how this espoused view is enacted in practice. Also, the congruency between parental expectations of nursing care and nurses' ability to meet these expectations is even less certain, particularly within the current health care environment which has inadequate staffing levels and focus on efficiency and cost-effectiveness.

Families are increasingly the primary care givers in chronic neurological childhood illness with, in practice, mothers providing most care. Chronic illness diagnosis may be protracted, either because of the vagueness of early symptoms or as a result of skepticism of professionals. Swallow and Jacoby (2001) found that professional skepticism, non negotiation of roles and inadequate information provision undermine parents' self confidence and impinge on their

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coping abilities. Some authors concluded that this places strain on the families' physical, financial, and emotional resources. Swallow and Jacoby (2001) indicated that the quality of relationships between families and professionals is central to the experience of living with chronic neurological childhood illness.

Attempts to understand the significance of relationships between patients, carers, and health professionals in chronic illness management have highlighted several factors that may influence their satisfactory development. Darbyshire (1994) in a study sought to understand the experiences of parents who live with sick children in hospital and their relationships with pediatric nurses. She concluded that during periods of hospitalization, although nurses and doctors make the child a priority, they also co-create relationships with parents. Whilst there is a growing body of literature addressing interactions between parents and nurses; parents and the hospitalized child; and between nurses and the sick children, there is paucity of literature exploring relationships with children with long-term chronic neurological illnesses and parents of these children. It was stated that the caring relationships were recognized as being problematic; however, little is known about the meaning this has for pediatric nurses' practice (Darbyshire, 1994).

Totka (1996) conducted a study exploring pediatric nurses struggle to find the right level and kind of involvement with children and their families, and found that highly synchronous relationships usually occur in long-term relationships and they appear more frequently though not exclusively, with chronically ill patients.

Interaction between parents and professionals is thought to be most effective when it is based on reciprocal interchange. Through reciprocally sharing knowledge, teaching skills and coaching families to navigate the health care system the knowledge competence gap between

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family and professional is narrowed (Espezel & Canan, 2003). Espezel and Canan (2003) indicated that the way in which information is exchanged between families and professionals, and is understood by each, helps to shape the tone of collaboration. Clear communication is a precursor to collaboration, as it expedites accurate determination of care needs. Mutual goals are developed more easily, and understandings leading to conflicts are avoided when the expectations are clearly articulated at the beginning of the interaction. The attitudes of health professionals will create a climate that can either support or impede collaboration. Willingness to participate in a collaborative relationship greatly affects the success of the collaboration.

Various authors have expressed differing views on parent professional interactions, although there seems to be general agreement that these interactions greatly influence the quality of children’s health care. The value of parent-professional collaboration is emphasized as the elements necessary for a successful collaboration between parents and nurses. These elements include establishing rapport, developing trust, and communicating clearly, and are influenced by professionals’ attitudes and families’ willingness to participate.

2.3 Establishing Rapport

Espezel and Canan (2003) examined qualitatively the experiences of parents who interacted with nurses in a hospital setting regarding the care of their children and found that establishing rapport appears to be a precondition to engaging in collaborative behavior. Families are better able to establish rapport with health professionals when there is a common and relevant goal. When rapport is established between parents and nurses, they could more easily work with each other to share children’s care, resulting in individualized care. It was concluded that the degree of rapport established between parents and nurses is influenced by the nurses’ knowledge of the child, and the nurses’ knowledge of the disease condition, and the ability to find a common

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connection. A key aspect of parents' perspective is the nurses' demonstration of interest in learning about the child's condition and the child as a person. When the nurses demonstrate that they know something about the child, parents feel more comfortable with the care that they receive.

2.4 Before the Diagnosis, Being taken Seriously

The relationships which developed between mothers and medical and nursing staff before diagnosis are strongly influenced by mothers' perceptions of these professionals' trustworthiness and credibility. The relationships are very important to mothers with children with special needs. One of the most important issues facing them is the need to identify staff in which they feel completely confident. Some mothers' started with little or no previous experience of communicating with doctors or nurses about their child. In this case, a professional's willingness to take seriously the concerns of these mothers about their child and the ability of that professional to communicate information at the appropriate level are qualities mothers' value. Perhaps because of the vague and confusing nature of early symptoms, mothers' first approaches to staff may often be very tentative. If concerns are dismissed as insignificant, they often feel resentful towards the professional and lose confidence in them. Some who have faced professional skepticism, subsequently lost trust in the professional and so are likely to delay pursuing the problem further. Those mothers with previous experience with a chronic illness, either their own or a child's are more likely to question the professional's competence if their concerns are trivialized and to approach other professionals until they receive satisfactory acknowledgement of their concerns (Espezel and Canan, 2003).

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2.5 After the Diagnosis, Managing Relationships

Moving along, mothers adopt various strategies for communicating with professionals. Some mothers are more confident in their ability to communicate successfully and consequently may attain a more interactive role in their children's management and reach a stage of participatory competence. Those who attend a hospital several times after their children's diagnosis, become selective about staff in whom they place their trust. This appears to depend on whether or not staff takes the mothers' concerns seriously early (Swallow & Jacoby, 2001).

Establishing rapport also involves sharing information between the parents and the nurses. Through this reciprocal exchange, parents come to know the nurses caring for their children. However, information is not immediately shared freely. Spending time together is important for each party to establish rapport, and to feel comfortable with each other. In general, more contacts translated to a better rapport. Consistency of staff is often mentioned as a positive aspect of care. Specifically, repeated contact with a small group of nurses was important in fostering a climate conducive to establishing rapport. Factors that influence or interfere with the development of rapport between parents and nurses are environmental barriers, which give rise to a colder, more impersonal atmosphere.

Espezel and Canan (2003) in their study found that the parents were not prepared for the impersonal tone of the health care settings and were appalled at the assembly line approach. The physical environment of the health care settings influences parents ease in establishing rapport with nurses working in those areas, and parents often comment on the impersonal nature of the environments. The hospital environment often causes a deep sense of fear and anxiety in parents, who feel insecure in hospital.

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Another factor was consistency of staff; although parents view consistency as positive, they mostly experience a high rate of staff turnover. The ease with which rapport is established between parents and nurses, and the degree to which the children's care is shared, is influenced by the parent's expectations of the nurse, and by changes in how care is shared between parents and nurses.

2.6 Parental Expectations of the Nurse

The parent-nurse relationship is considered to be a cornerstone of quality pediatric nursing care. Attempt to understand the significance of relationships between patients, careers, and health professionals in chronic illness management have highlighted several factors that may influence their satisfactory development. During periods of hospitalization, although nurses and doctors make the child a priority, they also co-create relationships with parents. Darbyshire (1994) sought to understand the experiences of parents who live in with sick child in hospital and their relationships with pediatric nurses. Totka (1996) who conducted a study exploring pediatric nurses struggle to find the right level and kind of involvement with children and their families, found that highly synchronous relationships usually occur in long-term relationships and they appear more frequently though not exclusively, with chronically or terminally ill patients.

2.7 Chronic Illness and Stress in the Family

A philosophy of family-centered care based on the belief that all families are deeply caring and want to nurture their children, is considered central to the nursing care of a hospitalized child (Ford & Turner 2000). Integral to the child's care there are many barriers to providing family centered care to hospitalized children in general and to children with special needs. This was also proposed by Ford & Turner, (2000).Several studies have demonstrated a noticeably elevated

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incidence of behavioral disturbances among families of children with neurological problems. Psychosocial adjustment of adolescents with health disorders has been studied extensively. However, it is unclear whether different health disorders have specific impact on adjustment, or disorder in general relates to the development of adjustment difficulties as a factor limiting adolescent's physical and social activity. Gostautas and colleagues (2006) have reported that psychosocial adjustment, difficulties and low self-esteem are more prevalent in clinical groups as compared to healthy controls. Among the clinical group, neurological disorders were associated with difficulties in emotional and cognitive functions and higher suicidal tendencies. Results showed that emotional-mood difficulties and low self-esteem were more prevalent and severe in the clinical groups compared with the healthy controls, while the prevalence and the severity of conflicts are higher among students. Comparison of both clinical groups shows that neurological disorders are related to higher prevalence of difficulties in emotional and cognitive functioning and higher severity of suicidal tendencies, while physical disorders relate to higher prevalence of behavior difficulties.

Korneluk, Kuehn, Keene and Ventureyra (2001) conducted a study in which psychosocial functioning following surgical treatment for intractable epilepsy in childhood was analyzed. Psychosocial functioning was examined in 13 children who had undergone surgical treatment for intractable epilepsy. The ratings of each child's social, emotional and behavioral problems were obtained via parent and teacher reports made an average of 2 years post-operatively. Results indicated that parents viewed their children as having greater social difficulties than reported in other samples. Although the overall level of difficulty fell below clinically significant cut-offs, the proportion of children who were rated as having clinically significant levels of difficulties approached significance. Teachers rated these children as displaying more symptoms of anxiety

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and depression, although the levels remained sub clinical. These results were discussed in view of the complex interaction between neurological and environmental variables involved in social, emotional functioning following surgical treatment for epilepsy.

The results cannot be generalized because the sample size was too small. The lens used by the researchers is not based on scores, instruments, or research design but lens established using view point of people who conducted, participated in or read and reviewed the study.

In another study by Rodenburg, Stams, Meijer, Aldenkamp and Dekovic (2005) to examine the types and severity of psychopathology in children with epilepsy. The results indicated effect sizes were medium to large for comparisons with children from the general population, which indicates that children with epilepsy are at increased risk for psychopathology, including internalizing and externalizing behavior problems. Comparisons with children with another chronic illness revealed small to medium effect sizes, indicating that psychopathology in children with epilepsy may partly be attributed to chronicity of the disease. Attention problems, thought problems, and social problems proved to be relatively specific to epilepsy. Comparisons with siblings suggested that psychopathology in children with epilepsy may be associated with family factors, especially where behavioral disorders appear to be more generic. It was concluded that clinicians should consider both neurological and psychosocial factors, including the family system, when treating psychopathology in children with epilepsy.

Psychopathology in children with epilepsy was sufficiently well-defined that warrant an evaluation of the studies. The objectives were stated clearly as behavioral objectives. Clients who have epilepsy will benefit from the evaluation in which neurological and psychosocial factors should be considered when treating psychopathology in children with epilepsy.

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Wiebe, Bellhouse, Fallahay and Eliasziw (1999) in their study assessed the frequency, general health, psychosocial function, and health care resource use among self-identified epileptic persons in the general population. The 1990 Ontario Health Survey is an omnibus, extensive health survey of 61,239 subjects representing the Ontario population. Self-reported epileptic subjects are compared with three groups, i.e., those with ≥ 1 other chronic illnesses, the general population, and those with no health problems. The point prevalence of self-reported epilepsy was 5.8 per 1,000 populations, a figure similar to that of active epilepsy in other studies. Quality of life, family function and social support were worse in epileptic than in other chronically ill subjects. Similarly, the epileptic population had more disability days and limitations in activities, and lower annual income than all other groups, including the chronically ill. Accidents were no more common among epileptic subjects than among controls. Epileptic persons were high users of health care resources, including hospitalization, emergency room, psychological/social work, nursing services and telephone contact with health professionals. Barriers to health care were experienced infrequently. Small area variations in health status and care are explored. It was concluded that the health profile of self-reported epileptic subjects is similar to that obtained in studies involving defined epilepsy patients. In the general population, self-identification as having epilepsy carries a significant burden of illness, reflected in poorer health, psychosocial function, and quality of life, and higher health care resource use.

Ohlsson, Breau, Stevens, McGraft, Beyene, Howlett, Finlay, Frank, Gibbins, Camfield, Mckeever and O'Brien (2003) conducted a study to determine whether health care professionals believe the pain experience of infants at risk for neurological impairment (NI) differs from that of other infants. A prospective questionnaire was answered by 99 health care professionals made up of 51 nurses, 19 physicians, 18 respiratory therapists and 11 others who worked in Level III

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Neonatal Intensive Care Units in two tertiary care children hospitals in Canada. Participants completed Pain Opinion Questionnaire (POQ) which elicited beliefs regarding the similarity of the pain experience of infants at low, moderate and high risk for NI to that of infants of with no risk for NI along five pain facets – sensation, frequency, and emotional reaction, behavioral reaction and communication. The results indicated that POQ scores varied due to level of NI (mild, moderate, and severe) and pain facet. Respondents in the study believed infants with NI were less likely to experience pain similar to infants without NI as level of NI increased. Post hoc matched sample t-tests revealed each facet differed significantly between the three groups. The infants with moderate NI were not viewed as having significantly reduced pain sensation or frequency relative to infants with mild NI POQ scores did not vary due to profession, experience, gender or age. It was concluded that professionals expressed the belief that neurologically impaired infants' pain experience is reduced, relative to infants without impairment, as their level of risk for neurological impairment increased.

In a similar study Ohlsson *et al*, (2003) studied whether healthcare professionals' awareness of infant's risk for neurological impairment (NI) affects their perception of the pain experienced by that infant. A prospective study based on a series of videoclips of infants presented as having differing risk of NI. The study participants were made up 50 nurses, 19 physicians, 17 respiratory therapists and nine others who practice in level III NICU in two tertiary care children's hospital in Canada. In the study, participants provided ratings of pain (0 – 10), Faces Pain Scale, distress (0 – 10), effectiveness of cuddling (0 – 10), expected time to calm, and degree of risk for NI for nine video clips of infants receiving painful procedure. The results showed that rating for pain varied nonsignificantly due to the level of risk described. More detailed analyses revealed professionals believed infants with moderate risk had significantly more pain than those with

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mild risk. Ratings of distress did not vary with level of experience with this population under study, site, gender, or age, but physicians rated all aspects of the pain infants experience as reduced, relative to other professionals. It was concluded that professionals caring for infants in the intensive care setting who rated the pain experience of infants were affected by the infants' level of risk for neurological impairment. They also believed that intervention will be less effective for infants with greater risk.

Also Bernal, Valdizan and Gamcia (2004) researched into a number of subjective reports (especially from parents) describing sleep disorders. The objective verification of these disorders and the exact nature of the sleep problems are still to be determined and the purpose of this study was to deal with these issues. They studied a sample of 48 children (9 females and 39 males) with a mean age of 8 (SD: 2.59) who met DSM IV criteria. They were submitted to a general exploration as well as a neurological exploration, including their patient record, and then they were evaluated using the DSM IV, which was carried out by parents and teachers (in order to evaluate two different environments), and a nocturnal polysomnographic study. In the sample there were 26 children with predominant attention deficit type ADHD (ADHD/AD); 4 children with predominant hyperactivity impulsivity type ADHD (ADHD/H); and 18 children with combined type ADHD (ADHD/C). The results showed the most frequently diagnosed subtype is the attention deficit subtype. The sleep architecture of children with ADHD presents the most consistent differences as compared to normal children in an increase in the percentage of phase 3 of sleep and, consequently, an increase in the percentage of slow sleep. Epileptiform type paroxysms were observed in 16.7% of the children who presented symptoms of ADHD. The number of epileptiform paroxysms is more usual in the attention deficit subtype. It was concluded that the increase in phase 3 may be related to the alterations in noradrenaline and

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dopamine transmission present in children who suffer from ADHD. Some children with ADHD can have a region of the brain with intense epileptic activity, which does not trigger epileptic seizures but gives rise to behavioral disorders, learning disorders and language problems.

The study used a standardized scale (DSMIV) which gave it more credibility. It is useful in adding new areas to existing knowledge.

Narcolepsy is a neurological disorder characterized by excessive somnolence during the daytime, with recurrent, irresistible episodes of sleepiness. The complete forms are associated with cataplexy, hypnagogic hallucinations and sleep paralysis. The incidence reported in adults is 4 10/10,000. A considerable proportion of adults consider their disorder to have started before the age of 15 years. It is essential to have neurophysiological confirmation of the short period of the onset of REM sleep for diagnosis. Martinez-Salcedo, Lioret-Sempere, Garcia-Navarro and Selles-Gallana (2002). Martinez-Salcedo et al. studied an eleven year old boy with diurnal hypersomnolence, behavior disorder and weight gain. He was evaluated in the Sleep Disorder Unit by polysomnography and the multiple latency tests, which confirmed the suspicion of narcolepsy. It was concluded that narcolepsy is a disorder which starts during childhood and usually goes unnoticed or is erroneously diagnosed and treated. At the present time there are valid criteria for the identification and diagnosis of children with this disorder. Treatment of these patients should be orientated towards adaptation of the environment to the child and prevention of the psychosocial problems which may be caused by this disorder, in view of the poor response to the drugs used. Because the researchers became intensely involved with the subject, objectivity might be compromised; it cannot be counted on to produce valid generalization. The dynamics of one person’s physiological or psychological functioning may bear little resemblance to those of other persons.

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Before the widespread introduction of combined antiretroviral therapy (1995) complications from HIV and AIDS in the central nervous system had been reported in larger proportion in infants and children than in adults: 80-90% versus 60-70%. Particular clinical manifestations tend to occur at different stages during the evolution of HIV infection (Kollar, Jelenik & Hegelsberger, 2004). Kollar *et al* (2004) reviewed the neurological aspects of HIV infection. First, a summary of the protocol of the neurological examinations and related experience is given. Then authors present the evaluation of neuro-psychological development, prevalence of neurological impairment and neuro-imaging of nine HIV infected children (seven boys, two girls) for the period of ten years (1991-2001). Three out of ten children had vertically transmitted HIV six out of nine were infected by a nosocomial route in their early childhood. Children were regularly followed up from the diagnosis of HIV. The median follow up time has been 79 month (range: 18-144 month). Four patients died during the study period. The neurological status, the motor and mental development were examined at three month intervals or monthly under one year of age. EEG was performed every six month and CT/MRI once a year. All patients received combined antiretroviral treatment and immunoglobulin therapy continuously. Results indicated that three out of nine children have normal development, one out of nine has hyperactive and attention deficit disorder with normal IQ range, two out of nine had slight, one/nine moderate and two/nine serious mental retardation. Mild neurological signs were found in two children, various moderate and serious neuro/psychological symptoms were found in four patients, one of them was treated for benign epilepsy too. There was also close correlation between the clinical symptoms and the results of EEG examination (diffuse background slowing) and results of neuroimaging studies (cortical atrophy, calcification of the basal ganglia, toxoplasma abscesses). According to the results of different examinations three out of nine children were found to be

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symptom-free, one out of nine cases showed the static form, two out of nine patients showed the plateau form, two out of nine the rapid progressive form and one out of nine the progressive infantile form of AIDS encephalopathy. The majority of the patients suffered from adopting problems and difficulties of socialization since their family lives were damaged by isolation and rejection from the community. It was concluded that the regular neurological and psychological examinations completed with EEG, CT/MRI were very informative to follow the course of neuro-psychological problems of HIV infected children. Symptom-free patients have to face psychosocial problems too, which cause much more damage in their mental progress than HIV itself.

In a study conducted by Boni, Brown, Davis, Hsu and Hopkins (2001) to examine social information processing, social skills, and adjustment difficulties in children with sickle cell disease (SCD) as rated by caregivers, teachers, and the children themselves, children were classified in two groups: cerebral vascular accidents (CVA) (n = 21) or without central nervous system (CNS) pathology (n = 20) on magnetic resonance imaging (MRI). Both groups had HbSS SCD. These two groups were compared with a third group of 11 children who had a milder type of SCD (HbSC). Participants referred for evaluation of learning and behavior problems were administered MRIs to ascertain the presence of pathology and a series of measures designed to assess nonverbal emotional decoding abilities and ratings of social emotional functioning. Results showed that Children with CVA displayed more errors on tasks of facial and vocal emotional decoding than did comparison controls without CVA. It was concluded that acquired neurological impairments in children with SCD seemed to be associated with difficulties in the decoding of emotions of other children and adults. The sample is not sufficiently large to be generalized. The subjects in the sample varied to some degree from one another with respect to

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the severity of SCD. There is slight difference in clinical manifestations of SCD in the two groups – HbSS and HbSC. However it provided useful information that would guide practice.

Spratt, Zebenholzer and Oder (1997) in their study of psychosocial long-term outcome of severe head injury as perceived by patients, relatives, and professionals, they systematically compared information on psychosocial outcome of severe head injury (SHI) gathered from different informants. They evaluated psychosocial outcome in 33 subjects 8.1 +/- 1.4 years after having suffered SHI using data gathered from the patients themselves, caring relatives, and an assessing neurologist. Their data confirm long-lasting negative effects of SHI on psychosocial functioning even in patients with only mild or moderate neurological impairment. Specific problems in, stemming from impaired self-control, are regularly reported by the relatives and probably underestimated by the patients and by the doctors. In contrast, they found a remarkable agreement between self-report and professional estimation in other aspects of psychological consequences of SHI such as depressed mood and social withdrawal. Their results challenge the common view that patients having suffered from severe SHI are altogether unreliable informants. However, SHI patients tend to have difficulties in monitoring their specific problems of control of behavior in social relationships. Therefore information gathered from the caring relatives should always be included when evaluating psychosocial sequels of severe SHI. The sample size is not large enough to be generalized. There is the question of validity and accuracy as verbal report instruments could potentially require respondents not to admit or admit to socially unpopular or popular behavior or beliefs.

Ornoy, Michailevskava, Lukashov, Bar-Hamburger and Harel (1996) studied the possible role of in-utro exposure to heroin and of the home environmental in the etiology of long-term developmental problems in children born to heroin-dependent parents in comparison to matched

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controls. The children were examined at five to six years of age by a developmental pediatrician and a developmental psychologist, for the children up to 2.5 years of age using the Bayley Developmental Scales, and for children aged 3-6 years using the McCarthy Scales for Children's Abilities. The researchers examined 83 children born to heroin-dependent mothers, and compared the results to those of 76 children born to heroin-dependent fathers and to three control groups; 50 children with environmental deprivation, 50 normal children from families of moderate or high socioeconomic class, without environmental deprivation, and 80 healthy children from kindergartens in Jerusalem. There were five children (6.0%) with significant neurological damage among the children born to heroin-dependent mothers and six (7.9%) children among those born to heroin-dependent fathers. The children born to heroin-dependent mothers had a lower birth weight and a lower head circumference at examination when compared to controls. The children born to heroin-dependent parents also had a high incidence of hyperactivity, inattention, and behavioral problems. The lowest DQ or IQ among the children with cognitive levels above 70 was found in the children with environmental deprivation, next was the DQ or IQ of children born to heroin-dependent fathers, then the DQ or IQ of the children born to heroin-dependent mothers. When the children born to heroin-dependent mothers were divided to those that were adopted at a very young age and to those raised at home, the adopted children were found to function similarly to the controls while those not adopted functioned significantly lower. Results showed that the developmental delay and behavioral disorders observed among children born to drug-dependent parents raised at home may primarily result from severe environmental deprivation and the fact that one or both parents are addicted. The specific role of the in-utero heroin exposure in the determination of the developmental outcome

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of these children (if they do not have significant neurological damage), seems to be less important in comparison to the home environment.

In a related study conducted by Sherman, Slick, Connlly and Eyrl (2007) to clarify the prevalence of Attention deficit hyperactive disorders (ADHD), its neurological correlates and the role of ADHD in health-related quality of life (HRQOL) in children with severe epilepsy, data from the ADHD Rating Scale-IV (ADHD-RS-IV) from 203 children (mean age = 11.8, SD=3.8) from a tertiary center serving children with severe epilepsy were reviewed. Results indicated that inattention was frequently elevated in the sample (40% vs. 18% for hyperactivity-impulsivity). Age of onset, epilepsy duration, and seizure frequency were not related to severity of inattention or hyperactivity-impulsivity. Over 60% of children met screening criteria for ADHD-Inattentive subtype (ADHD-I) or ADHD-Combined Inattentive/Hyperactive-Impulsive subtype (ADHD-C). Compared to ADHD-I, ADHD-C was associated with earlier onset of seizures, generalized epilepsy, lower adaptive level, and in normally developing children, a higher degree of intractability compared to ADHD-I. ADHD-I was more prevalent in localization-related epilepsy, and there was a trend for a higher use of AEDs with cognitive side effects in this group. ADHD was associated with poor HRQOL: children with ADHD-I and ADHD-C had a two- and four-fold likelihood of low HRQOL, respectively, compared to non-ADHD children. It was concluded that children seen at tertiary care centers for severe epilepsy are at high risk for attention problems and ADHD, and ADHD is a significant predictor of poor HRQOL in epilepsy, particularly in the case of ADHD-C. ADHD occurring in the context of severe epilepsy appears to be associated with specific neurological characteristics, which has implications for comorbidity models of ADHD and epilepsy.

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Prematurity represents one of the risk factors of newborns' mortality, morbidity and derangements of long-term neurological development. Kipiani, Tatishvili and Sirbiladze (2007) conducted a study into long-term neurological development of preterm newborn. The goal of their study was evaluation of the preterm newborn, with gestation age <=37 weeks, estimation of their neurological development at the later age (6-7) months and comparing them with full-term born infants of the same age. There were 94 preterm newborns and 50 full-term newborns were estimated in the neonatal period and then later at the age of 6-7 years. The methods of evaluation used at the age of six were: Standard full neurological investigation, GMFM scale (gross motor functional measure), Towen Scale for evaluation of minor motor activity, Raven Color Matrix for estimation of non-verbal cognitive functions, Coners Questionnaire for parents - for revelation of disadaptation. Cerebral palsy among preterm infants was observed in 15 cases-16%; in control group- one case-2%; Dyspraxia syndrome was observed in 32 cases-34%, in control group nine cases-18%. The results of evaluating gross motor function with GMFM score for term group was higher, than for preterm group: 95, 86 vs. 83, 52, p<0,001. The results of the evaluating nonverbal cognitive function with Color matrix of Raven test are higher in term group: 20, 20 vs. 16, 6; p<0,001 Syndromes of behavioral disadaptation have been observed more often among preterm newborns Score for each part (problem of control; impulsivity, index of hyperactivity) were higher in preterm children, p<0,001. Low birth gestation can be a real risk factor for the later neurological development. Cerebral palsy and dyspraxial syndrome is probably more among newborns with low gestation than among control group contingent; the results of the evaluation nonverbal cognitive function with Color matrix of Raven test are higher in term group. Syndromes of behavioral disadaptation have been observed more often among preterm newborns. Because of frequent//high percent of neurodevelopmental problems preterm

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contingent require continuing monitoring, evaluation in dynamically for early distinctions mild problems.

Were and Bwibo (2006) evaluated neurological outcomes of very low birth weight infants (VLBW) at two years of age. In the study, longitudinal descriptive survey of 120 infants born weighing by1000grams to 1500grams at Kenyatta National Hospital's Newborn Unit was followed up till the age of 24 months. Of the 120 infants evaluated, 14 (11.7 %) had cerebral palsy, 11 (9.2%) were delayed on cognitive assessment while 32 (2.7%) were found to have functional disabilities.

In another study, Dewey, Kaplan, Crowford and Wilson (2003), investigated the problems of attention, learning and psychosocial adjustment evidenced by children with developmental coordination disorder (DCD). Forty-five children identified with DCD, 51 children identified as being suspect for DCD and 78 comparison children without motor problems on standardized tests of motor function participated in this study. Results revealed that both children with DCD and children suspect for DCD obtained significantly poorer scores on measures of attention and learning (reading, writing and spelling) than comparison children. Children with DCD and those suspected for DCD were also found to evidence a relatively high level of social problems and display a relatively high level of somatic complaints based on parent report. These findings indicated that children with movement problems are at risk for problems in attention, learning and psychosocial adjustment. Assessment of children with movement problems, regardless of the degree or severity of these problems should examine a wide range of functions in addition to motor functioning. Such an approach would assist in determining the types of intervention that would provide the most benefit to these children. Care-giving is an exhausting task, and parents/caregivers experience a very significant amount of strain.

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Parents of children who have neurological illness face multiple psychological and economic problems that are often neglected. The balance of affective and instrumental communication employed by nurses appears to be essential, especially during admission interview with clients particularly those who have long-term illness. Kruijver, Kerkstra, Bensing and Van de Wiel (2001) studied communication skills employed by nurses during interactions with recently diagnosed cancer patients. Fifty-three ward nurses from Netherlands Hospital and simulated cancer patients were videotaped and analyzed using Roter Interaction Analyses System, in which a distinction was made between affective and instrumental communication. The results revealed that more than 60% of nurses' utterances were of an instrumental nature. Affective communication occurred, but was more related to global affect ratings like giving agreements paraphrases than to discussing and exploring actively patients' feelings by showing empathy, showing concern and optimism. The study provided useful information regarding training needs in which nurses can learn how to communicate effectively in relation to clients' emotions and feelings, and how to integrate emotional care with practical and medical task.

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CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 Study Design

This section presents information on the research design, targeted population, sampling procedure to be used, the tool that was used for data collection and the procedure. In addition data analysis procedures are described and ethical considerations are discussed.

To measure the psychological traits inherent in participants, a non-experimental research (descriptive correlation) design was applied. The design enabled the researcher to describe the relationship between parents/caregivers of children with neurological disorders and their demographic variables such as age, gender, level of education, employment and marital status, and religion.

3.2 Study Setting

The study site was Korle-Bu Teaching Hospital (KBTH). The (KBTH) is a tertiary level referral hospital situated in the Western part of Accra. It is the oldest and largest hospital in Ghana. The hospital is a 1600 bedded continuing care giving facility and has 17 clinical and diagnostic departments/units of which the Department of Child Health (DCH) is one. The Department of Child Health was used for the study because it has the only Neurodevelopmental Clinic (NDC) in the country. On average there are 1,000 clients and about 120 clients admitted daily.

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3.3 Target Population

The target population for the study was parents/caregivers whose children attend Neurodevelopmental Clinic. Clients are referred from all over the country and neighboring countries. Also KBTH being a specialist hospital takes care of a variety of clients and it has the largest population of the interested targeted group, allowing a larger sample size.

3.4 Sample Size and Sampling Technique

Permission for the study was obtained from the Hospital's Chief Administrator. An advertisement of the study was made and all prospective participants were invited to participate in the study. The data was collected between 22nd October and 26th November, 2007. All parents/caregivers of children with neurological disorders who reported on the specified days and agreed to participate in the study were recruited. Thus the convenient sampling technique of the non probability method was used to recruit the participants.

The parents/caregivers of children who attended Neurodevelopmental Clinic at KBTH were the appropriate potential participants for the study in relation to exploring the psychosocial problems associated with taking care of children with neurological illness in Ghana. Since all caregivers do not come to the clinic at the same time, the convenient sampling method was the most appropriate.

In all, 160 parents/caregivers participated in the study. Also participant information sheet indicating the overview of the study was provided to the participants (appendix II).

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3.5 Data Collection Tools

A questionnaire was used in gathering data for the study. It comprised three sections. Section A concentrated on demographic information of the participants such as age, gender, educational level, marital status, number of children, employment status and religion. In section B, the questionnaire also elicited information on informational needs, beliefs regarding causes and management and effects of neurological illness on family and social lives of respondents. This section was developed by the researcher. Section C is a scale also developed by the researcher and was used to assess the psychosocial problems of the parents. An important aspect of the research was to describe the relevance of the scale. The study is about psychosocial problems and it is expected to elicit information on Anxiety and Stress (Appendix I). The questionnaire was in the English language.

The investigator decided to develop a self-administered questionnaire which includes both open-ended and close- ended questions. An outline of question areas is then developed, keeping in mind each aspect of research objectives, purpose of the study and research problem for which questions would be needed.

The questionnaire/scale for the relevant content areas are then drafted. The wording of each question was carefully monitored for clarity and sensitivity to the respondents' psychological state, free from bias and reading levels.

The questionnaire/scale was formed with attention paid to its appearance and ease of use, this was critically reviewed by a colleague and my supervisor who are knowledgeable about the substantive area of study. Piloting was beneficial as ambiguous questions were restructured on the main questionnaire and scale.

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3.6 Data Collection Procedures

The selected participants were briefed on the study and after the briefing, they were asked whether they would like to participate in the study and those who agreed to do so were further briefed on how to complete the questionnaire. The questionnaires were administered to the participants by the researcher herself and it took about 40 minutes for each participant to complete. The completed questionnaires were collected immediately after filling them. Participants who could neither read nor write were aided by the researcher.

The aid took the form of reading and interpreting the questions and the responses to this category of participants. Their responses were ticked and written by the researcher. The principal languages in which this was done were Twi, Ga and Ewe.

3.7 Data Analysis

Statistical package for social sciences (SPSS version 160 was used for data analysis. The t – test and measures of central tendency that is (means and standard deviation) were used where appropriate.

3.8 Ethical Considerations

Informed, written consent was obtained from the participants. Further, they were also told about their right to withdraw from the study at any time on their own volition without suffering any consequence. Secrecy and confidentiality was also ensured in that names and identifying information were not collected. Further, data provided by the participants were handled and used by only the researcher and the supervisor. The completed questionnaires were kept in a locked cabinet and were accessible only to the researcher, supervisor and school of Nursing. Prior to undertaking the study, the School Nursing approved the study. The participant's were informed that the completed questionnaire will be kept for five years and if there is the need to use the

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data, they will be consulted. The data will be destroyed after five years in accordance with University of Ghana (College of Health Sciences ethics committee).

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CHAPTER FOUR

4.0 FINDINGS

This chapter presents the findings of the study. This is done in a form of frequency and percentage tables, graphs in relation to the objectives. The first part of the findings was on the demographic information of participants' children as well as the participants themselves. The second part was also on the experiences of parents of children with neurological condition.

4.1 DEMOGRAPHIC BACKGROUND OF RESPONDENTS

4.1.1 SEX OF RESPONDENTS

Majority of the respondents were females 148 (92.5%) and 12 (7.5%) were males. This is represented in table 1.

Table 1

Sex Distribution of Respondents

Sex	Frequency	Percent (%)
Female	148	92.5
Male	12	7.5
Total	160	100

Source: Field Data, 2007

4.1.2 AGE OF RESPONDENTS

Most of the respondents 66 (41.3%) were aged between 30 and 39 years, 44 (27.5) aged between 20-29 years, 34 (20%) were between 40-49 years, 14 (8.8%) were 50 years and above and 4 (2.5%) were under 20 years.

Relevant information on the age of the respondent is presented in table 2.

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Table 2

Age Distribution of Respondent

Age Range	Frequency	Percent (%)
Under 20 years	4	2.5
20 – 29 years	44	27.5
30 – 39 years	66	41.3
40 – 49 years	32	20.0
50 years and above	14	8.8
Total	160	100

Source: Field Data, 2007

4.1.3 EDUCATIONAL LEVEL OF RESPONDENTS

Most of the respondents 64 (40%) had secondary/technical/vocational/commercial education.52 (32.5%) had primary/JHS/elementary education, 28 (17.5%) had tertiary education, 16 (10%) of the respondents however had no formal education. This is presented in table 3.

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Table 3

Educational level of respondents

Educational Level	Frequency	Percent (%)
No formal education	16	10
Primary/JSS/Elementary	52	32.5
Secondary/Technical/		
Vocational commercial	64	40
Tertiary	28	17.5
Total	160	100

Source: Field Data, 2007

4.1.4 MARITAL STATUS OF RESPONDENTS,

Majority of the parents 134 (83.8%) were married, 12 (7.5%) were separated, 8 (5%) where singled, 4 (2.5%) were widowed and 2(1.3%) were divorced. This is shown in table 4.

Table 4

Marital status of respondents

Marital Status	Frequency	Percent (%)
Singled	8	5
Married	134	83.8
Separated	12	7.5
Widowed	4	2.5
Divorced	2	1.3
Total	160	100

Source: Field Data, 2007

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4.1.5 EMPLOYMENT STATUS OF RESPONDENTS

Most of the respondents 88 (55%) were self employed, 44 (27.5%) were employed by an organization, 28 (17.5%) were unemployed. Findings of the employment status of the respondents are in table 5.

Table 5

Employment status of respondents

Employment Status	Frequency	Percent (%)
Self-employed	88	55
Employed	44	27.5
Unemployed	28	17.5
Total	160	100

Source: Field Data, 2007

4.1.6 RELIGIOUS BACKGROUND OF RESPONDENTS

Majority of the respondents 132 (82.5%) were Christians and 28 (17.5%) were Muslims. Religious background of respondents is presented in table 6.

Table 6

Religious background of respondents

Religion Affiliation	Frequency	Percent (%)
Christian	132	82.5
Muslim	28	17.5
Total	160	100

Source: Field Data, 2007

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4.2 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS CHILDREN

4.2.1 AGE DISTRIBUTION OF RESPONDENTS' CHILDREN WITH NEUROLOGICAL CONDITION

Most of the children 84 (52.5%) age ranged between two to five years, 42 (26.3%) age was between six to nine years, 22 (13.8%) were under two years and 12 (7.5%) were between 10 and 13 years. This is presented in table 7.

Table 7

Age distribution of respondents' children with neurological condition

Age Range	Frequency	Percent (%)
Under 2 years	22	13.8
2 – 5 years	84	52.5
6 – 9 years	42	26.3
10 - 13 years	12	7.5
Total`	160	100

Source: Field Data, 2007

4.2.2 SEX OF RESPONDENTS' CHILDREN WITH NEUROLOGICAL CONDITION

There were 84 (52.5%) females and 74(46.3%) males, 2 respondents did not state the gender of their children. This information is provided in table 8.

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Table 8

Sex of respondents' children with neurological condition

Sex	Frequency	Percent (%)
Female	84	52
Male	74	46.3
Total	160	100

Source: Field Data, 2007

4.2.3 DURATION OF RESPONDENTS' CHILDREN'S ILLNESS

Fifty eight 58 (36%) of respondents indicated that the duration of their children's illness was between 1-2 years, 56(35%) indicated it's between 3-5 years and 32(20%) stated that the duration is under one year and 14(8.8%) said the duration of the illness is more than 5 years. This information is provided in table 9.

Table 9

Duration of respondents' children's illness

Duration	Frequency	Percent (%)
Under 1 year	32	20
1 – 2 years	58	36
3 – 5 years	56	35
More than 5 years	14	8.8
Total	100	100

Source: Field Data, 2007

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4.3 NUMBER OF HOSPITAL CONSULTATIONS

The majority of the respondents 70(43.8%) indicated they had hospital consultations once to twice a month, 66 (41.3%) indicated they had hospital consultations once in three months, 14 (8.8%) said they consulted in the hospital more than twice a month, 6 (3.8%) consulted once every six months, 4 (2.5%) consulted once in a while. This information is represented in table 10.

Table 10

Number of hospital consultations

Number of Times	Frequency	Percent (%)
Once to twice a month	70	43.8
Once in three months	66	41.3
More than twice in a month	14	8.8
Once every six months	6	3.8
Once a while	4	2.5
Total	160	100.0

Source: Field Data, 2007

4.4 BELIEFS ABOUT CAUSES OF CHILDREN'S DISEASE

As shown in Table 11, respondents considered birth problems 126 (78.8%) as the main cause of neurological condition in their children, infectious diseases 96 (60%), trauma or accidents 90 (56.3%), genetic or familial 70 (43.8%). Other causes reported by the respondents include witches and wizards 60 (37.5%), environmental factors 58 (36.3%), bad behaviors 32 (20%), evil forces or spirits 28 (17.5%), bad luck 14 (8.8%) and breaking of taboos 10 (6.3%).

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Table 11

Beliefs about causes of children disease

Causes of Child's Sickness	Frequency	Percent (%)
Birth problems	126	78.8
Infectious diseases	96	60
Trauma/accidents	90	56.3
Genetic/familial	70	43.8
Witches/wizards	60	37.5
Environmental factors	58	36.3
Bad behaviours	32	20.0
Evil forces/spirits	28	17.5
Bad luck	14	8.8
Break off taboos	10	6.3

Source: Field Data, 2007

4.5 REPORTED TYPES OF MANAGEMENT FOR CHILDREN'S CONDITION

With the causes in mind, different types of strategies were also stated by the respondents on the management of the condition. This is presented in the table 12.As shown in Table 12, all the respondents 160 (100%) stated that their children's condition can be managed through orthodox medicine or hospital management. This was followed by divine intervention 124 (77.5%), rehabilitation 118 (73.8%), healing by reverend ministers 90 (56.3%), herbal and traditional medicine 50 (31.3%), socially accepted conduct and behaviors 34 (21.3%), institutionalization 30 (18.8%), and pacification of gods 20 (12.5%). There were multiple responses for each participant.

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Table 12

Respondents' Reported Types of Management for Children's Condition

Types of Management	Frequency	Percent (%)
Orthodox medicine/hospital management	160	100
Divine intervention	124	77.5
Rehabilitation	118	73.8
Healing by pastors and revered ministers	90	56.3
Herbal and traditional medicine	50	31.3
Socially accepted conduct and behaviours	34	21.3
Institutionalization	30	18.8
Pacification of gods	20	12.5

Source: Field Data, 2007

4.6 SOCIAL CONSEQUENCES ON PARENTS

As shown in Table 13, majority of the respondents 154 (96.3%) stated that they are anxious of the child's future whilst 132 (82.5%) reported they feel tired, anxious and dispirited, 110 (68.8%) claimed socially the condition impact on them by having difficulty in caring for the child Others also indicated other social impacts such as encountering problems at work 104 (65%), great difficulty with discipline 86 (53.8%), strained spousal or family relationship 78 (48.8%), strained peer or friend relationship 58 (36.3%), change or stop work/cannot work 36 (22.5%) and family breakdown 32 (20%).

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Table 13

Social consequences on parents

Social consequences	Frequency	Percent (%)
Anxious of the child's future	154	96.3
Feels tired, anxious & dispirited	132	82.5
Difficulty in caring for the child	110	68.8
Problems at work	104	65
Great difficulty with discipline (child)	86	53.8
Sibling rivalry	80	50
Strained spousal/family relationships	78	48.8
Frequent conflicts in the home	64	40
Strained peer/friend relationships	58	36.3
Change/stop work/cannot work	36	22.5
Family breakdown	32	20

Source: Field Data, 2007

4.7 EMOTIONAL EXPERIENCE ASSOCIATED WITH HAVING A CHILD WITH NEUROLOGICAL DISORDER

As revealed in Table 14, most of the respondents 146 (91.3%) claimed it facilitates companionship and as a result they were happy with child's care and a similar number 144 (90%) claimed they had a healthy parent-child interaction. Those who reported that there was spousal involvement in child's care were 112 (70%). Other possible emotional experiences reported by the respondents include family support 108 (67.5%), rehabilitation 88 (55%), social support 82 (51.3%), feeling of adequacy 42 (26.3%) and cope well with child's care 38 (23.8%).

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Table 14

Emotional experience associated with having a child with neurological disorder

Emotional/relational Experience	Frequency	Percent (%)
Companionship & happy with the child's care	146	91.3
Healthy parent-child interaction	144	90
Spousal involvement in the child's care	112	70
Positive communication	112	70
Family support/cooperation	108	67.5
Rehabilitation	88	55
Social support	82	51.3
Feeling of adequacy	42	26.3
Coping well	38	23.8

Source: Field Data, 2007

4.8 THE STRESS OF CARING FOR A CHILD WITH NEUROLOGICAL CONDITION

All respondents experienced a moderately high level of stress (mean 69.7 out a total maximum value of 100. One Sample t Test Analysis confirmed the fact that stress associated with having a child with neurological condition is significantly high [t (159) = 3.409, $p < 0.05$]. This information is represented in table 15.

Table 15

The stress of caring for a child with neurological condition

Variable	Mean	Standard Deviation	Maximum Value	Minimum Value	df	t obs	P
Stress	69.7	2.45	100	25	159	3.409	<0.05

Source: Field Data, 2007

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4.9 PARENTS RECOMMENDATION ON HOW TO CARE FOR A CHILD WITH A NEUROLOGICAL CONDITION

As stated in table 16, 54(33.8%) recommended good parental care and hospital management, 48(30%) suggested hospital management and divine intervention, 16(10%) of parents recommended institutionalization and16 (10%) suggested more information on the condition, treatment and outcome, however 26(16.3%) of parents had no idea.

Table 16

Parent's recommendation on how to care for a child with a neurological condition

Recommendations	Frequency	Percent (%)
Good parental care and hospital management	54	33.8
Hospital management and divine intervention	48	30
No idea	26	16.3
Institutionalization	16	10
More information on the condition, treatment & outcome	16	10
Total	160	100

Source: Field Data, 2007

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4.10 KNOWLEDGE ABOUT CHILDREN'S CONDITION

Results in table 17 indicated 86 (53.8%) of the respondents had partial dependent care 72(45.0%) had total dependent care and 2 (1.3%) had other types of care.

Table 17

Category of care of respondents' children

Category of Care	Frequency	Percent (%)
Partial dependent care	86	53.8
Total care dependent care	72	45.0
Others	2	1.3
Total	160	100

Source: Field Data, 2007

4.11 KNOWLEDGE OF THE NAME OF CHILD'S CONDITION

Results in table 18 indicated 84 (52.5%) of the respondents knew the name of their children's condition whilst 76 (47.5%) did not.

Among those who claimed they knew the condition of their children, the following result was obtained.

Table 18

Knowledge of the name of child's condition

Response	Frequency	Percent (%)
Yes	84	52.5
No	76	47.5
Total	160	100.0

Source: Field Data, 2007

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Table 19

Respondents' knowledge of children's condition by name

Condition	Frequency	Percent (%)
Seizure/epilepsy	40	47.6
Cerebral palsy	14	16.6
Hydrocephalus & brain disease	14	16.6
Developmental delay	10	11.9
Attention deficit/hyperactive disorder	4	4.8
Hearing/Speech impairment	2	2.4
Total	84	100

Source: Field Data, 2007

4.12 EXPERIENCES OF RESPONDENTS

Findings of the study further revealed that respondents go through certain psychological experiences as a result of their children's condition. Relevant information on this is shown in table 20 a, b and c.

As revealed in Table 20, a number of psychological experiences are considerably common among the respondents. One such psychological experience reported by a sizeable number of respondents 70 (43.8%) is the time spent with the child with the condition. This was described as a lot of time. The table further revealed that 68 (42.5%) respondents also indicated that they feel tired most of the time. Other psychological experiences significant in the life of a parent who has a child with a neurological condition include resource constraints on necessities 60 (37.5%), having body pain 60 (37.5%), reservation or withdrawal from social activities 58 (36.3%), lack of resources 54 (33.8%), social isolation and discrimination 52 (32.5%), facing difficulty taking

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child to social gatherings or school 48 (30%) and social stigma and isolation 44 (27.5%). Other psychological experiences that may not be of a problem and experienced by insignificant number of respondents include finding it hard to calm down 8 (5%), receiving unhealthy treatment from people 8 (5%), or people giving bad treatment 10 (6.3%), lack of medical services 10 (6.3%), low self control 10 (6.3%), self blame or guilt 12 (7.5%), loss of friends or relationship 18 (11.3%), false accusation 18 (11.3%), feeling agitated and irritable 18 (11.3%), and over reacting to situations 20 (12.5%). Other psychological experiences which were not a problems as such include feeling of body image disturbances for child 30 (18.8%), feeling of tension or under pressure 42 (26.3%), getting angry easily 22 (13.8%), and crying or weeping 32 (22.6%).

Table 20

Experiences of Respondents

(a) Social Experience

SOCIAL EXPERIENCE	**RESPONSES**				
	Does not apply to me at all	Applies to me to some degree	Applies to me to a considerable degree	Applies to me very much	**TOTAL**
Social isolation and Discrimination	66(41.3)	26(16.3)	16(10)	52(32.5)	160(100)
Reserved or withdrawn from social activities	38(23.8)	44(27.5)	20(12.5)	58(36.3)	160(100)
Loss of friends or relationships/unable to make and maintain relationships	80(50.0)	40(25.0)	22(13.8)	18(11.3)	160(100)
Social stigma and Discrimination	50(31.3)	38(23.8)	28(17.5)	44(27.5)	160(100)
Difficulty taking child to social gathering or school	38(23.8)	46(28.8)	28(17.5)	48(30.0)	48(100)
People treat me badly	108(67.5)	28(17.5)	14(8.8)	10(6.3)	160(100)
People treat me well	102(63.8)	38(23.8)	12(7.5)	8(5.0)	160(100)

Source: Field Data, 2007

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(b) Physical and Economic Experiences

PHYSICAL AND ECONOMIC EXPERIENCE	**RESPONSES**				**TOTAL**
	Does not apply to me at all	Applies to me to some degree	Applies to me to a considerable degree	Applies to me very much	
Loss of appetite or eating a lot	78(48.8)	26(16.3)	34(21.3)	22(13.8)	160(100)
Lack of resources (financial, human and material)	16(10.0)	36(22.5)	54(33.8)	54(33.8)	160(100)
Lack of medical services	106(66.3)	34(21.3)	10(6.3)	10(6.3)	160(100)
Have body pain	4(2.5)	38(23.8)	58(36.3)	60(37.5)	160(100)
Spends a lot of time caring for a child	6(3.8)	26(16.3)	58(36.3)	70(43.8)	160(100)
Feels tired most of the time	8(5.0)	28(17.5)	56(35.0)	68(42.5)	160(100)
Resource constrain on Necessities	4(2.5)	30(18.8)	66(41.3)	60(37.5)	160(100)

Source: Field Data, 2007

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(c) Emotional Experience

EMOTIONAL EXPERIENCE	**RESPONSES**				
	Does not apply to me at all	Applies to me to some degree	Applies to me to a considerable degree	Applies to me very much	**TOTAL**
Becomes or feels sad	18(11.3)	58(36.3)	42(26.3)	42(26.3)	160(100)
Self-blame/guilt	54(33.8)	66(41.3)	28(17.5)	12(7.5)	160(100)
Gets angry easily	84(52.5)	22(13.8)	32(20.0)	22(13.8)	160(100)
Low self-control	82(51.3)	32(20.0)	36(22.5)	10(6.3)	160(100)
Feeling of tension or under pressure	6(3.8)	80(50.0)	32(20.0)	42(26.3)	160(100)
Feeling of body image disturbances for child	22(13.8)	66(41.3)	42(26.3)	30(18.8)	160(100)
I tend to over react to Situations	76(47.5)	42(26.3)	22(13.8)	20(12.5)	160(100)
False accusations	68(42.5)	52(32.5)	22(13.8)	18(11.3)	160(100)
I found it hard to calm down after something upsets me	102(63.8)	32(20.0)	18(11.3)	8(5.0)	160(100)

Source: Field Data, 2007

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CHAPTER FIVE

DISCUSSION

The study explored the beliefs of caregivers of children who have neurological disorders regarding causes and management of neurological conditions; the effects or impacts the family experienced as a result of such conditions; and psychosocial distress that caregivers feel. The aim was to find out psychosocial problems experienced by the parents/caregivers of children with neurological conditions. A survey method was used in this study in which a questionnaire comprising of informational needs, beliefs of causes, management and effects of neurological illness on family and social life and a scale describing experiences or feelings was given to participants to complete. Data analysis using descriptive statistics demonstrated that caregivers or parents experienced enormous amount of strain, anxiety and depression. Thus findings revealed that caregivers experienced moderate level of psychosocial problems – strain, stress, anxiety and depression. Those who perceived the neurological disorders of their children as a threat experienced more psychosocial problems than those who perceived it as a challenge.

The functional status of the patients also influenced the psychosocial problems participants experienced. Parents/caregivers whose children needed total dependent care and could not do anything for themselves especially those who could not achieve developmental milestones experienced more strain, stress, anxiety and depression compared to caregivers whose children achieved some milestones and so needed only partial dependent care or close supervision.

Parents/caregivers who cared for neurologically ill children for a short period (less than one year) experienced more psychosocial problems than their counterparts who cared for long period (more than one year). Thus in effect, the study found that length of care giving also affected the

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psychosocial problems experienced by the parents/caregivers. These findings are discussed in relation to existing literature as well as reasons in support of each.

Findings of the study revealed that caregivers experienced moderate level of psychosocial problems – strain, stress, anxiety and depression and this finding supports the findings of Kausa and Powell, Sanjeev and Bindu (1999), Adewuya and Fatoye (2006) who also observed that care-giving is a stressful job, which puts an immense amount of strain on caregivers. There are various reasons why caregivers experienced psychosocial problems. Psychologists such as Lazarus (1974) observed that an individual's perception of an object or event influences one's behavior either physically, emotionally or psychologically towards such an object or event. It therefore follows this argument as the study observed among the caregivers that those who perceived neurological condition of their children and for that matter the care giving as a threat experienced more psychosocial problems as compared to those perceiving it as a challenge. Meanwhile, perceiving an event as a threat to life can also be a stressor. This is because biologically, humans are programmed to see life as very important. As a result, an event that threatens this biological predisposition is avoided. However, the caregiver of a neurologically ill child may not be able to avoid the situation because of other pressures. Remaining in an event that one viewed as life threatening (care giving) as caregivers do only result in making them anxious daily, which consequently result in high levels of psychosocial distress.

Another reason why caregiver perception could have influenced the experience of more stress may be lack of knowledge of neurological disorders. This is because most of the participants have little or no knowledge and information on the disease, perceived care giving in neurological condition as a threat with few caregivers also perceiving it as a challenge. The influence of perception on caregiver stress as observed by this study has also been observed by

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other researchers. For instance Hyman, Chisholm, Kessler, Patel and Whiteford (2006) found that neurological disorders are neglected in terms of public health and lack of public knowledge about neurological disorders in children, stigmatization and discrimination associated with these disorders also remains substantial obstacle to the management of such disorders. Hyman et al (2006) also added the absence of these disorders from lists of the leading causes of death has contributed to their long-term neglect by both donors and policy makers in developing countries. The less knowledgeable caregivers experienced more stress because of their perception of neurological disorders and its associated care giving as a threat. Logically, one may argue that worries over the child's cluster of difficulties and future coupled with others might have resulted in anxiety leading to high levels of stress among caregivers who had little knowledge on the disease in general including prevention where applicable. This finding buttresses the point that perception has the tendency of influencing psychological conditions.

Also during pregnancy, every woman wishes for a perfect child and fears the birth of the one who is in some way damaged. When the child is born with a defect, developed a defect or long-term illness, the discrepancy between the fantasy and the reality precipitates a tremendous sense of loss – loss of a desired goal, of the expected child, of important elements such as self-esteem, and satisfaction in the birth process. An overpowering sense of failure is substituted for expected pride in this child. Profound grief is the normal response to such loss – grief characterized by preoccupation with each part of the loss and the special meaning it has for the parents and the family. The more serious the condition is perceived, the more powerful is the impact of the experience. Often parents frequently asked, 'why did this happen'? They are searching themselves for former sins or some biological inadequacy. For the mother, her failure to produce or care for a perfect child may be a threat to her sense of adequacy and her individual worth. This

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is understandable for the child is still an extension of the mother, and a defect in the child is therefore, a defect in her.

Further all parents feel deeply about the appearance and behavior of their children which is often a rigid standard set arbitrarily by society. This is particularly so with children who have handicaps. A child whose condition restricts his gross motor and fine motor adaptive skills has his world reduced to his immediate area for example a child with cerebral palsy. Again a child who has unusual or unpleasant appearance and/or behavior is a source of great concern and worry for the mother/caregiver; particularly in our society where there is such emphasis on physical beauty. He/she may be shunned by others who are shocked at his her appearance or behavior and do not know how to relate to him. He /she may well develop a negative self-concept and may not attempt to succeed in areas where he she has to interact with others. The feeling or experience can be very frustrating when the child could not achieve developmental milestones or there is regression in the milestones, which implies more strain, stress, and anxiety for mothers/caregivers.

Additionally many children with neurodevelopmental disorder(s) also experience sensory, communicative, motor, behavioral and intellectual impairments and may have complex limitations in self-care functions. Although care giving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges for parents is to manage their children's chronic health problems effectively and juggle this role with the requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers. The provision of such care may prove detrimental to both the physical health and the psychological well-being of parents of

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children with chronic neurological disabilities. The psychosocial problems of caregivers, who in this study were primarily mothers, were strongly influenced by child behavior and care giving demands. Child behavior problems were an important predictor of caregiver psychosocial distress, both directly and indirectly, through their effect on self-perception and family function. Care giving demands contributed directly to the psychosocial adversity of the caregivers. The practical day-to-day needs of the child created challenges for parents.

Although, there is consensus among researchers regarding the burden and distress among parents or caregivers, varying degrees of psychosocial problems have been reported by previous studies. Psychosocial problems reported by parents or caregivers in this study are relatively higher than that reported in some previous studies. The difference in the degrees of reported psychosocial problems could be due to the sampling from different populations, the wide range of assessment measures used and the operational definition of concepts. The study explored the beliefs of caregivers of children who have neurological disorders, regarding causes and management of such conditions; the effects or impact the family experienced as a result of such conditions; and psychosocial distress that parents/caregivers feel.

However the elevated levels of psychosocial adversity among parents/caregivers found in the present study require some explanation. One of the possible explanations for the findings of the present study could be the very nature of the care-recipients' conditions. The majority of the care recipients in the study might have cluster of difficulties that might have enhanced the parents/caregivers distress. Distress in caregivers can further be explained by the fact that they face a situation characterized by social isolation, reduced control over their lives, and loss of previously close friendships or relationships which are features that are generally associated with stress, anxiety and depression. These findings reinforce earlier study by Sanjeey and Bindu

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(1999) which have suggested that 80% of parents have a decline in social activities after onset of epilepsy in their children. It was also reported that parents experienced frustration and hopelessness, and that impaired emotional status and poor social adaptation were co-related with such disorders.

These findings reinforce earlier studies, which have suggested that care-giving is a stressful job, which puts an immense amount of strain on parents/caregivers. Thus, as far as psychological morbidity in parents/caregivers is concerned, the findings of the present study are consistent with previous research. Learning disabilities are hard on parents and the family which results in misunderstanding and conflicts. Siblings can resent the amount of attention given to a child with a neurological condition. Parents often feel guilty because they feel their children's learning disabilities or inability for example in cerebral palsy, ADHD and related disorders, are somewhat their fault. These children might have a cluster of difficulties that lead to academic or other failures or low achievements.

Krausar and Powell (2005) concluded that caregivers experienced burden, distress and negative effect on their physical and emotional well-being. Thus, as far as psychosocial distress in caregivers or parents is concerned the findings of the study are consistent with previous research. Another aspect of confusion for parents/caregivers lies in how hard it can be to distinguish between a child who can do something and a child who would not be able to do something, who can do and a child who cannot do.

The study found that most caregivers/parents believed that numerous factors were the causes of their children's sickness. While the majority believed that possible causes of their children's condition included birth problems, infectious diseases and trauma, a sizeable number also

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believed in spiritual dimensions as well as behavioral factors as causes of neurological conditions. The explanations of these beliefs are rooted in ignorance, tradition and religion.

Most parents/caregivers in the study might have either inadequate information or misinformation on health related issues particularly the area of pediatric neurology that has not received much attention from policy makers, donors or non-governmental organizations. It therefore implies that there is little or no information in the public domain in terms of health education on the prevalence, causes, management and outcome of these diseases. The educational background of caregivers/parents could explain their ignorance as indicated in the present study; about a third of the study population either had no formal education or primary education. Those who had secondary education might either not be interested in reading widely or could not understand the technicalities in these disorders or due to other pressures of life. The majority of the extremely poor cannot have access to higher education due to the endemic nature of poverty that characterizes developing countries like Ghana, thus contributing to their poor knowledge base.

The cultural orientation and traditional belief system of the people remains fresh in their minds and it is part of them because they have been socialized to believe in the tradition irrespective of their level of education. It is a common belief that evil forces and evil people still exist and have been causing harm to people. Therefore diseases which are uncommon and strange are believed to have come from these evil spirits and bad people especially if explanations cannot be given.

The final explanation of caregivers’ beliefs is rooted in the religion of the people. Religion deals with faith in the supernatural. These supernatural beliefs, practices and occurrence cannot

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be tested scientifically and yet they are taken seriously because people are passionate about their religion. Most misconceptions originate from the traditional belief system which is a challenge to continuous health education. The findings in this study indicated that parents have fairly inadequate knowledge on the possible causes of their children's condition and the local beliefs in alternate treatment – divine intervention – thereby unable to accept permanence of disability.

The study also demonstrated significant effects of neurological disorders on the family and social life of caregivers/parents. Almost all parents/caregivers reported anxiety for the child's future, feeling tired and dispirited, difficulty in caring for the children and work related problems ranked very high. Great difficulty with discipline, strained relationship, frequent conflicts at home, social isolation, discrimination and sibling rivalry were moderately high. There are several possible reasons for this and include: The functional status of the children also has social and emotional experiences on the caregivers. When the child is less dependent or needs less supervision, parents are likely to have less social and emotional experience compared to when the children are highly dependent on the caregiver especially older children.

Also the physical appearance and behavior of the child is another reason for social and emotional experience of parents. For example a child with physical deformity as in the case of cerebral palsy; or a child who has a problem of self-control as in the case of autism or ADHD create more social and emotional problems. This limits the parents' ability to enroll them in the normal schools or participate in other related social activities in an environment that unfortunately has no place for children with special needs.

Further social and emotional distress experienced by careers could be due to economic and vocational disruptions. The caregivers might not be able to work to earn enough money because

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of their children's disability. The same disability puts a lot of financial strain on their purse in terms of access to health care services, medication and transportation.

There was misinformation about the disease condition, possible causes, management, treatment and prognosis. Participants in the study also indicated that they were not involved well in treatment plans and were not provided with adequate information about the disease condition and were not satisfied with the manner in which information was given. The present study supported an earlier study by Kohler (1993) which reported widespread discontent with the amount of information parents received about their children's condition from health care professionals and the way such information is provided.

However the parents equally have positive experiences despite the disability that gives them inherent psychosocial problems. These include companionship and happiness with the child's care, healthy parent-child interaction and spousal involvement in the child's care reported by the caregivers as a source of their strengths. Others are family support or cooperation and social support. The explanation for this could be the fact that once there is life in the sick child, it is considered as a human being and should be cared for irrespective of the level of disability.

Summary

In summary, the significance of the findings was discussed in relation to psychosocial problems, their beliefs of the causes of their children's sickness, social impact experienced by respondents', emotional experiences associated with having a child with neurological condition, and demographic data. The summary and conclusion are presented in chapter six.

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CHAPTER SIX

Implications for Future Nursing Practice

Healthcare professionals and clinical nurse in particular, do work with clients and their families with complex health problems and other related problems. These problems do arise daily and tend to predetermine solutions. To meet this clinical situation, health professionals must engage in clinical judgment in a reflective manner toward their decision-making and problem solving.

The findings of this study provide health professionals with an insight into the potential ability of nurse practitioners in their clinical problem solving and decision making abilities For example the mean score of stress experienced by parents/caregivers would guide the nurse practitioner in patient teaching/education. For instance parents/caregivers could be introduced to clinical psychologist and social support groups if there is any and the use of relevant reading materials.

The scores for the parents/caregivers types of management beliefs of causes of children's illness could guide the nurse practitioner in teaching the parents/caregivers.

The scores of social impact experience by respondents could also guide the nurse in clinical teaching of nursing or medical students.

Implication for Future Nursing Administration/Management

The results of the type of category of care could also inform or guide the nurse manager to plan for continuous education of existing staff and also provide in-science education and orientation to newly recruited staff posted to the unit.

The results of the study could also help nurse managers in selecting staff of the unit

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Implication for Future Nursing Research

The findings in this study are solely about psychosocial problems facing parents/caregivers of children with neurological disorders attending NDC at Korle-bu Teaching hospital in Ghana. As such these findings are unique. Nonetheless the study of psychosocial problems of parents in pediatric neurology is in its infancy in Ghana. Therefore future replication of study in other hospitals is required. Findings do suggest that a psychosocial problem of parents of such children needs to be addressed in the Ghanaian nursing environment.

Concerning the psychosocial problems of parents/caregivers of children with neurological disorders of the participants in this study, there are some areas that were not explored. Such areas deserve further research. These could include coping strategies and the need for information of parents of children with neurological disorders; psychosocial and economic problems of parents with neurological and economic problems of parents with neurological disorder(s); impact of pediatric neurological illness on the family.

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Limitations of the Study

Using a convenient sampling technique to sample participants for a study and analyzing the data with descriptive statistics and one sample t-test is not the best. However, because of the nature of the area of the study (pediatric neurology) which is surrounded by social stigma coupled with the tendency of families to keep this secret, the random sampling technique would have been very difficult. This is because the majority of the caregivers consulted declined from participating. Closely related to the above is the small sample size used. The picture of a population is reflected by the sample size, provided it is a representative sample and large enough. This implies that findings of this study may not be applicable to other caregivers (lack of external validity). Nevertheless, the findings hold as far as participants studied are concerned. In addition to the above, larger sample size would have posed more problems and difficulties considering the limited resources available to the researcher.

Findings of the study could not be generalized to other caregivers of children with neurological disorders due to the convenient sampling technique used. In addition, the quantitative approach could not allow the researcher to delve deep into the psychosocial experiences of these caregivers.

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CONCLUSION

Several implications can be drawn from the findings of this study. Firstly even though parents have some knowledge about such neurological disorders, the information at their disposal is inadequate to prepare them well to live with the disability with minimal stress. Thus unable to accept the long-term nature of the disability and so feel hopelessness. This is likely to affect follow-ups. Most of the patients had problems dating from the neonatal period. This has several implications for antenatal, perinatal and postnatal services. The level of stress experienced by caregivers calls for psychological support to caregivers/parents and stress management interventions.

Further, health and social service agencies, and policy makers must recognize the potential psychological impact of care-giving on caregivers/parents of pediatric patients with neurological disorders. One should not assume that distress in caregivers/parents is related generally to the objective stressors of care-giving. Instead, specific aspects of disability, i.e. post-onset personality, behavioral and physical changes in the patient, which differentially contribute to the caregivers/parents distress, are of crucial importance.

Further, the results may be clinically relevant. More attention should be paid to the coping process, emphasizing particularly the use of practical problem-solving strategies rather than avoidance strategies, whilst dealing with post-onset sequelae of the patient. This may be especially important in order to reduce the caregivers/parents distress. Health professionals agree that the quality of care and the health of the care-recipient are of vital importance. However, the levels of distress experienced by caregivers/parents suggest that the health of caregivers/parents be considered as of equal importance, since the health of the care -recipient is dependent on that

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of the caregivers/parents. If more attention is directed towards caregivers/parents, it will help them approve of their attention to themselves and ease the guilt they may experience when they use time for themselves.

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SUGGESTIONS AND RECOMMENDATIONS

Recommendation for Parents

1. Parents should demand for information regarding medical management of their children.
2. Parents/caregivers who have difficulty in caring for the neurologically ill child should employ the services of other people to assist them if they can afford. They can also ask for help from family members,' friends, and support groups.
3. Parents should balance the provision of care to the sick children with other sibling to avoid or minimize sibling rivalry.
4. Parents/caregivers should not see the care giving function as a problem, but rather as a challenge this would help them cope better with the day to day care giving thus reducing frequent conflicts in the home, prevent family breakdown, and problems at work.

Recommendation for Healthcare Providers

1. Parents should be provided with adequate information concerning the health management of their children.
2. Parents should be referred to clinical psychologist to manage stress of care giving in such parents/caregivers.
3. The role of the health care professionals (nurses and doctors) and the impact on caregiver stress level as well as coping strategies was also left out. Future research should take this into consideration when designing a research in this area.

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Recommendations for Future Nursing Research

1. The findings in this study are solely about psychosocial problems facing parents/caregivers of children with neurological disorders attending NDC at Korle-Bu Teaching hospital in Ghana. As such these findings are unique. Nonetheless the study of psychosocial problems of parents in pediatric neurology is in its infancy in Ghana. Therefore future replication of study in other hospitals is required. Findings do suggest that a psychosocial problem of parents of such children needs to be addressed in the Ghanaian nursing environment.
2. Concerning the psychosocial problems of parents/caregivers of children with neurological disorders of the participants in this study, there are some areas that were not explored. Such areas deserve further research. These could include coping strategies and the need for information for parents of children with neurological disorders; psychosocial and economic problems of parents with neurological and economic problems of parents with neurological disorder(s); impact of pediatric neurological illness on the family.
3. Theories of care giving have not been assessed by the current study in terms of why family members give care. Future research should examine this and evaluate the link between this and caregivers' psychosocial problems. The correlation between caregiver knowledge of neurological disorders, coping strategies and burnout in the caregiver should also be studied.

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Recommendations for Policy Makers

1. It is also recommended that in order to reach out to the rural population, Neurodevelopmental clinics (NDC) should be set up in all regional hospitals. These units should be well resourced to reduce work overload on the staff and the existing facilities.
2. There is the need for a multidisciplinary set up to improve quality of life to deal with the sense of hopelessness; training of specialists, psychological support and schools for children with special needs.
3. There is the need to draw public attention to the incidence and prevalence of neurological disorders in children. Also the possibility out there for the prevention of these disorders or where it they have occurred, emphasize on prevention of complications

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APPENDIX I

QUESTIONNAIRE

This questionnaire is designed to solicit information for a study on psychosocial problems facing parents of children with neurological disorders. Your contribution to this research through honest completion of this questionnaire is very much appreciated. Confidentiality is assured (no names required) and information provided would be used strictly for academic purpose. Thank You.

Study ID……………

SECTION A DEMOGRAPHIC DATA

1. Age of the child in years ----------------------

2. Date of birth …………………………..

3. Gender of the child:

Male……………..1 ☐
Female…………...2

4. Duration of your child's condition-------------

5. Age of respondent: -------------------------

6. Gender of respondent:

Male…………1 ☐
Female………..2

7. Educational level of respondent:

No Formal Education………..1
Primary/JSS/Elementary…….2
Sec/Tech/Voc/Comm………..3 ☐
Tertiary………………………4
Other(s) specify……………………

8.Marital Status of respondent:

Single………..1
Married……...2
Separated…….3 ☐
Divorced……..4
Widowed…….5

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9. How many children have you given birth to?

One……………....1
Two……………...2
Three…………….3
Four……………...4
Five or more….......5

☐

10. Employment status of respondent:

Unemployed………..1
Employed…………..2
Self-employed……...3
Others Specify………………

☐

11. Religion of respondent:

Christian ……………….1
Moslem………………....2
Traditional religion……..3
No religion……………...4
Others Specify………………

☐

SECTION B
INFORMATIONAL NEEDS, BELIEFS, CAUSES AND EFFECTS OF NEUROLOGICAL ILLNESS ON FAMILY AND SOCIAL LIVES OF RESPONDENTS.

12. To which of the following categories does your child's care belongs?

Partial………...1
Total…………2
Others Specify ……………

☐

13. Number of consultations/admissions:

Once to twice a month………1
More than twice a month……2
Once in three months………..3
Once every six months………4
Once a while………………...5
Others Specify…………………

☐

14. Do you know the name of your child's illness/sickness? (Diagnosis)

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Yes [ ] No [ ]

If yes what is it……………………………………………

If no why? ....

15. Were you informed about the management?

Yes [ ] No [ ]

16 Were you told the outcome of treatment of your child's condition?

Yes [ ] No [ ]

17. If yes are you satisfied with the information given on the condition, its management and outcome?

Yes [ ] No [ ]

18. Were you told what to do when the child becomes ill?

Yes [ ] No [ ]

19. Which of the following do you believe are the possible causes of your child's sickness? Tick as many as applicable.

Infectious diseases……………….1
Witches/wizards…………………2
Genetic/familial…………………3
Bad behaviors……………………4
Trauma/accidents………………...5
Breaking of taboos……………….6
Environmental factors……………7
Evil forces/spirits…………………8
Bad luck…………………………..9
Birth problems…………………..10

20. Which of the following do you believe are possible types of management of your child's condition? Tick as many as apply

Divine interventions……………………….1
Healing by pastors & reverend ministers….2
Rehabilitation……………………………...3
Institutionalization…………………………4
Herbal and traditional medicine……………5
Orthodox medicine/Hospital management...6
Pacification of gods………………………...7

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Socially accepted conduct and behaviors…..8

21. Which of the following impact(s) have you and your family experienced as a result of your child's condition? Tick as many as apply

Family breakdown……………………..1
Frequent conflicts in the home………...2
Strained spousal/family relationships….3
Anxious of the child's future…………..4
Feels tired, anxious & dispirited………5
Great difficulty with discipline (child)...6
Strained peer/friend relationships……...7
Problems at work………………………8
Difficulty in caring for the child………9
Change/stop work/cannot work………10
Sibling rivalry…………………………11

☐☐☐☐☐☐☐☐☐☐☐

22. Which of the following statements are true of your experience of having a child with neurological illness Tick as many as apply?

Healthy parent-child interaction…………1
Spousal involvement in the child's care….2
Companionship & happy with the child….3
Family support/cooperative………………4
Social support…………………………….5
Positive communication…………………6
Rehabilitation…………………………….7
Feeling of adequacy………………………8
Cope well…………………………………9

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SECTION C

This section contains statements describing your experience or feelings. Tick (√) appropriately the response that most describes your experience or feelings

Statement	Does not apply to me at all 1	Applies to me to some degree 2	Applies to me a considerable degree 3	Applies to me very Much 4
1.Fear of social isolation and discrimination				
2. Reserved or withdrawal from social activities				
3. Loss of appetite or eating a lot				
4. Becomes or feels sad				
5. Crying or weeping				
6. Loss of friends or relations/unable to make and maintain relationships				
7. Self-blame/guilt				
8. Gets angry easily				
9. Fear of social stigma and discrimination				
10. Lack of resources (financial, human and material)				
11. Lack of medical services				
12. Difficulty taking child to social gathering or school				
13. People treat me badly				
14. People treat me well				
15. Have body pain				
16. Low self-control				
17.Feeling of tension or under pressure				
18. Feeling of body image disturbances for child				
19. I tend to over react to situations				

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20. False accusations				
21. Feels agitated and irritable				
22. Spends a lot of time caring for a child				
23. Feels tired most of the time				
24. Resource constrain on necessities(treatment, transport, diapers)				
25. I found it hard to calm down after something upsets me				

Recommendations on how to care for a child with neurological condition……………………………….

………

………

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………

……………………………………………

Thank you

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APPENDIX II

School of Nursing, Collage of Health Sciences, University of Ghana, Legon

INFORMATION SHEET

Project Title: Psychosocial Problems Facing Parents of Children with Neurological Disorders

Researcher: Peace Delali Nyasor Msc (Nursing) Student, University of Ghana, Legon.

Thesis Supervisor: Dr Florence Naab

Purpose: I will investigate Psychosocial Problems Facing Parents of Children with Neurological Disorders. Psychosocial Problems means stress, anxiety and depression associated with caring for a child who has a neurological condition.

I am a graduate student in School of Nursing at the University of Ghana I am interested in stress, anxiety and depression associated with neurological illness and to determine whether parents are provided with adequate information on the management and outcome about neurological condition of their children. This has prompted me into conducting a research in Psychosocial Problems Facing Parents of Children with Neurological Disorders. In order to explore these areas, I want parents/caregivers attending Neurodevelopmental Clinic at KBTH who are willing to complete a questionnaire which measures characteristics of psychosocial problems and provision of adequate information. This will take about 20 minutes, and would be arranged for respondents during clinical consultation period. You do not have to put your name on the questionnaire no one will know your answers. You do not have to be in the study if you do not want to. Your decision will not affect your attendance at the clinic.

The outcome of this study will provide nurses, doctors and other healthcare professionals involved in the care of your child valuable insights into management of these children and their families. Strategies that might facilitate the improvement of your child's condition and those that

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will minimize your stress and anxiety will be recommended. The data may be presented at a research conference or published in a scholarly journal.

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APPENDIX III

CONSENT TO PARTICIPATE IN RESEARCH

Project Title: Psychosocial Problems facing Parents of Children with Neurological Problems

I have been asked to participate in the above research to be conducted by Peace Delali Nyasor, from the school of Nursing, University of Ghana. I give my free consent by signing this form and I understand that:

a) The research will be conducted as described in the information sheet, a copy of which I have retained.

b) If I decide to withdraw, my decision will be accepted. I do not have to give any reason for withdrawal of my consent.

c) My consent to participate is voluntary.

d) The information and findings of this research may be presented at the research conference or published in a scholarly journal. However my right to privacy will be retained and personal details will not be revealed, as a code number will appear on any form or questionnaire.

e) I have read and understood the information sheet and had all my questions answered to my satisfaction.

………………..........	……………………
Signature of Participant	Date
……………………….	……………………
Signature of researcher	Date