RUNNING HEAD: CHALLENGES OF PARENTS …

Challenges of Parents with Spina Bifida Children and their Coping Mechanism: The Case of Parents Receiving Service at Zewditu Memorial Hospital

By: Admassu Sodere

A Thesis Submitted to School of Social Work, Addis Ababa University Presented in Partial Fulfillment of the Requirements for the Degree of Master of Social Work

November, 2017
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ADDIS ABABA UNIVERSITY

SCHOOL OF GRADUATE STUDIES

This is to certify that the thesis prepared by Admassu Soder, entitled "*Challenges of Parents with Spina Bifida Children and their Coping Mechanism*" and submitted in partial fulfillment of the requirements for the Degree of Master of Social Work complies with the regulation of the university and meets the accepted standards with respect to originality and quality.

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DECLARATION

I declare that "*Challenges of Parents with Spina Bifida Children and their Coping Mechanisms"* my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of reference and that the work has not been submitted before any other degree at any other institution.

Admassu Sodere

Signature: _________________________

Date: _____________________________

Place: Addis Ababa University, Ethiopia

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TABLE OF CONTENTS

LIST OF FIGURE

LIST OF TABLES

ACRONYMS/ ABBREVIATION

CT scan	Computerized Tomography scan
FGD	Focus Group Discussion
IFSB	International Federation Spina Bifida
MMC	Myelomeningocele
MRI	Magnetic Resonance Image
NTDs	Neural Tube Defects
HOPE-SBH	HOPE-Spina Bifida and Hydrocephalus
RAF	Reach Another Foundation
SB	Spina Bifida
SCI	Spinal Cord Injury
ZMH	Zewditu Memorial Hospital

ABSTRACT

Spina Bifida (SB) is considered the commonest of the neural tube defects (NTDs).Folic acid could significantly reduce the birth incidence of NTDs by as much as 70%, both as first occurrences and in high-risk women. Women of reproductive age should make sure their folic acid intake is adequate. The objective of this study was to asses challenges of parents diagnosed with Spina Bifida children and their coping mechanism. Specifically, it aimed to answer research questions: What are the major challenges of parents with spinal bifida children in relation to psychological, social, economical and marital? and how parents of Spina Bifida children cope those challenges. This study was carried out in Zewditu Memorial Hospital. The study employed a qualitative research method with case study design A total of twenty one participants (Eighteen parents and Three key informants) were purposively sampling technique selected to take part in the study. Data was gathered through in-depth interviews, focus group discussion and observation. The findings of this study show parents of children with Spina Bifida had indicated several challenges faced psychological, emotional, social, economical. However, participant parents used coping mechanism such as problem focused coping, emotion focused coping. For many of the participant parents believing in their respective faith was the first emotion oriented strategy coping mechanism. Findings from this study further suggested health social worker should be aware of the concern of parents and solve such challenges with their education, counseling and supportive methods.

Key words: Spina Bifida, diagnosis, treatment and psychosocial.

CHAPTER ONE

INTRODUCTION

1.1. Background of the Study

Parents have an expectation that their children will develop and build up in a holistic health it means physically, emotionally and socially. Children are their parents' pride and happiness. On the other hand when the life and health of a child is exposed to accident or illness, parents find themselves in extremely vulnerable circumstances. For this reason when a child is diagnosed with a chronic condition such as Spina Bifida, the parents' expectations are challenged and parents grieve for the loss of their child's health (Lowes, Lyne & Gregory, 2004).

Spina Bifida (SB) is considered the commonest of the Neural Tube Defects (NTDs) and hydrocephalus commonly occurs in association, which occurs within the first four weeks of pregnancy. Due to spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system. Infants born with Spina Bifida may have an open lesion on their spine where significant damage to the nerves and spinal cord occurs. Although the spinal opening is surgically repaired shortly after birth, the nerve damage is permanent. This results in varying degrees of paralysis of the lower limbs, depending largely on the location and severity of the lesion. Even with no visible lesion, there may be improperly formed or missing vertebrae, and accompanying nerve damage (Spina Bifida and Hydrocephalus Association Canada, 2010, P.8).

Professional pronounces that women of reproductive age must make sure their folic acid intake is adequate. Because of women who do not have enough folic acid during the pregnancy have a higher chance of giving birth to a baby with Spina Bifida. The documentation of folic acid deficiency in a group of mothers with children affected by NTDs lead to the discovery that periconceptional supplementation with folic acid could significantly reduce the birth incidence of NTDs by as much as 70%, both as first occurrences and in high-risk women (Fieggen, Fieggen K, Stewat , Lazarus, Donald , Dix-peek, & Toefy Z, 2014,P.1).

The worldwide prevalence of NTDs ranged from 1 to 10 per 1000 and each year, 300,000 to 400,000 infants worldwide are born with NTDs (Godfrey,1998). In Ethiopia there is no official data that show the prevalence of NTDs. According to Gemechu and Eyasu (2015) they had described Neural tube defects (NTDs) is one of the most common congenital malformations and potentially preventable cause of prenatal morbidity and mortality. To give baseline description of NTDs their study result showed at two teaching hospitals in Addis Ababa, Ethiopia. A retrospective cross sectional descriptive study conducted by Gemechu and Eyasu from September 2009 to August 2012. During the study period out of 28,961 deliveries 177 cases of NTDs were identified, giving an overall NTD prevalence of 6.1/1000.

Children with Spina Bifida exist with a range of physical or mental that limits movements, “Depending on where in the spinal column formation. The defect is located and whether it is closed or open. Since the mid 1960s, early surgical treatment of Spina Bifida has increased the survival rates of children with severe forms of Spina Bifida.”(Tulipan, Sutton, Bruner, Cohen & Johnson, 2004,as cited in Vermaes, Janssens, Bosman, & Gerris, 2005, p. 2). Parents of children with neurodevelopment disabilities can experience very heavy emotional, financial and social burdens. They have to come to terms with these burdens, which may be present in the family for their entire lifespan (Good, Whyte, Harris, Glynn, Nicholl & Greene, 2005). The stress can be aggravated by a lack of coping strategies and negative societal attitudes (Buckley, 2002).They also often face enormous challenges in gaining knowledge about the child's condition and in understanding the needs of the child (Good et al., 2005).

The focus of the study on identifying and describing the different psychological, social, and economical challenges on parents of children with diagnosed Spina Bifida and how they try to cope with those challenges. The study area of this research is Pediatrics Neurosurgery Inpatient Unit of Zewditu Memorial Hospital.

1.2. Statement of the Problem

Parental stress and support of parents of children with spina bifida in Uganda Femke, Richard & Geert (2016) they had explored perceived stress and support of parents of children with spina bifida living in Uganda and the factors that influence them. The study result that showed Parents of children with Spina Bifida experience high levels of stress and to reduce this stress, rehabilitation services should focus on improving accommodated in vehicle mobility. Advocacy to reduce stigmatization and peer support networks also need to be strengthened and developed.

Another research conducted by Vermaes, Janssens, Bosman, and Gerris (2005) the aim of the study was to identify if parents of children with Spina Bifida have more psychological distress than controls, if mothers and fathers differ in their levels of psychological distress, and to describe which factors correlated with variations in psychological adjustment. The questions addressed were, Do parents of children with

Spina Bifida have more psychological distress than controls? Do mothers and fathers differ? The finding from the study was that parents of children with Spina Bifida, specifically mothers more likely experienced greater psychological distress.

Bozena,Janusz &Wojciech (2013) they had conducted study the aim of their study was to assessed the quality of life of parents of children with myelomeningocele. They had indicated children with myelomeningocele, it is major type of Spina Bifida require complex treatment and long-term commitment from the family in the therapeutic and educational process. All the burdens of the chronic disease affect the quality of life of parents and guardians. Their conclusions signified mothers of children with myelomeningocele had a lower quality of life in all the analyzed domains compared with mothers of healthy children. Deterioration in the quality of life of mothers with sick children is more common among those living in the city.

Demilew & Asres (2017) they assessed the knowledge of health professionals on folic acid use and their prescribing practice in Bahir Dar city Administration, Northwest Ethiopia. Using cross-sectional study show taking folic acid supplement during preconception period is effective to prevent neural tube defects. Unfortunately, a minority of Ethiopian women took folic acid supplement during this period. Low consumption of folic acid might be correlated with knowledge and prescribing practice of health professionals. The result show that about 47.7% of health professionals had sufficient knowledge and 9.7% of them had prescribed folic acid to women during preconception period. Age, having work experience in ante natal care, and being a general practitioner were independent predictors for knowledge of health professionals. The reasons for insufficient knowledge and poor practice described such as lack of guideline to use as a reference, refreshment training and clear direction from health bureau, time limitation, opposed patient priorities, and challenging topics.

Taye, Afework, Fantaye, Diro, & Worku (2016) studied the magnitude of birth defects in central and northwest Ethiopia from 2010-2014. The major objective of this study was to estimate the magnitude of birth defects in Ethiopia a hospital based retrospective, cross sectional and descriptive study was conducted. The study populations were babies' or children aged 0±17years who visited selected hospitals between 2010 and 2014. Studies setting were fourteen hospitals (8 in Addis Ababa, 6 in Amhara Region) were selected purposively based on case load. The result shows that magnitude of birth defects increased from 2010±2014. Orofacial (congenital malformation relating to the mouth and face) and neural tube defects contributed about two thirds of the birth defects and they mentioned that there is an urgent need for registry and surveillance system strategies for intervention and control of birth defects in Ethiopia.

In Ethiopia, existing researches have looked at modes of medical, surgical, magnitude detection and treatment on Spina Bifida. I have not found any studies conducted that had tried to look into challenges and coping mechanism faced by parents of children diagnosed with Spina Bifida. This shows that there is a knowledge gap in the area of challenges of parents with Spina Bifida children and their coping mechanism.

1.3. Research Questions

The research question of this study answered:

Specific questions:

- What are the major challenges of parents with Spina Bifida children in relation to psychological health?
- What are the major challenges of parents with Spinal Bifida children in relation to social relationship?
- What are the major challenges of parents with Spinal Bifida children in relation to economic challenges?
- What are the major challenges of parents with Spina Bifida children in relation to marital relationship?
- How do parents of Spina Bifida children cope with challenges?

1.4. Objective of the research

1.4.1. General Objective

The general objective of the study was to assess challenges of parents with Spina Bifida children and their coping mechanism.

1.4.2. Specific Objectives

- Identify and describe the social challenges of parents with a child diagnosed with Spina Bifida.
- Identify and describe the psychological challenges of parents with a child diagnosed with Spina Bifida.
- Identify and describe the marital challenges of parents with Spina Bifida child.

- Identify and describe the economical challenges of parents with a child diagnosed with Spina Bifida.
- Identify and describe how parents cope with the challenges.

1.5. Significance of the Study

Children with Spina Bifida have a severe psychosocial impact on their parents and the rest of their families. In my experience, as a professional Nurse involved in caring of children with Spinal Bifida, I developed an interest in this area of research parents mostly find it very difficult to accept their child's disability and they also experience a lack of support from other family members. According to Canary (2008) had explained that the main objective of the social worker is to shrink stress and depression, and give support for parents affected by the child's disability to make stronger their coping abilities and recognition of their child's disability. Furthermore social worker could be a great advantage to parents to maintain and link them to relevant resources to alleviate or reduce current stressors.

So this study may help to understand different dimensions of challenges, coping mechanisms and psychosocial support accessed by parents living with children diagnosed with Spina Bifida. And the study will be providing for social workers and the rest of the multi-disciplinary team with input on concerning psychosocial challenges of parents. It will also supply as a source for further study for other researches in this area. In addition to that, it will initiate government and nongovernmental organizations to be more conscious about the issue in order to take actions on the condition of such vulnerable parents.

1.6. Limitation of the Study

This study was limited by participation of parents of only those children who were receiving treatment in Pediatric Neurosurgical Inpatient Unit of Zewditu Memorial Hospital. This means the researcher only found those parents whose children admitted neurosurgical care in Pediatric Neurosurgical Inpatient Unit of Zewditu Memorial Hospital.

1.7. Working Definitions of Terms

Challenge:-challenge refers to a new and firm task that tests once ability and skill (Hornby, 2000). Hence in this study the term challenge was used to show that it is a new or difficult situation faced by parents with diagnosed with Spina Bifida children.

Coping mechanisms – refers to the system of adjusting to environmental stresses and challenges without altering personal goals weather it is consciously or unconsciously.

Parents: - biological or legal guardians of a child diagnosed with Spina Bifida.

Physical impacts: - sleep disturbance or sleeplessness, back pain, weight loss and other health (biological) related problems rising as a result of child diagnosed with Spina Bifida.

Psychological impacts: - experiencing feelings of anxiety, fear, anger, shock, stress and depression due to child's diagnosis.

Social impacts: - limitations in social activities, marital problems, change of family roles, added responsibilities, and lack of support from family and friends, and economical problems that brings about stress and negative frame of mind.

CHAPTER TWO

REVIEW OF THE LITERATURE

2.1. Spina Bifida

Spina Bifida is a type of neural tube defect and it is the most prevalent deficiency of the central nervous system birth defects. Spina Bifida is a congenital disorder that is inborn through a variety of different means that is differentiating by an incomplete closure of the spinal column (Children's Hospital of Philadelphia, 2011). It occurs during the first month of pregnancy, when the central nervous system is forming. The neural tube forms early in fetal development when a flat plate of cells roll into a hollow column of nerves that extends from the head down the length of the back. In the normal course of development, the neural tube usually closes smoothly, with one end forming the brain and the rest becoming the spinal cord, and after this, the bones of the spine develop.

A neural tube defect happens, “when the neural tube does not close properly. This, in turn, prevents the bones of the spine from closing and leaves part of the spinal cord exposed. The meninges, and sometimes the nerves of the spinal cord, bulge outward through this opening. This prevents the spinal cord from developing normally and interrupts the messages sent from the brain to the affected parts of the body. The amount of damage to the spinal cord and nervous system depends on where the defect is located on the spine and how many nerve pathways are damaged” (Spina Bifida and Hydrocephalus Association of Canada,201,5 p. 5). The defective region can be found anywhere within the spinal column. Despite the fact that lower thoracic, lumbar, and sacral portions of the spine are spinal cord regions which are Spina Bifida most commonly observed. (Sandler, 1997).

During pregnancy, “The human brain and spine begin as a flat plate of cells (i.e., neural plate), which migrate inward to form the neural tube. In general, complete fusion of the neural tube is believed to occur during the fourth week of gestation, often before women are aware they are pregnant.” (Menkes & Till, 1995 as cited in Lauren,2012, p.8). “The mechanism of neural tube closure is not fully understood, although the prevailing theory posits that there are multiple sites of closure (e.g., cervical and lumbar regions), as opposed to prior theories of a single starting point in the cervical region that moves downward in a “zipping” fashion. When this process is interrupted and the neural tube fails to fully close, it results in an opening in the spine or disruption of the tissue covering the spine.” (Van Allen, Kalousek, Chernoff, Juriloff, Harris, & McGillivray,1993 as cited in Lauren,2012, p.8).

The worldwide prevalence of NTDs ranged from 1 to 10 per 1000 .Each year, 300,000 to 400,000 infants worldwide are born with NTDs (Godfrey, 1998). Incidence and prevalence rates in Ethiopia may be higher due to the practice of periconceptional folic acid supplementation is negligible (Gemechu & Eyasu, 2015).

Most children born with Spina Bifida need surgery to close their back in order to prevent infections. Spina Bifida and progressive hydrocephalus also often need surgery to prevent secondary impairments. Children with Spina Bifida require the use of assistive devices and continence management because they experience mobility challenges and incontinence which affect their participation in daily activities (International Federation of Spina Bifida and Hydrocephalus, 2014 as cited in Femke, Richard and Geert,2016,p.128).

Rehabilitative and surgery care is costly and difficult to get to for many children born with a disability in Africa. Their families are often their main source of care and protection (Guyer, 1981). To provide this care and protection for children with Spina Bifida and Hydrocephalus, families living in poverty often struggle to find resources (Miles, 2002).

2.2. Causes and Detection Method of Spina Bifida

Currently, no single etiology has been identified to explain for the development of Spina Bifida. Instead, researchers believe that Spina Bifida is a disorder, it happen as a result of interactions between an individual's genes and other factors in the environment. Recent research has shown that Spina Bifida and other neural tube defects are less likely to occur when women get enough of the B vitamin folic acid during their childbearing years, either in their diets or through supplements. Neural tube defects occur during the first month after conception, before most women even know they are pregnant. For this reason, it's important to have a healthy, balanced diet and to be sure you are getting 0.4 mg of folic acid every day, as long as there is a possibility of becoming pregnant (Fernández & De-Regil, 2011 as cited in International Perspectives on Spinal Cord Injury,2013,p.52).

Scientists and researchers list the following factors as risk factors and causes:

Genetic disorders: Genetic factors can be moved from one generation to another, family history of a genetic disorder have chance of development of that neurologic developmental disorder in next generations. Congenital impairments are passed through the mother to the unborn child (Behrman &Butler, 2007; Cerebra, 2010).

Nutritional deficiencies: Iodine deficiency and folic acid shortage at some stage in pregnancy have been related with a high risk for neurodevelopment disabilities in the unborn infant (Cerebra, 2010; Gillberg, 2010).Folic acid is a B-vitamin mostly found in vegetables, whole grains, fruits and dairy products, which can reduce the development of neural tube defects such as Spina Bifida and anencephaly (Cerebra, 2010). These neural tube defects include malformation and dysfunction of the central nervous system, which cause severe physical disabilities and emotional. Iodine deficiency creates a variety of neurodevelopment disorders such as emotional disturbance, obsessive-compulsive disorder and mental retardation (Behrman & Butler, 2007; Gillberg, 2010). Blood tests of the mother and an ultrasound of the baby in the uterus may find the defect. Most health care providers now offer pregnant women a blood test called the maternal serum alpha-fetoprotein screening test (IFSBH, 2014).

2.3. Types of Spina Bifida

The three most common types of spina bifida are:

Myelomeningocele (pronounced my-low-meh-NIN-go-seal)- a severe form of spina bifida in which the spinal cord and nerves develop outside of the body and are contained in a fluid- filled sac that is visible outside of the back area. These babies typically have weakness and loss of sensation below the defect. Problems with bowel and bladder function are also common. “Myelomeningocele is the most common and severe form of spina bifida and accounts for approximately 90% of cases This type of spina bifida often requires a more intense and complex medical regimen” (Norman, McGillivray, Kalovsek, Hill, & Poskitt, 1995 as cited in Lauren,2012,p.9). A majority of babies with myelomeningocele will also have hydrocephalus, a condition that causes the fluid inside of the head to build up, causing pressure inside of the head to increase and the skull bones to expand to a larger than normal size. The level at which the spinal lesion occurs determines the effects of the deformity, as well as the extent of the effects, to a large extent.

Myelomeningocele can occur at any level in the developing spine, but occurs most often in the lumbosacral region. The higher the defect on the spine, the more severe the complications. Areas below the level of the defect (Children's Hospital Of Philadelphia, 2017, P.5). About seventy to ninety percent of children with myelomeningocele develop hydrocephalus, which is characterized by the dilation of the ventricles of the brain, leading to the accumulation of excess cerebrospinal fluid a build-up of fluid in and around the brain This results in compression of the brain, and possibly, enlargement of the head (Spina Bifida and Hydrocephalus Association Canada, 2010, P.7).

Cerebrospinal fluid cushions and protects the brain and spinal cord. When the fluid is unable to circulate normally, it collects in and around the brain, causing the head to be enlarged. Those who develop progressive Hydrocephalus need surgery. Without treatment, Hydrocephalus can cause brain damage and mental retardation. "Shunt failure is the most common indication for reoperation and occurs frequently, both in developed countries and low income countries" (Enger, Svendse, Sommerfelt & Wester, 2005 as cited in Tsegazeab, Abenezer, Hagos, Deeptha,Knut &Wester,2017,p.2).

- **Spina Bifida Occulta -** a mild form of spina bifida in which the spinal cord and the surrounding structures remain inside the body, but the back bones in the lower back area fail to form normally). Most often, X-ray examinations are utilized as the chief diagnostic tool in cases of Spina Bifida occulta (Sandler, 1997).Commonly occurring in the sacral regions of the spinal cord. There may be a hairy patch, dimple, or birthmark over the area of the defect. Other times, there may be no abnormalities in the area.

- **Meningocele (pronounced me-NIN-go-seal)** - Meningocele is the final and least prevalent form of spina bifida, accounting for only five percent of all cases of Spina Bifida and meningocele is rarely associated with central nervous system deformities, and therefore rarely results in neurological dysfunction (French, 1990).

2.4. Can Spinal Bifida be prevented?

Studies have found that the B-vitamin folic acid may help to prevent spinal bifida in some cases. Some of the studies for instance, " an Israeli study demonstrated that three years after implementing folic acid supplementation (2002 and 2004) the incidences of spina bifida decreased from 14.4 to 8.9 per 10 000 live births" (Zlotogora, Amitai & Leventhal,2006 as cited in International Perspectives on Spinal Cord Injury,2013,p.52). And another studies Hungarian researchers carry out "a randomized double blind multicenter trial of folic acid to see if it had a protective effect for a first occurrence of NTD. One group of 2104 women received 0.8mg of folic acid with their multivitamins while the second group of 2052 women received no folic acid with their multivitamins. The folic groups had no cases of NTD while the non folic groups had 6 cases" (Richard& Ellenbogen, 2002 as cited in Ndegwa, 2004, p. 24).

Women who have a family history of these defects and could become pregnant should take a vitamin with 4000 micrograms of folic acid daily. They should also eat foods rich in folic acid such as green vegetables and whole grains. The key is having enough folic acid in the system before and during the early weeks of pregnancy, before the neural structures close. “Periconceptional folic acid supplementation (three months before and after conception) has been shown to reduce the rate of infants born with neural tube defects, including Spina Bifida” (Fernández & De-Regil,2011 as cited in International Perspectives on Spinal Cord Injury,2013,p.52).

2.5. Spina Bifida Children Clinical Manifestation and Treatments

The nerve damage consequences in reduced or absent of sensation and may cause people with the condition to experience lower limb paralysis, motor impairment, incontinence of the bladder or bowels, or all of these. For individuals with hydrocephalus, the brain can show lasting effects, both short and long term. These may include impaired vision, headaches, sensitivity to changes in external pressure, hearing sensitivity, muscle weakness, hormonal imbalances, or seizures. Furthermore to physical and mobility difficulties, many individuals with Sspina Bifida and/or hydrocephalus may have some form of learning disability. (Spina Bifida and Hydrocephalus Association Canada, 2010, P.7).

There is no cure for Spina Bifida. “The current standard of care for treating patients with Spina Bifida, particularly myelomeningocele, is to perform neurosurgical repair within 48 hours of birth. In order to prevent infection and to preserve nervous tissue and function, a neurosurgeon will reconstruct the closure of the spinal cord. Some improvements in infants’ ability to move have been observed following surgery, but most of the complications associated with incomplete formation of the central and peripheral nervous system are irreversible.”(McLone & Bowman, 2005 as cited in Laurn, 2012, p.10).

2.6. Conceptualizations of Disability

The World Health Organization (WHO) notes that, “Disabilities can be intellectual, developmental, physical, sensory or mental in nature. The term “disability” is an overarching term that describes activity limitations, impairments and participation restrictions: impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.” (World Health Organization, disabilities, 2011).

Federal Democratic Republic of Ethiopia define disability on proclamation may be cited as “The Rights of Disabled Persons to Employment Proclamation number 101/1994. “Disability” is defined as follows:

> ‘A disabled person’ means a person who is unable to see hear or speak or suffering from injuries to his limbs or from mental retardation, due to natural or man-made causes; provided, however, that the term does not include persons who are alcoholics, drug addicts and those with psychological problems due to socially deviant behaviors.

Different cultures describe disability regarding their norms differently because disability is comparative expression this means the circumstance that forms disable and subjective meaning (Ingstad, & Whyte, 1995). Children with Spina Bifda live with a range of functional impairments, including weakness or paralysis of the legs, bladder incontinence, bowel constipation, and cognitive deficits (Mitchell, Adzick, Melchionne, Pasquariello, Sutton & Whitehead, 2004). Children disposed by this condition manifest “neurological, orthopedic, renal and urogenital complication, needing lifelong healthcare provisions. Thus, Spina Bifida is characterized as a chronic condition” (Caseiro, Gonçalves & Malheiro, 2013,p.122). Chronic health conditions have a biological, psychological or cognitive basis and make function limitations activity or social role, causing dependence medication, special nutrition, medical device technology and social care support requiring healthcare or related services in order to be continued normal life (Van der Lee, Mokkink, Grootenhuis, Heymans, & Offring 2007).Robinson (2006) he states that many adults and children throughout the world are segregated, deprived of nearly all their rights, sometimes lead heartbroken, often live in terrible conditions and face physical social difficulties because of their disability.

2.6.1. People Beliefs and Attitudes about Cause of Disabilities

Thinking about source of disability in the observed literature was disabilities are “regarded as punishment from the gods or bad omens, and hence people with disabilities are rejected or abandoned.” There are also descriptions of taboos that, when broken, are thought to cause a disability. For example, the Nandi community of Kenya considers “It wrong to kill animals without good reason during a wife’s pregnancy” (Mbah-Ndam,1998; Ogechi & Ruto, 2002 as cited in African Studies Centre Leiden 2008,p.5).

The study on Cause of child disability in Tanzania found that “the majority of tribal elders believed that disabilities were caused by God’s will (44%) or witchcraft (39%), whereas 82% of classroom teachers believed the disabilities were caused by diseases. In other studies examined, parents of children with disabilities explained that their child was a gift from God or that is was God’s will for a child to have a disability. God(s) can either bless or curse families who have a child with a disability. In several instances, although disability was accepted as an medical mishap, this explanation was accompanied by the belief that divine intervention caused the accident” (Mashiri, 2000; Kisanji 1995b; Devlieger, 1999a; Kiyaga & Moores,2003 as cited in African Studies Centre Leiden 2008).

Attitudes to people with disabilities in east Africa have both positive and negative aspects and are often connected to beliefs about the causes of disability. Throughout Africa, “it is considered inappropriate to laugh or ridicule people with disabilities” (Ogechi & Ruto, 2002; Talle, 1995 as cited in African Studies Centre Leiden,2008,p.6). Even when nondisabled people avoid these preconceived opinion that is not based on actual experience, disability is still considered to be unable to get along with a good quality of life; for example, the general public often views tetraplegia(also known as quadriplegia, is paralysis caused by illness or injury that results in the partial or total loss of use of all four limbs) to be worse than death (International Perspectives on Spinal Cord Injury, 2013, p.124).A Kenyan study of families with children with spina bifida on attitude of family revealed that only six of forty families found their community very helpful; seven had been rejected, whereas nine felt that they were cursed because of the birth of a disabled child (Eide & Kamaleri,2009).

Parents of children with neurological disabilities come to with practical contact of emotional, economic and social challenges, which may be continues in the family for their entire lifetime (Good, Whyte, Harris, Glynn, Nicholl & Greene, 2005). The stress can be aggravated by a lack of coping strategies and negative societal attitudes (Buckley, 2002). They also in many instances face massive challenges in obtain knowledge about the child’s condition and understanding the needs of the child (Good et al., 2005).

2.7. The Role of the Social Worker

Parents normally expect their children will be born or live without any disabilities. However, Parents practice shock, disappointment and stress when children diagnosed with disabilities. This often cause psychological crisis (Raina,,O’Donnell, Schwellnus, Rosenbaum, King, Brehaut, Russell, Swinton, King, Wong, Walter & Wood, 2004). Hepworth, Rooney, Rooney G, Stom-Gottfried & Larsen, (2006, p. 39) they referred to a ‘crisis’ as “A perception of an event or situation as an intolerable difficulty, that exceeds the resources or coping mechanism of the person” and notes that extended the duration of crisis related stress can greatly affect the family’s functioning.

According to Canary (2008) had explained that the major objective of the social worker is to shrink stress and depression, and give support for those parents affected by the child’s disability to make stronger their coping abilities and recognition of their child’s disability. Furthermore social worker could be a great advantage to parents to maintain and link them to relevant resources to alleviate or minimize current stressors.

2.8. Theories and Models

This study considers family stress theory in trying to understand the psychosocial, physical and economical impact of child diagnosed Spina Bifida on parents and their coping mechanisms.

2.8.1. Family Stress Theory

The family stress theory asserts that any occurrence (stressor), positive or negative, will have an impact on families. Grounded in the ABC-X model, the theory's basic statements declare that coping or get into crisis with circumstances depends on how the family perceives or defines that event (Smith, Suzanne, Hamo, Raeann, Ingoldsby, Bro, Miller & Elizabeth,2009, pp. 96-97).

The effects of a child with Spina Bifida disability on the parents can be described through the Family Stress Theory. McCubbin (1995) first proposed the Family Stress Theory model in 1995 to explain the effects of stress on the family unit.

The "A" aspect consists the stressor event. In this study could be the birth or diagnosis of a child with a severe disability. The "A" aspect could be anything that is stressful and overwhelming to an individual that leads to stress on the entire family (Darling, Senatore & Strachan, 2012).

The "B" aspect consists of the coping methods that are used to deal with the stressor event. Family resources include an individual's personal resources, the family system's internal resources, social support, spiritual guidance and coping. The family's resources are the strengths the family has available to them, which help the family adapt to the stressful occurrence. The more resources that are available in the coping stage can better shield the family from stress (McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980).

The "C" aspect consist the definition of the stressful event individual or family perceives the stress that is being challenged on the family. In other word how the family perceives the stress. The stress can be manageable and feel they are able to deal with the added strain at the same time as stress factor completely overwhelming and feel they are unable to cope with the stress.

The final aspect of the Family Stress Theory is the “X” aspect. The “X” combines the other three aspects (the stressor, the resources, and perceives of the stress) and formulates a level of adjustment the family has achieved. The range of how the “X” factor is noticeable could go from a well-adjusted family to one with very high stress and maladaptive ways of dealing with that stress (Darling et al,.2012).

The ABC-X model describes how having a child with Spina Bifida disability can create challenges for parents that cause them to reorganize the way the parents functions. A major factor of this model is the meaning the parents allocate to the stress of having a child with Spina Bifida disability and the resources the parents has to cope with the stress.

The application of the ABC-X model of the family stress theory to this study is shown in the diagram below.

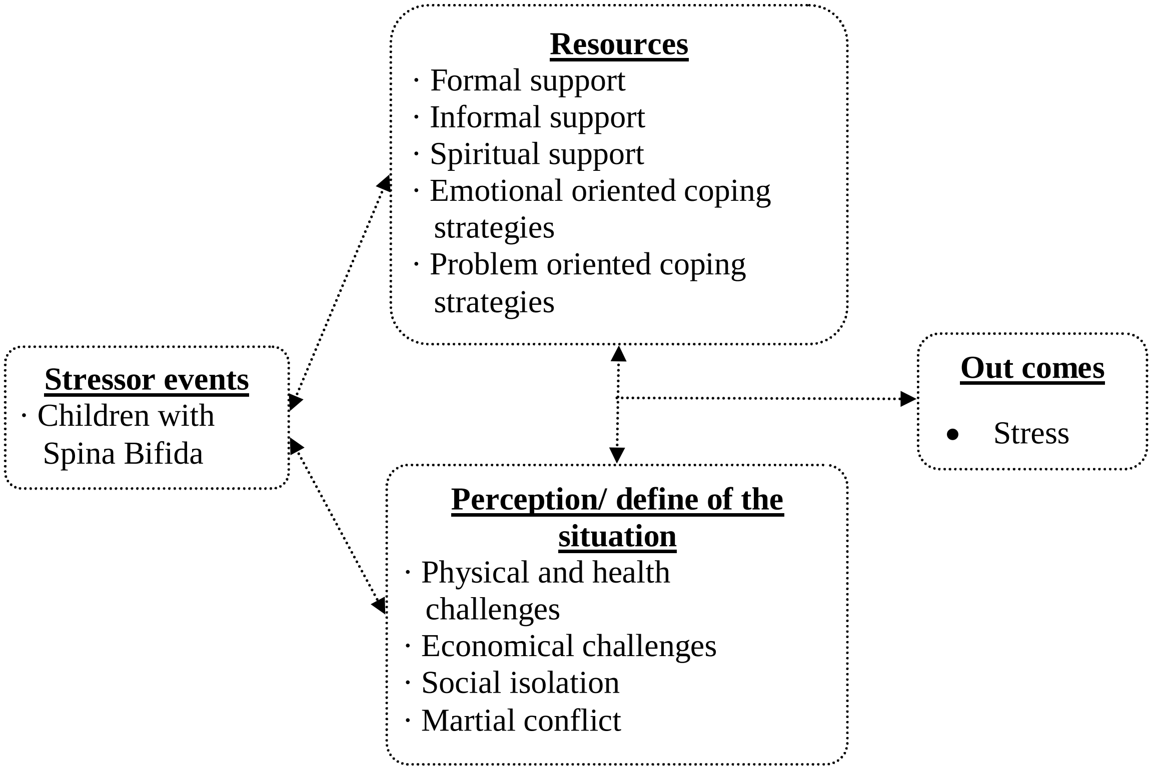

Figure 1: ABCX Model of the family stress theory

The above figure shows the inter-relation between the A, B, C, and X factors in the study of Challenges of parents with Spina Bifida and their coping mechanism.

2.9. Impact on Parents with Children Diagnosed with Spina Bifida

Parents experience physical and health, economical and psychological, and social challenges in related to their child's diagnosis with Spina Bifida.

2.9.1. Physical and Health Impact of Children with Spina Bifida on the Parents

Caring for a child with a birth defect such as Spina Bifida can negatively impact the physical and mental health of parents. Many parents experience significant depression, fear and anxiety, which may have a devastating effect on the whole family if left untreated. Mackey &Goddard (2006) they had reported that due to having to be constantly attentive and watchful, and lack of respite from the work of caring for a child with a disability parents are expose to fatigue and tiredness. Parents to children with chronic conditions have reported poorer sleep quality and greater sleepiness than parents to healthy children and mothers of children with physical disabilities report more headache, psychological exhaustion and pain due to heavy lifting than fathers (Park, Meltzer-Brody & Stickgold,2013;Morelius & Hemmingsson, 2014). Another study also reported parents caring for a child with a chronic condition illness such as Spina Bifida sleep deprivation and sleep disruption are common problems in parents (Matthews, Neu, Cook & King,2014; Herbert, Monaghan, Cogen & Streisand,2015 & Bourke-Taylor, Pallant, Law, & Howie,2013). And Meltzer and Booster, (2016) they had described that sleep deprivation and sleep disruption have a negative impact on the parents' care giving tasks.

Sleep loss in parents is connected with feeling of dissatisfied, lack of tolerance and easily angered towards the child, and frequent irritable actions towards their child affect the parents´ sense of confidence, self-esteem and competence (Cooklin, Giallo & Rose,2012).As Herbert et al., (2015) they pointed out poor sleep quality may result in sleep-related daytime dysfunction-losing the guts to complete routine tasks as well as the motivation to perform care for the child. This is particularly acute for parents of children with spina bifida. Sawin & Thompson (2009) wrote, Parents of children with spina bifida may be mostly at risk for depression due to increased care burden. These parents, caring for a child with this neurological condition which has multisystem involvement, have “A long complicated journey” (Sawin & Thompson, 2009, p. 284). Having a child with a serious illness can have a detrimental psychological effect on parents (Kent, King, & Cochrane, 2000). Concerns about their child's health and future can create stress that cannot only impact on the parent's own health, but may feedback to impact the child, as well (Ohleyer, Freddo, Bagner, Simons, Geffken, Silverstein & Storch, 2007).

2.9.2. Economic Impact of Children with Sipina Bifida on the Parents

Parents with children of Spina Bifida also bear adverse impact economically. In the first place, as Lemacks, Fowles, Mateus, & Thomas, (2013) they noted that the impact comes in the form of resistance from their employer who often does not understand why they constantly visit doctors and why is more confounding here is appointments are rarely available outside traditional work hours. Lemacks reiterates "Some parents may lose jobs, need to change jobs, or even decide that one parent needs to quit his or her job and stay at home" (Lemacks, et al,. 2013, p.4). And(Child Neurology Society, 2012 as cited in Lawal, Anyebe, Obiako & Garba, 2014, p.59)reported that financial disadvantages as a result of the need to care for the children are a major experience by families of affected children.

Parents experience financial burden, as Lemacks, et al, (2013, p. 4) they described "Parents who have to leave employment may feel offended, and the working parent may also feel offended as he or she has to carry the entire financial burden of the family. In extreme cases, families may divorce or move to another state so they can afford their child's medical care." Goudge, Gilson, Russell, Gumede & Mills, (2009); Harris, Goudge, Ataguba, McIntyre, Nxumalo & Jikwan,(2011) they said that along with the poor and those live in rural area transports costs are a main obstacle to health care services.

Parent’s employment and family income fall suddenly because of Caring for children with disability (Heller, Caldwell and Factor, 2007). There are factors that impact parents economic for instant “The complexity in getting medical treatment for the affected children. The distance covered to assess medical treatment was an additional economic challenge”. Also highlighted the treatment difficulties centered on obtains expensive drugs, frequent investigations or test. In addition to this, such children need a involvement of specialized professional and series of investigations such as computerized tomography scan and magnetic resonance imaging which create financial consequences on their parents (Rochelle, 2005, Batual, 2011 and Baxamussa 2011 as cited in Lawal, Anyebe, Obiako & Garba, 2014, p.59). The fundamental reason can be the condition of being insufficient support in care giving (Chou, Fu, Pu and Chang, 2012, p.260).

2.9.3. Social Interaction Impact of Children with Sipina Bifida on the Parents

Having a child with birth defect can enormously affect parents’ social interaction and relationship. And this situation also persists even after a child is released to a regular life. As such, Parents are often not willing or unable to participate in typical social activities. So that, parents’ may become isolated from social life and fearful of negative response by friends or relative (Vijesh,2007 as cited in Lawal, Anyebe, Obiako & Garba, 2014, P.59).

Lemacks, et al,. (2013) they described that especially in circumstances where the child’s birth defect unusual and there is little support parents often live with the sense of isolation. This can cause significant feeling of being anxious in social settings and even lead distressed parents to further isolate themselves because they feel “different” from their peers (p.5). Davis, Shelly, Waters, Boyd, Cook and Davern, (2009, p.67) they also explained that Parents considered they were unusual than their friends, who had children without disability because of this parents of children with disability had difficulties in continue social relationships. As a research by Oyewole, Adeloye and Adeyokunnu, (1985) they pointed out many parents tried to hide their children's condition from friends, neighbors and extended family. Parents perceived the birth of the child with such condition as their personal failure thus must be concealed.

2.9.4. The Impact of Children with Spina Bifida on the Marital

Parents of children with birth defects often experience significant strain on their marital relationship because of the stress they experience. The day-to-day interactions with children who have birth defects change the dynamics of spousal interactions, and as a result, this particular demographic is more likely to divorce than their non-affected counterparts. This is especially true if parents have limited support from family, friends, or professionals (Price,2011,p.28). Another study by Davis et al,.(2009) they had founded that lack of time due to the burden of care as a reason Australian parents of children with disability also fight back with their marital relationship.

The marital relationship may suffer unduly from added stress of blame, guilty, and anxiety. Child disability attacks the fabrics of marriage in different ways and reshape the organization of the family, creating a fertile ground for conflicts (Vijesh, 2007 as cited in Lawal, et al,. 2014,p.59). Other studies on similar issues reported that having a child with disability while expecting a healthy child leads to feelings of loss and grief. Feelings of grief and guilt cause tension in marriages (Yıldırım and Gokyıldız 2004). Another study by

Parke (1986) had explained that the birth or diagnosis of a child with a disability and leading to reduced spousal support. Such stressful events are can be interrupted marital relationships. Divorce experience more likely common understood that families with children who have disabilities. Balfour,(2007) had also indicated Because of the husbands not being concerned on children with disabilities married couples happened conflict and disappoint by husbands.

2.9.5. The Impact of Children with Sipina Bifida on the Mothers

Hovey, (2005, p. 86) he had indicated mothers were most affected emotional distress, career disruption, and stressful interfaces with the medical system because of mothers were most affected in their daily lives by the impact of the child's disability in addition to that a mother's role for a frequently ill child is the primary caregiver and to take accountability for childcare, doctor's appointment and other health maintenance issues. Mothers develop a sense of personal control and are able to have an active role in their child's treatment plan. Mothers who participated in the process of empowerment were "associates, collaborators, and participants in their child's care" (Gibson, 1995, p. 1208).

In the review by Vermaes et al. (2008) they described that child, parent, family and environmental factors were found to be connected with variations in parents' psychological adjustment. Due to role differences in care and work mothers are often at higher risk for parenting stress than fathers. And similar study the character of the child's disease, have to handle symptoms, and the difficulty of treatment and mothers of a chronically ill child may great effort to meet the load of parenting all these cause direct to emotional strain on mothers (Hopia, Tomlinson, Paavilainen, & Astedt-Kurki, 2004).

2.9.6. Common Reactions of Parents to Child's Diagnoses with Spina Bifida

Before a child diagnosis with a birth defect, parents had a dream of life with their child that changes completely after a child is diagnosed with a birth defect. Parents in fact lose healthy child that they were expecting. Parents experience felling deep sorrow the typical stages of grief due to loss of what they predicted. Grief counseling may be very helpful to these parents (Stone, Botto, Feldkamp, Smith, Roling, Yamashiro, & Alder, 2010, pp.1359-1361).

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge.

Shock

Shock is the primary reaction on hearing the news that their child has a learning disability. Oeckerman (2001, p.11) he had explained that when parents heard that their child has a disability, parents run through with different phases of reaction usually shock is the first feedback of parents after hearing the information that their children have disabilities, go after by denial, there may be feelings of guilt and anger, sadness and depression may continue and final phase is acceptance and it is defense mechanism used by parents as they feel when unable to cope (Ho & Keiley, 2003, p.239).

Denial

When parents unable to accept the fact that their child might have disability. Denial is explained as a defense mechanism used by parents because they feel unable to cope with this new situation (Ho & Keiley, 2003, p.239).

Grief

Grief is a difficult reaction with the failure of the expected normal child and the necessity to develop a new role of attachment to the abnormal child. Often the initial diagnosis of the child's disability will create a grief reaction in parent. This may be the result of initial confusion and uncertainty. Grief and bereavement are normal reactions to the loss of expected health baby Olshansky (1962, p.190) had described parents all their life go with grief due to a disabled child.Heiman (2002, p.160) he had also described Parents articulated an original sorrow for the children not being able to live a life similar to other health children because of impairment their children.

Guilt

One of the common reactions of the parents to the birth of a child with disability is guilty. Disappointment, anger and rejection are parents felling. Since the parents cannot tolerate or suffer these negative feelings, they deny the feelings by directing the anger towards them the feeling that this is a penalty for their past sins. In other cases, the guilt feeling is directed as a result of negative feelings towards other people, such as a spouse or a physician, or towards spiritual matters. Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, “Why me?” or “Why my child?”, “Why has God done this to me?” “What did I ever do to deserve this?” (Patricia,2010).

Fear

Another immediate response is fear. People often fear not familiar more than they fear the known. Having the full identification of the nature of an illnes and some knowledge of the child’s future prospects can be easier than uncertainty. Fear of the future is a common emotion on most parents of disable children: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?” Then other questions arise: “Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?” Other unknowns also inspire fear. Parents fear that the child’s condition will be the very worst it possibly could be. These fears can almost immobilize some parents (Patricia,2010)

Acceptance

Acceptance is the stage at which the parents can look past the disability and accept the child as he or she is. The aim is to reach acceptance to be able to make conclude about how their child will be assisted. Lerner & Kline (2006, P.154) they had indicated that to continuing to live a normal life parents must accept their child with disabilities along with their special needs and they also stated that acceptance is vital stage to continuing to live a normal life. Siklos & Kerns, (2006) they had indicated parents began the process of acceptance look for and occupied with support systems after parents developed knowledge about their children’s neurodevelopment disability, this help parents to cope with current problems.

2.10. Coping Mechanism

Coping is seen as “A stabilizing factor that can help individuals maintain psychosocial adaptation during stressful periods”, which includes efforts to reduce or eliminate stressful conditions and its associated emotional distress (Holahan, Moos and

Schaefer,1996, p.25). Coping is defined as the use of thoughts and actions, regardless of how well it works, to manage the stressful situations and negative emotions related to stress. If, coping succeeds the person is no longer in jeopardy and reasons for emotional distress disappear. The things that the people do in order to alter the stress or to cope, depends on the situation being faced, the threat, the personality and beliefs of the persons and the immediate results (Lazarus, 1984). Broger and Zeni (2011) noted the importance of coping by stating that the "effective use of coping mechanisms can be a successful tool in improving the overall outcome of a child's well-being," (p. 102).

Parental coping skills and abilities are significant indicators of future success in such families. Each individual will choose which coping strategies to engage in response to his/her cognitive evaluation of the stressful situation (Lazarus & Folkman,1984). Problem focused coping, which involves strategies to solve, re-conceptualize or minimize the effect of a stressful situation or a problem. The emotion focused coping dimension relates to strategies that regulates the emotional response to the problem (Parker and Endler, 1996, p.9). And Gona, Mung'ala-Odera, Newton and Hartley,(2010,p.179) who investigated coping strategies among parents of children with disability in Kenya found problem focused coping strategies to be learning new skills, search for cure and external support. For emotion focused coping they detected belief in God and sharing of experiences. Lightsey & Sweeny (2008) they found that emotion oriented strategies more commonly used by women to cope with chronic illness such as Spina Bifida of a children and problem-focused coping more often males used and Nazemi,(2007) he had indicated one of the familiar emotion oriented strategy is blaming.

2.10.1. Informal Support

Informal assistance and support have been shown to be more effective when combined with several formal care systems and services. For instance, respite care allows families to take a break from the stresses associated with informal care giving to children with Spina Bifida (International Perspectives on Spinal Cord Injury, 2013,p.128). Shilling, Morris, Thompson-Coon, Ukoumunne, Rogers, Logan and Peer,(2013,p.602) they had indicated Parents support one another through the process of caring their children when parents bond with other parents of children with birth defects because it gives opportunity to them build up a shared social uniqueness which can give a feeling of hope as parents see one another successfully coping.

Social support is defined as “the perception or experience that one is loved and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations” (Taylor & Stanton, 2007, p. 381). From family, friends, spouse, health care professionals and other families in the same condition are sources social support. Positive interactions with similar individuals are give greater knowledge, understanding, support each other and become stronger (Gibson, 1995).

2.10.2. Formal support

Formal assistance and support services cover several different areas, including residential support services, community support, respite care and others. Formal services may be delivered by means of public or private for-profit and private not-for-profit sectors, or by a combination of these (WHO,2011). For low-income countries, however, resources may not be available for this type of service or the cost to the consumer may be too great (Sekaran, Vijayakumari, Haviharan, Zachariiah, Joseph & Kuma, 2010). Residential provision, which has been the traditional approach to formal care in high-income countries, undermines the choice and freedom of people with disabilities to lead normal lives.

Healthcare professionals can play an important role in helping families cope with the challenges involved for children who have birth defects. Healthcare professionals should take extra care to educate families on what to expect when caring for their child and how to manage their child's care. Several studies found that parents of children with neurodevelopment disabilities need and depend on professional support services (Heiman, 2002; Nachesehen, Garcin & Minnes, 2005). And Churchill, Villareale, Monaghan, Sharp and Kieckhefer (2010, p.48) they had described to reduce the presence of depressive symptoms and specific coping skills as a useful strategy to improve coping abilities health professional should put emphasis on education parents. Other studies also showed to cope with the situation of having a sick child education offered for parents has been accounted to be helpful (Atkin, 2000; Pain,1999 and Van den Borne, Van Hooren, van Gestel, Rienmeijer, Ffyns, and Curfs,1999).

Improve quality of life of all family members through the process of serving should be family-centered helps to maintain the goal to have effective social and health interventions with parents and children with neurodevelopment disabilities. Parents have to involving in decision making throughout the duration of treatment intervention of their children, obtaining social, health information and treating parents with mutual respect and support are standard of family centered services. Uses of family centered interventions are advantageous on decreased levels of parental stress, greater emotional well-being, and parental empowerment (King, Teplicky, King & Rosenbaum, 2004).

2.10.3. Spiritual Support

Moreira Almeida & Koening (2006, p.844) defined spirituality as the individual search for understanding respond to vital questions about life, about meaning, and about relationship with the holy. Hexem, Mollen, Carroll, Lanctot & Feudtner (2011) they found that the majority of parents who did follow a religion, spiritual affiliation, or life philosophy "felt…[it was] very important in providing support, peace, comfort, and moral guidance" (p. 42). Kloosterhouse and Ames (2002) they determined that religion and spirituality were a "source of strength and an anchor to help center the family during a crisis" (p. 74). And Krok (2008,p.645) he had indicated that religious strivings offer a universal viewpoint of life and religious strivings are make powerful as a result can provide stability and support in critical times.

Spirituality is difficult to define because it means different things to different people. Spirituality can be described in various ways: faith in humanity, ethical behavior, concern for others, or interaction in relation to a greater Being (Stinnett & DeFrain, 1985). "Spirituality helps people appreciate what they themselves cannot control" (Pargament, 1997, p. 8). It is a personal way of life in which a person strives to find meaning and significance. Many people find spiritual support in the form of prayer, literature, participation in religious activities, joining organizations, or attending religious services, Stress and Coping Strategies of parents of children with developmental disabilities. In a Kenyan study of families having children with spina bifida, three quarters of families had been be friend by someone from their church, and half of them knew other families with disabled children, which suggests that sources of mutual aid and support are available (International Perspectives on Spinal Cord Injury, 2013,p.128).

Faith and religious coping methods are the most frequently reported coping strategies among parents who have children with developmental disabilities (Pargament, 1997). Others use religious reframing as a way to put things in a new perspective and make the situation more manageable. Religion offers guidelines for living and offers a sense of stability. Families may view the difficult situation as an opportunity for spiritual growth (Pargament, 1997).

The above literature review indicated different challenges of parent with Spina Bifida such as parent's physical health, social relationship, marital relationship and economical challenges and coping mechanism such as formal support, informal support and spiritual support. The research methodology used to examine these relationships is discussed in the following chapter.

CHAPTER THREE

RESEARCH METHODOLOGY

This chapter outlines how the study was conducted to achieve its objectives. The key aspects regarding the methodology of the study are discussed. It includes the study design, study setting, study population, sampling, data collection, data analysis, and ethical implications of the study.

3.1. Research Design

Research designs are plans and procedures that engage decision of essential assumptions to characteristic method of data collection and analysis (Creswell, 2009, p.3). Philosophical world view use a research explaining the selection for the type of methods of approach in a research (Creswell 2014, pp. 5-6). In conducting a study on research topic under study a social constructivist philosophical world view was chosen. According to Creswell (2014, p. 8) social constructivists consider that individuals seek understanding of the world in which they live and work. Individuals develop subjective meaning of their experience, meanings directed toward certain objectives or things. Using the social constructivist philosophical world view the researcher seek to understand the meaning of different dimension of challenges and coping mechanisms presented by parents having a child diagnosed with Spina Bifida.

In quantitative research, hypotheses inform the direction of the study. This is known as the hypothetical-deductive method (Willig, 2008). However, qualitative research is conducted by provisional research questions and Qualitative research seeks to describe various aspects about behavior and other factors. In qualitative research data are often in the form of descriptions, not numbers. The goal of qualitative research is to search for meaning and stress is laid on the socially constructed nature of reality. Therefore, for this study the researcher used qualitative approach because a qualitative approach enables the researcher to get an in-depth understanding of the issue and allow research participants to express their views broadly. It is also more appropriate in terms of documenting rich and detailed information (Snap & Spencer, 2003). Qualitative research method was chosen because it is an appropriate research method to address the central question which tries to assess overall conditions of parents with children diagnosed Spinal Bifida. Knowledge is located in the meaning people make of it and can be acquired through communication about their meaning. A close relationship with the research participants bring success for qualitative research (Creswel 2003,p.173).

According Kreuger and Neumann (2006, p.21) social research purposes are structured into three groups, exploratory, descriptive and explanatory. The researcher seek to understand parents with Spina Bifida children their different dimension of challenges, coping mechanisms and sources of psychosocial support as presented by parents, therefore a descriptive research presents a picture of the specific details of a situation, social setting or relationship (Kreuger & Neumann, 2006, p.22). With regards to time dimension, the study was a cross-sectional research looking into the psychosocial and economical challenges on parents and how they cope at a single point of time; it was selected because it is less costly and less time taking.

Case study design is chosen from different research design such as,Narrative, Phenomenological, Ethnography and Ground theory because case study approach provides a researcher for holistic understanding of a problem, issue or phenomenon within its social context (Hesse-Biber & Leavy, 2011, p.254). In order to gain an in-depth and detailed information on the topic of interest, the study used collective case study method that enabled researchers to take in a single issue and conduct multiple cases to demonstrate the issue (Creswell, 2007,p.74). In accordance with the research design selected, non-probability sampling, specifically purposive sampling was use to identify participants and collect data. The idea behind qualitative research is to purposefully select participants or sites that will best help the researcher understand the problem and the research question (Creswel, 2014, P.180).

3.2. Study Population

The study population included parents of children with diagnosed Spina Bifida, children aged from birth up to 5 years, who were admitted at the Neurosurgical Inpatient Pediatric Unit at Zewidtu Memorial Hospital, Addis Ababa, Ethiopia.

3.3. Study Setting

The study was conducted at the Neurosurgical In patient Unit at Zewidetu Memorial Hospital Addis Ababa, Ethiopia. Zewditu memorial hospital was established and owned in 1925 E.C by American Adventist missionary as a private hospital in order to give service for 250, 000 people of Addis Ababa. Its aim was only to give maternal and child health care. The place where the hospital established was near the Great National palace. But in 1963 it became under the government authority and transferred to the present building which is located in Addis Ababa region Kirkos sub city Wereda 07. Zewditu Mimorial Hospital is controlled and operated by Addis Ababa region Health Bureau. It is giving service for 34 health centers under 7 sub cities as a referral hospital and all types of emergency cases with 250 hospital beds. The Hospital is ruled based on National health policy and Addis Ababa city administration health service and health facilities management regulation number 26/2001.

ZMH started neurosurgical treatment in 2009. Activities performing associated with Addis Ababa University and Reach Another Foundation (RAF) to improve the care for children with Spina Bifida and hydrocephalus in Ethiopia. At the time of researcher study Spina Bifida surgical treatment for children that is neurosurgical intervention performed in Ethiopia only in two hospitals. The governmental hospital was Zewidtu Memorial Hospital (ZMH) and the other private hospital was MyungSung Christian Medical Center.

The Neurosurgical Inpatient Pediatric Unit is located on the fourth floor of the main building of ZMH. Patients are cared for by an interdisciplinary team including pediatrician, neurosurgeon, neurosurgeon residents, physicians, nurses, and other health professionals such as social workers. Neurosurgical Inpatient Pediatric Unit gives services in two wide rooms. In one wide room there are twelve and the other room has ten beds with a small locker table and chairs for individual patients. All patient rooms have their own bath rooms. There were also infants with Spina Bifida in neonate intensive care unit.

3.4. Sampling Technique

To select the participants the study used non-probability sampling, specifically purposive sampling was used to identify participants and collect data. The idea behind qualitative research is to purposefully select participants or sites that will best help the researcher understand the problem and the research question (Creswel, 2014, P.180). The reason why the researcher chooses purposive sampling was that, for the sake of meeting directly parents who have a child diagnosed with Spina Bifida. Purposive sampling is one of sampling techniques in qualitative research that is deliberately made to select respondents based on their natural ability to give the required information (Padgett,2008, P. 53). The researcher used purposive sampling to twenty one participants, among of them eighteen parents of children, who diagnosed Spina Bifida and received treatment at the Pediatric Neurosurgical Inpatient Unit during the study period and three key informants. The participants were chosen because of their ability to provide information needed to address the objectives of the study (Strydom, 2005). Participants were identified with the assistance of chief Nurse from Neurosurgical Inpatient Unit at ZMH. To ensure maximum variability, the parents sampled represented the whole spectrum of parents of children admitted at the Pediatric Neurosurgical Inpatient Unit. The sample included parents of children with Sipna Bifida disabilities, parents from different socio-economic, different age groups, education levels,Source of income and different religion.

3.5. Inclusion Criteria

Parents or legal guardians of children with a confirmed diagnosis of Spina Bifida aged between birth–5 years old who received treatment by occupied bed or admitted more than fifteen days at the Pediatric Neurosurgical Inpatient Unit at ZMH and signed informed consent by the parent or guardian to participate in the study.

3.6. Exclusion Criteria

Parents or legal guardians of children with not confirmed diagnosis of Spinal Bifida aged between birth–5 years old who received treatment by not occupied bed or not admitted more than fifteen days at the Pediatric Neurosurgical Inpatient Unit at ZMH and parents or guardians who not to sign informed consent.

3.7. Methods of Data Collection

Three techniques of data collection were engaged for this study. In-depth Interview, focus group discussion and observation were conducted.

In-depth Interview

The study made use of open-ended semi-structured interviews (see appendix 3 &4), which were in-depth in nature and allowed me to search the topic of interest more openly, while allowing participants to express their opinions and ideas in their own words (Esterberg, 2002). A total of twenty one participants among of this six parent's in-depth interviews and three key informants were conducted in the study area. The interviewees were recruited among parents who have a child diagnosed Spina Bifida and received treatment at the Pediatric Neurosurgical Inpatient Unit during the study period. The researcher received interview at the office of case team leader of Pediatric Neurosurgical Inpatient Unit. This was done to ensure parents and prevent interruptions during interview sessions.

Focus Group Discussion

The second method of data collection was focus group discussion (FGD). One focus group discussion, consisting of six mothers participant and the other focus group discussion consisting of six fathers were conducted. Similarly, in qualitative interviews the researcher conducts face-to-face interviews with participants or engages in focus group interviews with six to eight interviewees in each group (Creswel, 2014, P.239). The focus of the FGDs was important to identify the coping mechanisms used by parents and resources available which help them to cope with the challenges they face. The discussion was conducted with the open ended questions (see appendix 5 & 6). Focus group discussion allows researchers to gain further insight into the study topic when different people who are knowledgeable in the topic are involved (Alston & Bowles, 2003, p. 119). The interview questions were prepared in Amharic because it is a language that is understandable and relevant to the participants and the interviewer. The data collected by note taking only participants in focus group discussion are not allowed using audio recorded.

Observations

Most interviews were conducted on face-to-face and the researcher was observing participant's behaviors, gestures, body languages and actions concerned in the study and notes were taken.

3.8. Ethical Considerations

The ethical procedures in this study were including consent, confidentiality, anonymity, privacy, and the right to withdraw from the study. To perform the study the school of Social Work wrote a formal letter to Zewidtu Memorial Hospital. The researcher presented detailed information to the participant parents about the purpose of the study and why they had been chosen to participate in the study then researcher scheduled the interviews after meeting all the parents and made sure that they are willing to give rich information regarding challenges of parents with diagnosed Spina Bifida and coping mechanism. Written informed consent was obtained from the participants, (see Appendix 1&2) and permission to use an audio recorder was also obtained from participant parents.

The researcher described that participants had the right to withdraw from the study at any time and withdrawal or refusal to participate and the researcher also described this study did not affect his or her child's healthcare at ZMH. All information was kept confidential and ensured confidentiality by not citing participant parents name within the study. The researcher conducted the interviews in Amharic language.

3.9. Data Analysis

Data analysis was done at the same time with data collection since the design of the research is qualitative. Creswell, (2009, p.184) described that analyzing qualitative data is a continuous process beginning from the time of data collection and involves different steps (Creswell, 2009, p.184). After transcribed verbal data into written form and translation from Amharic to English repeatedly read the data and also check the transcripts back against the original audio recordings for accuracy of the data before begin coding then identified coded using colored pens those data related to research question. All the coded were listed together organized into groups of similar codes and become theme. The themes reviewed with regard what was included and excluded. The themes finalized to describe participant parents of children with Spina Bifida challenges and coping mechanism. The organized and summarized data discussed and interpreted carefully. Burns & Grove, (2003) had stated that data analysis is a mechanism for reducing and organizing data to produce findings that require interpretation by the researcher.

3.10. Trustworthiness of the study

Triangulation is one method for increasing validity of findings, through deliberately seeking evidence from a wide range of sources and comparing findings from those different sources (Thorogood and Green 2004, p.191). In this study the researcher used In-depth interviews, focus groups discussion and key informant compared the findings from each for increasing validity of findings. Another method of ensuring the assuring the quality of the data is through using rich and thick description. In this study data collected through in-depth interview, focus groups discussion and observation. Therefore, the findings of the study were improved trustworthiness. Using rich and thick description to convey finding is a strategy to enhance trustworthiness of a study (Creswell, 2009, 191).

CHAPTER FOUR

FINDING OF THE STUDY

The findings of the study are described in this chapter according to the objectives of the study. It also includes the demographic profiles of parents and the children with Spina Bifida disabilities of participants in in-depth interview, focus group discussion and key informants. The data are presented as emerging themes that were identified from the semi-structured interviews and were broken down into categories. These themes were based on the challenges and coping mechanism of the study participants as described during the study. The emerging themes focused on the objectives of the study. Numbers represented the names of all participants.

4.1. Socio-Demographic Profile of Parents, Children with Spina Bifida and Key Informants

Table 4.1.Demographic data of participants in in-depth interview parents

Participant	Age	Sex	Marital Status	Education Level	Source of Income	Region ofResidence	Religion
Participant 1	48	F	Divorce	Diploma	Salary	Oromiya	Orthodox
Participant 2	26	F	Single	Grade 12	Unemployer	AdissAbaba	Orthodox
Participant 3	38	M	Married	Degree	Salary	AddisAbaba	Protestant
Participant 4	56	M	Married	Diploma	Self-employer	S/N/N/P	Muslim
Participant 5	30	F	Married	Grade 2	House wife	S/N/N/P	Protestant
Participant 6	40	F	Divorce	Grade 4	Self-employer	Oromiya	Orthodox

As displayed in Table 4. 1, the participants in in-depth interview parents interviewees included two fathers and four mothers. All were parents of a child with Spina Bifida disability. The demographic information reflects the parent's marital status, education level, source of income, region of residence, and religion. The parent's ages ranged from mid-20s to mid-50s.The education levels of the parents ranged from grade two to Bachelor Degree, with one of Participants having Bachelor Degree and two participants having Diploma, the other three participants 2,5 and 6 were grade twelve, two and four respectively. Regarding source of income two participants were monthly salary two participants were self-employed and others participants were unemployed. Three participants were orthodox religion follower and two participants were Protestants and one participant was Muslim.

Table 4.2.Socio- demographic information of children of in-depth interview participants

Child	Age	Sex	Child Age at diagnosis	Medical Statues
Child 1	8 months	F	In the womb	SB
Child 2	4 years	M	At birth	SB&HCP
Child 3	9 month	F	At birth	SB &HCP
Child 4	3 years	M	At birth	SB
Child 5	2 month	M	In the womb	SB
Child 6	3 years	M	At birth	SB & HCP

As displayed in Table 4.1.2, the children's ages ranged from 2 months to 4 years old. All of the children with Spina Bifida disability and child 2, 3 and child 6 were Spina Bifida with hydrocephalus. And all of the children received medical care from ZMH Pediatric Neurosurgical Inpatient Unit.

Table4.3. Demographic data of participants in focus group discussion mothers and fathers participants.

Participant	Age	Sex	Education Level	Source of Income	Region of Residence	Marital Status	Religion
Participant 1	45	F	Diploma	Self-ployer	Oromiya	Single	Orthodox
Participant 2	25	F	Grade 10	un employer	Addis Ababa	Single	Muslim
Participant 3	34	F	Degree	Salary	Amhara	Married	Protestant
Participant 4	40	F	Grade 4	House wife	Gambella	Single	Orthodox
Participant 5	30	F	Grade 2	un employer	S/N//N/P	Divorce	Orthodox
Participant 6	38	F	Diploma	Salary	Oromiya	Married	Orthodox
Participant 1	60	M	Grade 5	Farmer	Oromiya	Married	Orthodox
Participant 2	45	M	Grade 12	Trade	Addis Ababa	Married	Orthodox
Participant 3	39	M	Grade 6	Farmer	Amhara	Married	Muslim
Participant 4	37	M	Diploma	Salary	Gambella	Married	Orthodox
Participant 5	58	M	Grade 12	Salary	Addis Ababa	Married	Protestant
Participant 6	47	M	Grade 4	Farmer	Oromiya	Married	Muslim

Table 4.4.Socio-Demogeaphic Information of key Informants

No	Key Informants	Age	Sex	Martial states	Education Level	Profession	Works experience
1	Participant 1	38	F	Married	Degree	Social work	18 years
2	Participant 2	32	F	Married	Degree	Nurse	5 years
3	Participant 3	36	M	Single	Degree	Nurse	7 years

4.2. Themes Identified From the In-Depth Interviews and Group Discussion

Emerging themes were identified from the interviews and group discussion, which was based on the participants challenges and coping mechanisms that were described in the study. These themes were broken into various categories. The themes that emerged were challenges on parents physical and heath, challenges on parents economic, challenges on social relationships, challenges on marital relationships, challenges on the health care system and parents coping mechanism. Nearly all the parents were described some form of these problems because they had a child with Spina Bifida.

4.2.1. Parents' Life and Relationships

Having a child with Spina Bifida disabilities affected the parents in many ways. From this theme, the following categories were identified.

4.2.1.1. Challenges on Parents Physical and Health

Parents experienced physical problems as a result of care their children. These occurred as a result of having to care, lift and carry their children in the same way assisting the children with their functional activities participant 6 in depth interview stated that,

> The child has open wound on the back. He is able to sit on his own, but he cannot crawl or walk. He has to be lifted for all activities. He cries a lot during the night and I cannot sleep and I only rest when my sister visits.

During the interview ten participant parents were described that tiredness and fatigue because of without rest caring the children .participant 4 FGD. stated that," I am so tired and fatigue no one assist me and relived me from carrying my son." Another mother

FGD participant 2 described “he cannot able walk and he does not want to carry by others the only me carry him day and night without break.”

The hospital allowed only one person to spend the night next to the child’s bed primary care giver most of the time mothers. The husband would have to find his own place to sleep. This adds to mother’s stress, participant 3 of mother FGD. Said that, “My husband is suffering a lot and sometimes he sleeps outside the room on corridor Yesterday I don’t know where he slept. He had lie in the corridor on the cold floor for the last one month. He still has back pain because of it.” Another participant 5 in depth interview stated that, “I always think about my husband. He slept on this floor without blanket. When he wake up the first complain is headache.” Participant 3 in depth interview stated that, “when the night comes I feel stress about today, where I would sleep?”

All eighteen participant parents regarding challenges they describe in their own physical and health challenges due to the care of their children with Spina Bifida. Most parents that participated in the study described the changes they practiced in their own physical and health due to the care of their children are fatigue ,tired, sleeping problems, back pain, headache and stress.

Twelve participant parents described lack of sleep, disturbance of sleep and it becomes challenges in their daily task. Participant 6 in depth interview stated that, “I watch carefully his body fever, inhalation and the bag that contained fluid it comes from the head with plastic tube. If something happens I immediately inform to the nurse. These are some of my duties. How could I sleep? Even if I tried to sleep but I wake up now and then.” another participant 3 in depth interview. Said, “I could not perform properly my job at work place due to lack of sleep. I attended the condition of a baby all over the night the next day become difficult to do my duty.”

4.2.1.2. Challenges on Parents Economic

Four parents showed a great effort on a monthly source of income to provide the fundamental require of the Spina Bifida children treatment. Participant 1in depth interview said that,

> A child with such kind of illness is costly, the child needs now and then diapers, additional medication and laboratory investigations. I do not have free paper which is getting from living woreda it gives grant for getting service freely. Half of my salary deducted because of absented from work place. I am here (hospital) most of the days caring my son it is financially burden, financially I am not coping at all.

Participant 2 in depth interview also stated that, “The doctor give me a prescription on it a lot of medication written. I told him I can’t afford no more because I expenditure all money for medication and CT scan.” Fourteen participant parents complained the burden of the non-availability of some laboratories investigation recommended by physician, some had to go to other diagnostic centers for finding investigations, for this reason increasing the financial cost. Participant 6 in depth interview stated that, “The doctors ordered CT scan and blood laboratories. Those things are not available here in this hospital. Therefore, I search where it is found. I found it around Lancha, Afi diagnostic center I paid 1,200 birr for CT scan only. I am here for the last one month and fifteen days with different type of expenditure. I spent until now 8,000 birr.

Eight participant parents stated that non-availability of most of the prescribed drugs was a problem. One of father participant 3 in depth interview complained that, “The hospital pharmacy doesn’t have some of the drugs, especially the expensive ones, So that we are forced to pay for private pharmacies at expensive cost.”

Another issue raised by participant parents was transport. Transport also one of the greatest challenges that most of the parents described. They talked about difficulties with finding transport from ZMH to home. Most Participants parents who lived far from Addis Ababa expressed concerns about transport. They indicated that they would experience transport cost difficulties if they were expected to return to ZMH for a follow-up appointment. Participants 2, 4 and 5 in FGD stated that, If they discharged us today and appoint us to come back to ZMH for follow up there will be transport cost problem. Participant 5 in depth interview also stated that, "I cannot afford to move from here Addis Ababa to my residence. It is just 400 birr to one trip how can I afford it is too much money and assume then we return after a week for follow up” Almost most parents were concerned about how they would afford transport to go home when the child was discharged from ZMH. They were worried about how they would go home. Mothers FGD participant stated that, “we are worried because we don’t know where we will find money to go back when the baby discharged from here.”

Twelve participant parents defined the change in their daily lives during treatment process as a disorder in their daily income, the housework and daily routines because they only take care of their children. Participant 2 and 5 in depth interview defined the change in their daily lives not only as a disorder in the housework but also closed her business. Participant 5 said: “I only take care of this child, I cannot do anything else therefore I closed my small shop.” Another participant 2 stated that, “I could not guide my usual life as I did before, I was work one of the famous café but now I stopped working.”

4.2.1.3. Challenges on Social Relationships

Seven participant parents expressed a lack of support from family and friends. This resulted in them being socially cut off which were partly as a result of fear among parents that people would not accept their children or blame them for the condition of the children. Participant 2 in-depth interview stated that, “My mother remarried after divorce with my father. If she know that I had disable child might not accept. I had disable child (cry) therefore, I live alone. I do not want to call her.” Another Participant 3 mothers of FGD described as, “when I think about my life it is hard, especially to have a child with such kind. I cannot go back to my work; I do not have social activities because of this child.”Participant 2 in depth interview said that, “how can I go out? I do not have anybody to stay with the child”. Another participant 6 in depth interview said that, “I don’t attend social activities because some people talk about us and I observed that nobody want to kiss my son including my sister.”

Eight participant parents defined the change in their social lives during treatment as lack of social life, and not being able to get out of the hospital and some of parents stated that their own movement was in a poor condition while most of participant parents missed their social interactions due to the health conditions of their children.

4.2.1.4. Challenges on Marital Relationship

Children with Spina Bifida put tension on seven of the participant parents with their marital relationship. Participant 3 in depth interview described her child had put tension on the relation with her husband because of challenge of caring a child with Spina Bifida. She thought she did not spend time with her husband because she always had to give her focus to Spina Bifida baby. She stated that,

> My husband does not able waiting here more than one or two hours. He insists me to out from compound for refreshment. I say no I am tired. I am taking care of my daughter every day and night. I am here for the third times she admitted and operated. I do feel guilty that I do not give him (husband) time, what can I do.

Another participant 6 in depth interview stated that, “we were always fight he was too rough about the condition of the child and did not want others to know about it. He wanted us to keep the condition of the child as a secret, I could not agree. This lead conflicted on our relationship then now we divorced”. Another participant 1 in depth interview stated that, “He my husband and his family does not support me and the fact that I have a child with big head and paralyzed legs. I heard now he married recently.”

FDG mother participant 5 stated that having a child with Spina Bifida with other complicated the medical condition of the child significantly impacts on the marriage,

> He (husband) ran away when he saw the condition of child become worsen and deteriorated day after day. His families have not accepted the condition of the child because they thought never and ever such kind of child happened in their family.

4.2.1.5. Parents Reaction

All eighteen participant parents in the study passed throughout a lot of emotions with consider to the child having a Spina Bifida disability. The emotions mostly described by parents were shock, grief, guilt and acceptance.

Shock

Eighteen participant of the parents showed that they were shocked when the health professionals informed them that their child had Spina Bifida disabilities. They recognized that the child's development would not the same as for other children who are not affected by Spina Bifida. Participant 3 in depth interview described his situation: "My daughter was diagnosed with Spina Bifida at birth. The physician told us that our daughter's has vertebra problem and she would not be normal as any other children, It was shock to us."Participant 4 in depth interview also stated that, "Everything during the pregnancy was fine. I never expected that our first child will be like this. It is really shock." It looks like that having had a normal pregnancy elevated this mother's shock because nobody prearranged her to expect that something might be wrong with the child. Participant 2 in depth interview stated, "The time I was pregnant I attended at health center. The health professional follow my pregnancy and described everything is all right. I delivered well without any problems but when the child came out; I observed this thing on the back. Midwifery nurse explained to me this new born child become disable. The moment when I heard disable word, I become shock."

Grief

Six participant parents described grief about their children's Spina Bfida disabilities. Sometimes the child's disability is showed as sorrow by the parents for the suffering that the child experienced. Participant 2 in depth interview expressed her sorrow as upsetting. Participant 2 stated that "My four year old child cannot walk and his head is very big. Most of the day he spends lay on the bed. It is even more painful to see that my child will never participate with other children. It is a great sorrow to me"(cry). Another participant 3 in depth interview described that,

> The moment that my daughter born I was far from Addis Ababa for duty. My wife call to my mobile and she told me that the new born baby needs surgical intervention, Therefore the physician referred them to Zewidtu Memorial Hospital. I thought how this new baby resist the operation it was terrible."

Participant parents also show sadness. Participant 1 parent in depth interview described her approach of sadness regarding to her child's Spina Bifida. "I cried now and then every day and I always ask my Lord why he gives me such kind baby and what I did wrong.

Guilt

Throughout the interviews, five parents stated that guilt in relation to being accountable for the child's Spina Bifida disability. They consider it was caused by somewhat that they did. Participant 2 in depth interview stated that, "I feel guilty for my son's disability. His father denied when I was three months pregnant. I drank herbal medicine to abort but not succeeded, I think the herbal medicine affected my child during the pregnancy. I'll always blame myself for his disability. If I didn't drink the herbal medicine then my child would most likely be normal today." Another participant 4 in depth interview stated that, "I know I am sinner. This happened as a punishment for me (cry) please my Lord forgives me.''

Acceptance

During the interviews thirteen of participant parents showed form of acceptance regarded to their children Spina Bifida disability and concerned on a hope for the children. Participant 4 in depth interview stated that, "No choose my son is my flesh, I cannot able cast out it is the well of Allah. I hope Allah changed it." Another participant 3 in depth interview said, "It was hard to admit my daughter with Spina Bifida, but now we leave it to almighty Lord." Another participant parent of a child with Spina Bifida decided to accept her son as a gift from God. Participant 2 in depth interview stated that, "I would like to assist my child up to the end of my life. It is the gift of God &God gift is always perfect."Another father FGD participant 2 stated that, "I know it is very hard child with Spina Bifida but I really accepted it we are not the first one."

4.2.2. Parents Challenges on Health Care System

Participant parents described different challenges on health care system of the hospital such as challenges of support system, include non-available of diagnostics device, non-available of medication and lack of transportation. Other participant parents described were challenges of counseling system.

4.2.2.1. Challenges of Support System

Five participant parents were showed that there were challenges of support systems for parents of children with Spinal Bifida. These parents described that support system have to expand and encourage. Participant 2 in depth interview said that, “I am so tired it was nice if there was a place where my child can be temporary taken care.” Participant 4 in depth interview also stated that, “Numbers of volunteer supporter are few why the hospital management advertise come and see our problems to those want help us.” Challenges that participant parents described on the health care system included a lack of medication, diagnosis devices like computerized tomography scan (CTS), magnetic resonance image (MRI), attitudes of health care professionals and a lack or provision of transport as participant 3 in depth interview described, “ If the government cared, we would not be suffering the way we do. I was ordered to bring CT scan by doctors; I cannot afford CT scan or MRI. I do not even have enough money to return my village.” And another father FGD participant stated that, “The government should at least provide transport or provide transport money, to those who could not afford it”. Furthermore, one participant 2 in depth interview mother wanted the hospital to provide wheelchair for her children who unable to walk. She said that, “I have no work or money to buy a wheelchair it is expensive I ask the hospital to give me a wheelchair.”

4.2.2.2. Challenges of counseling

Seven participant parents described that lack of counseling from health professional participant parents experienced repeated follow up bothered them. Participant 6 in depth interview she stated that, “they appointed me frequently I do not see any improvement from his illness. I thought it becomes worse.” Three of the participant parents concerned about the lack of information they were experiencing concerning their child’s lesion. Even though, parents attending antenatal care. Participant 2 in depth interview stated that, “The time I was pregnant I attended at health center my follow up no body informed me. They thought I had healthy baby, I delivered well without any problems but when the child came out, I noticed this thing on the back of new born child.” About social workers lack of awareness roles of social worker in hospitals were common among a four participant parents. Participant 3 in depth interview stated: “I’m not sure what the social workers do. I don’t really know what they do.”Another participant 5 in fathers FGD stated that, “hospital social workers assisted my child with allowed me to get free services I mean not paid. I think social workers are only providing support to children only.”

Nine participant parents were described that the health workers were not explaining things to them. Furthermore, the participant parents said they had no previous knowledge about Spina Bifida participant 1 in depth interview she said that, “I never saw and heard such kind disease before.” Another participant 4 in mother FGD explained, I was attending at clinic my pregnancy one times looks for ultra sound but no one told me that such kind of problem presented.” While three participant parents wanted explanation from health professional to know what kind of surgery performs on their children. Participant 5 in depth interview stated that, “The physician not described to me what kind of surgery done he simple said we will operate him.” Another participant 3 in depth interview said, “we are here for the second time because the shunt become infected so that to repair or substitute another shun the operation will be done. Here the doctors not give us any clarification about the next operation."Participant 1 also stated that, "A group of doctor comes and look at the back of child and discussed each other with English language then went out."

4.2.2.3. Parents Coping Mechanisms

Study participant parents developed different methods to try to cope with the challenges of Children with Spina Bifida. This section describes how parents cope with the situation as well as the different psychosocial supports that assist them in coping.

Formal Support

Sixteen participant parents described that professional support was emotionally and economical helpful to cope with challenges faced. Participant 2 in depth interview reported that, "social worker assisted me to get a lot of medication and investigation freely those are available in the hospital." Another participant 5 in depth interview stated that, "I always remembered one of the nurses the way she treated us. Her advice and counseling are help me to cope with such child disabilities."

Regarding parents support group participant parents expressed that meeting others who have a child with a similar condition helped to cope challenges of parents with Spina Bifida children. Participant 2 in depth interview she said that, "when I saw similar case with my child I feel I am not alone with such challenges."Another participant mother FGD described, "We share our problems with her (signed) because her child bed next to my child. We discussed most of the night about our children. She always said that do not fade up this helped me too much." And four parents described that the education that they received helpful to feed their children. Participant 2 stated that, "Now I can feed my child with nasal gastro tube every two hours. You know there is syringe. For example, take milk with syringe then inserted to the tube hole then pushed slowly finally cleans the tube with water.”

One of the social worker participant 1 the key informant explained about the services that social work unit provided for those parents with diagnosed Spina Bifida. Said that,

> We give them special attention those are vulnerable parents. We always are trying our best to support them. For example, we link them with different support group such as, governmental, non-governmental and individuals those are a great need to help those vulnerable parents. We observed that those linkages with those support groups help those parents with Spina Bifida children to cope their challenges.

Participant 4 in depth interview explained that social worker assist him by referred to organization for shelter service. It helped him by some means reduced the economic challenges of parents .stated that,

> The social worker ask us some information and written on a paper. Then she (social worker) rearranged transport and sends us with that paper to HOPE organization. It was a nice place the gate open for who wants to take a shower, wash their clothes, have something to eat and have clean clinic. After a week we return to hospital and admitted here. I want to say thank you hospital social worker if she not linked us, where we stayed? We do not have relativities to stay or we do not have money for hotel.

Another key informant was expert nurse, he described that counseling and education are vital to manage the challenges of parents with diagnosed Spina Bifida. Stated that,

"I am closed relationship with those parents. Most of them stayed here more than a month they spent their money during the duration of admitted days. I appreciate social workers because they allowed medication freely for those helpless parents .I observed that most of parents after we giving them counseling and education their hope and manage of their problems improved actually a few of health professional ignore the counseling and education part."

Participant 1 key informant stated that, "Mostly we serve them by giving them education about cause and way of prevention and counseling to cope with the challenges and provide dipper, second hand clothes and hair oil that collected from individuals who wants to help those vulnerable parents. The hospital also provided food three times a day.

Informal Support

Social support from friends and relatives was discovered to be a large help to many parents. Parents described the need for both family support and government support are vital and helpful to cope up with challenges being parents diagnosed with Spina Bifida children. Some of parents participants 2, 4, 5 and participant 6 received support from their families and friends. When financially support needs, families and friends assisted parents who needed to pay for medication, different investigation and transport to go home when they are discharged from hospital. Participant 6 stated that, "My elder sister sometimes assists me financial concern issue she covered the expense of medication and investigation.

Another participant 2 mothers FGD also described her relatives had helped her she said that, “I leave the child with my sister; he likes to stay with her in the meantime I going to home and prepared food.” Five participants reported that it’s extremely helpful when they have a good relationship with social worker. Participant 2 in depth interview said “I have a good relationship with social worker. They are very supportive, when I told them that the burden of finical is heavy so that I was decided to not continue the treatment. They allowed getting medication and investigation freely from the hospital. Another financial coping mechanism that was used by participants 5 in depth interview was selling their properties participant 5 stated that, “we sold our washing machine to manage our financial crisis.”

Spiritual Support

For eighteen of the participant parents believing in super natural power, was the first emotion oriented strategy coping mechanism, which gave them relief and help in accepting the situation of having Spina Bifida children. Eighteen participants described that it is helpful that they have found some meaning as to why their child has Spina Bifida or they find a positive purpose behind it. Four participant parents in depth interview 2, 5, 6 and 3 reported that their faith is a big part of being able to cope and that connect some meaning to a higher power is helpful for them. Participant 3 in depth interview said that he knew that his situation was part of God’s plan and participant 5 stated, “We have the attitude that this is our course and our faith is important.” Participant 3 reported trying to give explanation about child disability is purposely said that, God has big plans for her and us.” Another participant 2 in depth interview used her faith to find a meaning in the illness. She stated that, “I am a Christian, I belief that in our suffering join with Christ on the cross. I can hold a purpose behind the suffering.” Christian

All eighteen of participant parents achieved emotional relieve through prayer and spirituality. The Parents participant 2, 3 and 5 who spoke most about this experience describe a sense of acceptance. Participant 3 parent described, “We’re Christians so we prayed about it, we prayed that she'd come out manifested work of God like Alazar in the bible.” according to God’s plan and that the child was a gift from God also helped the parents through challenges. Relay on God’s care for the potential gave parents hope.

Support Institution

Participant 1 key informant described about support institution stated that, Reach Another Foundation (RAF) has been active here for several years by supporting different medical supplies. Every Saturday there is Neurosurgical campaigns operation and eight up to ten children operated Spina Bifida and hydrocephalus. According to a key informants, hospital social worker described, HOPE-Spina Bifida and Hydrocephalus(HOPE-SBH) established by parent who has Spina Bifida child. It is non- governmental organization they support parents and Spina Bifida children. They have reserved a place that is shelter to those parents and Spina Bifida children came from out of Addis Ababa until their appointment of hospital date arrive. They provide freely shower services; wash their clothes and providing food services.

CHAPTER FIVE

DISCUSSION

This section presents the discussion of the findings under different sub themes in light of research objectives, research questions and the related literatures. The major themes which the researcher discusses in relation to various literatures included, challenges on parents physical and heath, challenges on parents economic, challenges on social relationships, challenges on marital relationships, challenges on mothers, challenges on the health care system and parents coping mechanism.

5.1. Physical Challenges of Parents

It was obvious from the findings of this study that participant parents were experiencing physical challenges. Eighteen parents were describing that tiredness and fatigue as a result of carefully carrying the children without break. This finding was similar to the findings by Mackey and Goddard (2006) they had reported that due to having to be constantly attentive and watchful, and lack of respite from the work of caring for a child with a disability parents are expose to fatigue and tiredness.

The finding of the study showed that twelve participants described lack of sleep and disturbance of sleep. It becomes challenges in their daily task. Similarly, parents caring for a child with a chronic condition illness such as Spina Bifida sleep deprivation and sleep disruption are common problems in parents (Matthews et al., 2014, Herbert et al., 2015 & Bourke-Taylor et al., 2013). Meltzer and Booster, (2016) they had described that sleep deprivation and sleep disruption have a negative impact on the parents’ care giving tasks.

5.2. Parents Reaction

The finding of the study showed that one of the most common challenges on the parents of children with Spina Bifida in this study were handling the initial diagnosis, All parents in the study went through many emotions with regard to accepting the child having a Spina Bifida. The emotions mainly manifested by parents were shock, guilt, grief and acceptance. Shock was the first reaction of all participant parents after hearing the initial diagnosed that their children have Spina Bifida. This is in line with, Oeckerman (2001, p.11) had explained that when parents heard that their child has a disability, parents run through with different phases of reaction usually shock is the first feedback of parents after hearing the information that their children have disabilities, go after by denial, there may be feelings of guilt and anger, sadness and depression may continue and final phase is acceptance. However, this study had not found anger and depression from participant parents initials emotions after heard their children have Spina Bifida.

Another finding of the study shows most of participant parents expressed some form of acceptance in relation to their children disability after counseled and oriented the cause and prevention method and focused on a future for the child. Similarly, researchers Siklos & Kerns, (2006) they had indicated parents began the process of acceptance look for and occupied with support systems after parents developed knowledge about their children’s neurodevelopment disability. This helps parents to cope with current problems. Furthermore, Lerner and Kline (2006) they had indicated that to continuing to live a normal life parents must accept their child with disabilities along with their special needs and they also stated that acceptance is vital stage to continuing to live a normal life.

The finding of the study indicated the child's disability is expressed as sorrow by most parents for the children not being normal as any other children at the same age. Similarly, study by Heiman (2002, p.160) had described Parents articulated an original sorrow for the children not being able to live a life similar to other health children because of impairment their children.

5.3. Marital Relationships Challenges of Parents

Four participant mothers did not spend enough time with their husband since they always had to give their attention to the children. The finding of the study showed that a child with Spina Bifida disabilities puts strain on some of the parent's relationship with their marital relationship due to not spent enough time together and emphasized more on children care. This is supported in the literature with studies Davis et al, (2009) they had founded that lack of time due to the burden of care as a reason Australian parents of children with disability also fight back with their marital relationship.

Parke (1986) had explained that the birth or diagnosis of a child with a disability and leading to reduced spousal support such stressful events are can be interrupted marital relationships. Divorce experience more likely common understood that families with children who have disabilities. The same finding in this study, two of the participant mothers were divorced with their husband because of a birth of child with Spinal Bifida and lack of support from their husbands.

Another finding of the study indicates a three participant mothers described that disappointed about their husband does not help their in caring activities. In line with, Balfour,(2007) had indicated because of the husbands not being concerned with children with disabilities .married couples happened conflict and disappoint by husbands.

5.4. Economical Challenges of Parents

The finding of this study showed most participant parents complained as increasing the burden was the non-availability of some investigative procedures recommended by physicians and few participant parents stated that non-availability of most of the prescribed drugs was a problem. This is supported in the literature with (Rochelle, 2005; Batual, 2011 and Baxamussa 2011 as cited in Lawal, Anyebe, Obiako & Garba, 2014, p.59). They described that “The complexity in getting medical treatment for the affected children. The distance covered to assess medical treatment was an additional economic challenge”. Also highlighted the treatment difficulties centered on obtains expensive drugs, frequent investigations or test. In addition to this, such children need a involvement of specialized professional and series of investigations such as computerized tomography scan and magnetic resonance imaging which create financial consequences on their parents.

As mentioned in the literature review, (Goudge et al.2009, Harris et al. 2011) they said that along with the poor and those live in rural area transports costs are a main obstacle to health care services. The same finding in this study, Most Participants parents who lived far from Addis Ababa expressed concerns about transport cost. They indicated that they would experience transport difficulties if they were expected to return to ZMH for a follow-up appointment.

Another finding of the study shows all participants whose children received treatment in Pediatric Neurosurgical Inpatient Unit described the change in their daily income and disruption in the house work because they only take care of their children. This is in line with support, parents employment and family income crashed because of Caring for a children with disability (Heller el al., 2007, p.136).Child Neurology Society, (2012) obtained similar results studies, and reported that financial disadvantages as a result of the need to care for the children is a major experience by families of affected children.

5.5. Social Relationships Challenges of Parents

Davis et al, (2009, p.67) they described that parents considered them self as unusual as their friends, who had children without disability because of this parents of children with disability had difficulties in continue social relationships. This is in line with the findings of this study most of the parents were expressed a lack of support from family and friends. This resulted in them being socially isolated which were partly as a result of fear among parents that people would not accept their children.

5.6. Mothers Challenges

Hovey, (2005, p. 86) had indicated mothers were most affected emotional distress, career disruption, and stressful interfaces with the medical system because of mothers were most affected in their daily lives by the impact of the child's disability in addition to that a mother's role for a frequently ill child is the primary caregiver and to take accountability for childcare, doctor's appointment and other health maintenance issues. This is supported in finding of the study that mothers of a disabled ill child may effort to meet the demands of parenting, the nature of the child's disease, the need to manage symptoms, and the complication of treatment all cause emotional strain. As described above and similar study the character of the child's disease, have to handle symptoms, and the difficulty of treatment and mothers of a chronically ill child may great effort to meet the load of parenting all these cause direct to emotional strain on mothers (Hopia, et al,.2004).

5.7. Coping Mechanism of Parents

One of the social worker the key informant participant 1explained that, social work unit provided special supports for those parents with diagnosed Spina Bifida children, such as counseling, linking with non- governmental organization and individual who need to assist those parents. These were helped parents to cope up with challenges and decrease stress. In line with, According to Canary (2008) had explained that the major objective of the social worker is to shrink stress and depression, and give support to parents of affected by the child's disability to make stronger their coping abilities and recognition of their child's disability. Furthermore social worker could be a great advantage to parents to maintain and link them to relevant resources to alleviate or minimize current stressors.

The finding of the study showed education and counseling are vital to manage the challenges of parents with diagnosed Spina Bifida children. This is in line with support, to cope with the situation of having a sick child education offered for parents has been accounted to be helpful (Atkin, 2000; Pain, 1999; & Vanden Borne et al.,1999). As described above and similar studies Churchill, et al (2010, p.48) they had described to reduce the presence of depressive symptoms and specific coping skills as a useful strategy to improve coping abilities health professional should put emphasis on education parents.

The result of the study indicated most participant parents used emotion oriented and problem oriented coping strategies. Emotion oriented coping strategies were acceptance, blame and cry. Few participant mothers used crying as emotion oriented coping strategies and one participant parent used blaming as emotion oriented coping strategies Problem oriented coping strategies were to great effort for treatment and education, learning new skills, educating others and having free grant card. Some of the participant fathers used learning new skills as problem oriented coping strategies. In line with, Lightsey & Sweeny (2008) they founded that emotion oriented strategies more commonly used by women to cope with chronic illness such as Spina Bifida of a children and problem-focused coping more often males used. And Nazemi, (2007) has indicated one of the familiar emotion oriented strategy is blaming.

The finding of the study provided some parents supported each other practically with strong emotional support existed among the parents and discussed about children's condition. They encouraged each other and the feeling of loneliness was reduced when meeting others in similar situations. This is in line with, Shilling et al,. (2013, p. 602) had indicated Parents support one another through the process of caring their children when parents bond with other parents of children with birth defects because it gives opportunity to them build up a shared social identities which can give a feeling of hope as parents see one another successfully coping.

Another finding of the study showed all participants described that they have found some meaning as to why their child has Spina Bifida disability and find a positive purpose behind it and some participant parents also stated that it helps to improve their fellowship with almighty creator. In line with, Moreira et al, (2006,p.844) they defined spirituality as the individual search for understanding respond to vital questions about life, about meaning, and about relationship with the holy.

All participant Parents of hospitalized children are constantly faced with neurosurgical decision making and may have a greater dependence on faith in God and spirituality as a coping mechanism and many parents state that their child’s illness has strengthened their spiritual beliefs. In line with, Krok (2008,p.645) he had indicated that religious strivings offer a universal viewpoint of life and religious strivings are make powerful as a result can provide stability and support in critical times. Additionally, Hexem et al.(2011,p.42) they described that the majority of parents who did go behind a religion, spiritual attachment, or life viewpoint believed very important in providing support, peace, relieve and moral guidance.

The family stress theories stated that any event, positive or negative will have an impact on families (Smith,et al, 2009, pp. 96-97). In line with, the finding of study indicated that having a child with Spina Bifida disability can create stress for parents. The stress of having a child with Spina Bifida disability is due to challenges such as economical, psychological, marital, social factors that determine the functional care strain in the parents. The social resources are determined by the extent to which parents have accesses to emotional as well as social support from family support, informal support, formal support, spiritual support and professional caregiver.

CHAPTER SIX

CONCLUSION AND SOCIAL WORK IMPLICATION

6.1. Conclusion

The aim of the study was to assess the challenges of parents diagnosed with Spina Bifida children and their coping mechanism, the case of parents receiving service at Zewditu Memorial Hospital. The study population included parents of children with diagnosed Spina Bifida aged from birth up to 5 years, who were treated at the Pediatric Neurosurgical Inpatient Unit at Zewidtu Memorial Hospital, Addis Ababa. The study has described parents challenges and coping mechanism in relation to physical health, economic, social relationships and marital relationships aspects.

Finding revealed that having children with Spina Bifida disabilities had a major challenge on parent's physical health. Study participants experienced tiredness, fatigue, lack of sleep and disturbance of sleep related to carefully carrying children without break and it affected parents daily task. In addition to that, Study participant parents indicated emotion reactions after hearing initial diagnosed for example, shock, guilt, grief and acceptance. Furthermore anxiety and depression experienced associated with neurosurgical procedure.

In some parents a child with Spina Bifida disabilities put strain on the marriage. Two participants mothers experienced conflict due to frustrations directed at husbands not being involved in caring for the child with Spina Bifida disabilities, and lack of support to them in their care giving role. Moreover, emphasized lack of time due to the burden of care as a reason place strain on the marriage.

Parents also experienced additional economic burden, due to non-availability of most of the prescribed drugs and non-availability of diagnostic devices such as computerized tomography scan (CT scan) and Magnetic Resonance Image (MRI) in the hospital. In additional, parents worry transport cost if they were expected to return ZMH for follow up appointment. Furthermore, parents of Spina Bifida children experienced disruption in their daily income and housework.

According to the results of the study, parents mostly experience social problems during the treatment period. They expressed a lack of support from family, friends and community members. This resulted in them being socially isolated and needed support systems to assist with continued care giving of a child with Spina Bifida disabilities. Children with Spina Bifida disabilities required long-term care giving from parents and health care provider. It was also indicated that a few parents were frustrated by attending multiple follow up appointments with healthcare providers.

The participants in this study applied different coping strategies in order to meet their difficulties while caring for their Spina Bifida children. Participant parents used both emotion oriented coping strategies such as acceptance, blaming and crying and problem-oriented coping strategy for instance, great effort for continue treatment, educating and having free grant card. In addition to this, parents had special supports from social workers to facilitate coping mechanism and participants described that they have found some meaning as to why their child has Spina Bifida disability and find a positive purpose behind it. As well as, some parents supported each other practically with strong emotional support existed among the parents and discussed children’s condition. They encouraged each other and the feeling of loneliness was reduced when meeting others in similar situations.

6.2. Social Work Implication

The findings of the study challenges of parents with Spina Bifida and their coping mechanism identifies the social work implications part are implication for practice, implication for research, implication for education and implications for policy.

6.2.1.Implications for Practice

As the findings of the study show social work unit provided special supports for those parents with diagnosed Spina Bifida children, such as linking with non-governmental organization and individual who need to assist those parents. Social workers were helped parents to cope up with challenges and decrease stress. Infat Social workers are able to create connection bridges between challenges and resource. In addition to that social worker should explain to patients, parents and caregivers what the role of a Social worker in the hospital such as provide counseling, advocate for patient needs, find a solution to financial, social and psychological challenges associated to the health condition. The other vital issue is creation of awareness about challenges of parents diagnosed with Spina Bifida to governmental, non -governmental organization and volunteer supporter to provide different support.

6.2.2. Implications for Research

Several implications for future social work research were looking from these challenges of parents with diagnosed Spina Bifida children and their coping mechanism study. One of future social work research could be a larger sample size should be used in future research. Another recommendation for further research are made conduct research on perception and psychosocial needs of all family members including siblings and grandparents of children with Spina Bifida disabilities. More studies are recommended in Ethiopia regarding of psychological, social and economical challenges of parents with Spina Bifida children because there is lack of study in this area. The previous research emphasizes on medical and surgical treatment of Spina Bifida.

6.2.3. Implications for Education

Social worker have great role to alleviate challenges of the Spina Bifida disabled child and their parents. This entails training and assisting the parents. Therefore, health social worker needs to have sufficient knowledge on challenges of parents face when their children become exposed to chronic illness or disabilities. Moreover, social work curriculum should integrate psychosocial counseling courses in social work health education.

6.2.4. Implications for Policy

The main implication of this study for policy makers is that they need to understand how caring for a child with Spina Bifida affects the psychological, social and economical life of parents. Therefore, policy makers should pay due attention regarding eligibility requirements for financial assistance to ensure parents of children with Spina Bifida receive the financial support needed and construct a conducive care giving conditions in hospital set up for parents with Spina Bifida children. Hence, policies and services should be designed and put in ground to support those vulnerable parents.

REFERENCES

African Studies Centre Leiden (2008). Disability in Africa. Retrieved from http://www.ascleiden.nl/Library/webdossiers/DisabilityInAfrica.aspx

Alston, Margaret & Bowles, Wendy (2003). Research for social workers an introduction to methods (2nd ed.). Singapore: South Wind Production.

Atkin, K. (2000). Family care-giving and chronic illness: How parents cope with a child with a sickle cell disorder or thalassemia. Health & Social Care in the Community,8: 57– 69.

Balfour, L. (2007). A Needs Assessments of Parents on How to Raise An Autistic Child. Pretoria: University of South Africa.

Batul NB. (2011). Neurology Disorders. Available at www.buzzle.com/articles/neurological disorders/; Accessed on 29/6/2017.

Behrman, R. E. & Butler, A. S. (2007). Preterm Birth: Causes, Consequences and Prevention. Chapter 11: Neurodevelopmental, Health, and Family Outcomes for Infants Born Preterm. Washington (DC): National Academics Press (US).

Bourke-Taylor, H., Pallant, J. F., Law, M. & Howie, L. 2013. Relationships be-tween sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities. Journal of Paediatrics and Child Health,49,775-782.

Bożena Okurowska-Zawada, Janusz Wojtkowski, Wojciech Kułak. (2013) Quality of life of mothers of children with myelomeningocele. Retrieved fromhttps://doi.org/10.1016/j.pepo.2013.02.001.

Broger, B., & Zeni, M., Beth. (2011). Fathers' coping mechanisms related to parenting a chronically ill child: Implications for advanced practice nurses. Journal of Pediatric Healthcare, 25(2), 96-104.

Buckley S. J. (2002). Issues for families with children with Down syndrome. Down syndrome issues and information. African Journal of Special Needs Education, 1(2),78-81.

Canary, H. E. (2008). Creating Supporting Connections: A Decade of Research on Support for Families of Children with Disabilities. Health Communication, 23(5):413-426.

Caseiro, J., Gonçalves, T. and Malheiro, M.I. (2013) Construção da Autonomia dos Jovens Portadores de Spina Bífida - Child Neurology; 285-366.

Cerebra (2010). Information for parents: Neurological disorders. Accessed, 2017.06.18 atwww.cerebra.org.uk

Children's Hospital of Philadelphia.(2017).Center for Fetal Diagnosis & Treatmen. Retrieved from fetal surgery.chop.edu/spinabifida

Children's Hospital of Philadelphia.(2011).Treatment for Spina Bifida Center for Fetal Diagnosis and Treatment. http://www.chop.eduiservice/fetal-diagnosis andtreatmentlfetal-diagnoses/spina-bifida.html

Chou, Y., Fu, L., Pu, C., and Chang, H. (2012). Difficulties of care-work reconciliation: Employed and nonemployed mothers of children with intellectual disability.Journal of Intellectual & Developmental Disability, 37(3):260-268.

Churchill, S.S., Villareale, N.L., Monaghan, T.A., Sharp, V.L., & Kieckhefer, G.M. (2010).Parents of children with special healthcare needs who have better coping skills have fewer depressive symptoms. Maternal Child and Health Journal, 14, 47-57. Doi: 10.1007/s10995-008-0435-0

Cooklin, A. R., Giallo, R. & Rose, N. 2012. Parental fatigue and parenting practices during early childhood: an Australian community survey. Child: care,health and development, 38, 654-664.

Creswell, W. John, (2003), Research Design: qualitative, quantitative and mixed methods approach, 4th ed., University of Nebraska Sage Publication.

Creswell, W. John, (2007). Qualitative inquiry & research design, choosing among five approaches (3rd ed.). California: Thousand Oaks, Sage Publication.

Creswell, W. John, (2009). Research design qualitative, quantitative, and mixed methods approaches (3rd ed.). California: Thousand Oaks, Sage Publication.

Creswell, W. John, (2014). Research design qualitative, quantitative and mixed methods approaches (4th ed.). London: Thousand Oaks, Sage Publication.

Darling, C. A., Senatore, N., & Strachan, J. (2012). Fathers of children with disabilities: Stress and life satisfaction. Stress & Health: Journal of the International Society for the Investigation of Stress, 28, 269-278.

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K. and Davern, M. (2009). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers.Child: Care, Health and Development, 36(2):63–73.

Demilew YM, Asres Nigussie A (2017) Knowledge of Health Professionals on Folic Acid Use and Their Prescribing Practice in Bahir Dar City Administration, Northwest Ethiopia: Cross-Sectional Study. PLoS ONE 12(1): e0170116.https://doi.org/10.1371.

Devlieger, P. J. (1999a). Frames of reference in African proverbs on disability. International Journal of Disability, Development, and Education, 46, 439-451.

Eide AH, Kamaleri Y. (2009).Living conditions among people with disabilities in Mozambique: a national representative study. Oslo,SINTEF.

Esterberg, K. G. (2002). Qualitative methods in social research. Boston: McGraw Hill.

Femke Bannink, Richard Idro, Geert van Hove(2016). Parental stress and support of parents of children with spina bifida in Uganda African Journal of Disability; 5(1).

Fieggen G, Fieggen K, Stewat C, Lazarus J, Donald K, Dix-peek S, Toefy Z,(2014).South Africa medical journal,104(3)213-217.Doc.10,7196.SAMS.8079.

French BN. (1990). Midline fusion defects and defects of formation. Neurological surgery, 3 rd ed. Phi1adep1phia: Sauders 1091-1235.

Gemechu Sorri,, Eyasu Mesfin, (2015). Patterns of neural tube defects at two teaching hospitals in Addis Ababa, Ethiopia a three years retrospective study. Ethiop Med J, 5(3).

Gibson, C.H. (1995). The process of empowerment in mothers of chronically ill children. Journal of Advanced Nursing, 21, 1201-1210

Gillberg, C. (2010). The ESSENCE in child psychiatry: Early Symptomatic Syndromes Eliciting Neuro developmental Clinical Examinations. Research in Developmental Disabilities, 31(6):1543-155.

Godfrey, P., Oakley, Jr (1998). Centers for Disease Control and Prevention, Atlanta, GA, USA Bulletn of the World Health Organization.1998; 76 (SuppI 2): 116-117.

Gona, J.K., Mung'ala-Odera, V., Newton, C.R. and Hartley, S. (2010). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? Child: Care, Health and Development 37(2):175–183.

Good, A., Whyte, J., Harris, S., Glynn, J., Nicholl, H. & Greene, S. (2005). An exploratory study of the impact of childhood disability on individual family members, relationship, family life and dynamics. Sydney: Australian Family and Disability Studies Research Collaboration.

Goudge, J., Gilson, L., Russell, S., Gumede, T. & Mills, A., 2009, 'Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa', BMC Health Services Research 9, 75.

Guyer, J. I. (1981).Household and community in African studies. African Studies Review, 24, 87-137. doi:10. 2307/523903

Harris, B., Goudge, J., Ataguba, J.E., McIntyre, D., Nxumalo, N., Jikwana, S., et al.,(2011). 'Inequities in access to health care in South Africa', Journal of Public Health Policy 32 suppl 1,S102–S123. http://dx.doi.org/10.1057/

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping and future expectations: Journal of Developmental and Physical Disabilities, 14:157-171.

Heller, T., Caldwell, J., and Factor, A. (2007). Aging family caregivers: Policies and Practices. Mental Retardation & Developmental Disabilities Research Reviews, 13(2):136-142

Hepworth, D. H., Rooney, R. H., Rooney, G. W., Stom-Gottfried, K. & Larsen, J. (2006). Direct Social Work Practice. Theory and Skills. 7th Edition. Belmont: Thomson Brooks/Cole.

Herbert, L. J., Monaghan, M., Cogen, F. & Streisand, R. 2015. The impact of parents' sleep quality and hypoglycemia worry on diabetes self-efficacy. Behavioral sleep medicine, 13, 308-323.

Hesse-Biber, Nagy Sharlene & Leavy, Patricia (2011). The practice of qualitative research. (2nd ed.). United States of America: Sage publication Inc.

Hexem, K.R., Mollen, C.J., Carroll, K., Lanctot, D.A., Feudtner, C. (2011). How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. Journal of Palliative Medicine, 14(1), 39-44. Doi: 0.1089/jpm.2010.0256.

Ho, K.M. & Keiley, M.K. 2003. Dealing with Denial: A Systems Approach for Family Professionals Working With Parents of Individuals with Multiple Disabilities. The Family Counseling Journal: Counseling and Therapy for Couples and Families, 11(3):239 -247.

Holahan, C.J., Moos, R.H., and Schaefer, J.A. (1996). Coping, Stres Resistance and Growth: Conceptualizing Adaptive Functioning. In M. Zeidner, and N.S. Endler, ed. (1996). Handbook of Coping. New York: John Wiley & Sons, Inc.

Hopia, H., Tomlinson, P. S., Paavilainen, E. & Astedt-Kurki, P. (2004). Child in hospital: Family experiences and expectations of how nurses can promote family health. Journal of Clinical Nursing, 14(2), 212–222.

Hopia, H., Tomlinson, P. S., Paavilainen, E. & Astedt-Kurki, P. (2004). Child in hospital: Family experiences and expectations of how nurses can promote family health. Journal of Clinical Nursing, 14(2), 212–222.

Hovey, J.K. (2005). Fathers parenting chronically ill children: Concerns and coping strategies. Issues in Comprehensive Pediatric Nursing, 28(2), 83-95.

Ingstad, B., & Whyte, S. R. (Eds.). (1995). Disability and culture. Berkley: University of California Press.

International Federation of Spinal Bifida and Hydrocephalus, (2014). Spina Bifida-Fact Sheet. Retrieved from http://www.ifglobal.org/images/documents/

International perspectives on spinal cord injury,(2013). World Health Organization. Retrieved from (www.who.int).

Kent, L., King, H., and Cochrane, R. (2000). Maternal and child psychological sequelae in paediatric burn Journal of Advanced Nursing, 21, 1201-1210.

King, S., Teplicky, R., King, G. & Rosenbaum, P. (2004). Family-Centered Service for Children with Cerebral Palsy and Their Families: A Review of the Literature. Seminars in Paediatric Neurology, 11(1):78-86.

Kisanji, J. (1995b). Interface between culture and disability in the Tanzanian context: Part I. International Journal of Disability, Development, and Education, 42(2), 93-108.

Kloosterhouse, V., & Ames, B. D. (2002). Families' use ofreligion/spirituality as a psychosocial resource. Holistic Nursing Practice, 16(5), 61-76.

Kreuger, L. W. & Neuman, W. L. (2006). Social work research methods: qualitative and quantitative applications. New York: Pearson Education, Inc.

Krok, Dariusz. (2008).The role of spirituality in coping: Examining the relationships between spiritual dimensions and coping styles.Mental Health, Religion, & Culture, 11(7), 643 653. Doi: 10.1080/13674670801930429.

Lauren Kelly,(2012). "Neuropsychological Functioning, Parenting Behaviors, and Healthcare Behaviors Among Youth with Spina Bifida" (2012). Dissertations. Paper 373.Retrived from http://ecommons.luc.edu/luc_diss/373

Lawal, H., Anyebe, E.E., Obiako, O.R. & Garba, S.N.,(2014) ‘Socio-economic challenges of parents of children with neurological disorders: A hospital-based study in northwest Nigeria’, International Journal of Nursing and Midwifery 6(4), 58–66. Retrieved from http://dx.doi.org/10.5897/IJNM2014.0122

Lazarus, R. S. & Folkman, S. (1984).Stress, appraisal and coping, New York: Springer Publishing Company.

Lemacks, J., Fowles, K., Mateus, A., & Thomas, K. (2013). Insights from Parents about Caring for a Child with Birth Defects. International Journal of Environmental Research and Public Health, 10(8), 3465–3482. MDPI AG. Retrieved from http://dx.doi.org/10.3390/ijerph10083465.

Lerner, J. & Kline, F. 2006. Learning Disabilities and Related Disorders. Characteristics and Teaching Strategies. Boston: Houghton Mifflin.

Lightsey Jr., O. R., & Sweeny J. (2008). Meaning in life, emotion-oriented coping, generalized self-efficacy, and family cohesion as predictors of family satisfaction among mothers of children with disabilities. The Family Journal: Counseling and therapy for couples and families, 16(3), 212-221.

Lowes L, Lyne P, Gregory JW.(2004) Childhood diabetes: parents’ experience of home management and the first year following diagnosis. Diabet Med.21(6):531–538.

Mackey, S and Goddard, L.D., (2006) The experience of health and wellness in mothers of young children with intellectual disabilities. Journal of Intellectual Disabilities. 10(4), 305-315.

Mashiri, P. (2000). The socio cultural and linguistic aspects of childhood disability in Shona culture. Zimbabwe Journal of Educational Research,12(2), 170-194.

Matthews, E. E., Neu, M., Cook, P. F. & King, N. 2014. Sleep in mother and child dyads during treatment for pediatric acute lymphoblastic leukemia. Oncology Nursing Forum, 41, 599-610.

Mbah-Ndam, J. N. (1998). Caring for the disabled: The African experience. The Parliamentarian: Journal of the Parliaments of the Commonwealth, 79, 251-252.

McCubbin, H.I., Joy, C.B., Cauble, A.E., Comeau, J.K., Patterson, J.M., & Needle, R.H. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42, (4) 855-867.

Meltzer, L. J. & Booster, G. D. 2016. Sleep Disturbance in Caregivers of Children With Respiratory and Atopic Disease. Journal of Pediatric Psychology, 41,643-650.

Miles M.(2002) Children with hydrocephalus and spina bifida in East Africa: can family and community resources improve the odds? Disability & Society, 17:643-658. doi: http://dx.doi.org/10.1080/0968759022000010425.

Mitchell, L. E., Adzick, N. S., Melchionne, J., Pasquariello, P. S., Sutton, L. N., & Whitehead, A. S.(2004). Spina bifida. Lancet, 364, 1885–1895.

Moreira-Almeida, A. & Koenig, H.G. (2006). Retaining the meaning of the words religiousness and spirituality: A commentary on the WHOQOL SRPB Group's "A Cross-Cultural Study of Spirituality, Religion, and Personal Beliefs as Components of Quality of Life". Social Science & Medicine, 63, 843-845.

Morelius E, Hemmingsson H.(2014) Parents of children with physical disabilities perceived health in parents related to the child's sleep problems and need for attention at night. Child Care Health Dev;40(3):412–418.

Nachsehen, J. S., Garcin, N. & Minnes, P. (2005). Problem behavior in children with intellectual disabilities: Parenting stress, empowerment, and school services. Mental Health Aspects of Developmental Disabilities, 8:105-114.

Nazemi, H. (2007). Coping Strategies of Panic and Control Subjects Undergoing Lactate Infusion during Magnetic Resonance Imaging Confinement. Ph.D. Seattle Pacific University.

Ndegwa. D. pattern of presentation of Spina bifida as seen and managed in Kenyatta national hospital,(2004). A dissertation submitted as part of fulfillment for the degree of master of medicine in surgery in the university of Nairobi.

Oeckerman, R. (2001). Children with Special Needs: Helping Parents Through the Grief. Texas Child Care, 25(1):10-13.

Ogechi, N., & Ruto, S. (2002). Portrayal of disability through personal names and proverbs in Kenya: Evidence from Ekegusii and Nandi. Vienna Journal of African Studies, 3, 63-82.

Ohleyer, V., Freddo, M., Bagner, D.M., Simons, L.E.,Geffken, G.R., Silverstein, J.H., Storch, E.A. (2007).Disease-related stress in parents of children who are overweight: Relations with parental anxiety and childhood psychosocial functioning. J Child Health Care, 11: 132–142.

Olshansky, S. (1962). Chronic sorrow: a response to having a mentally defective child. Social Casework 43, 190–195.

Oyewole A, Adeloye A & Adeyokunnu Aa (1985) Psychosocial and cultural factors associated with the management of Spina bifida cystica in Nigeria. *DevMedCN* 27: 498-503

Padgett, D. K. (2008), Qualitative Methods in Social Work Research 2nd edition. New York.

Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: The function of information. Child: Care, Health and Development, 25: 299 - 312.

Pargament, K.I. (1997). The Psychology of Religion and Coping: Theory, Research, Practice. New York: Guilford Press.

Park, E. M., Meltzer-Brody, S. & Stickgold, R. (2013). Poor sleep maintenance and subjective sleep quality are associated with postpartum maternal depression symptom severity. Archives of Women's Mental Health, 16, 539-547.

Parke, R. D. (1986). Fathers, families, and support systems: Their role in the development of at-risk and retarded infants and children. In J. J. Gallagher & P. M. Vietze (Eds.), Families of handicapped persons: Research, programs, and policy issues (pp. 129–142). Baltimore: Paul Brookes

Parker, J.D. and Endler, N.S. (1996). Coping and Defense: A Historical Overview. In: M. Zeidner and N.S. Endler, ed. (1996). Handbook of Coping. New York: John Wiley & Sons, Inc.

Patricia McGill Smith, (2010).You arenotalone: For Parents When You Learn That Your Child Has a Disability. Retrieved from / Center for Parent Information and Resources http://www.parentcenterhub.org/notalone/

Price, M.S.(2011). Divorce issues and the special needs child. J. Fam. Law, 25, 28–36

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, R., King. G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter. S. D. & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. BioMed Central Paediatrics, 4(1).

Robinson JE. (2006).Employment for people with disabilities: Findings of a consumer-led project. Disability and Rehabilitation, Sage Publications, Inc.

Sandler A.(1997). Living with spina bifida: a guide for families and professionals. North Carolina Press.

Sawin, K. J., & Thompson, N. M. (2009). The experience of finding an effective bowel management program for children with spina bifida: The parent's perspective.

Sekaran P,Vijayakumari F, Haviharan R, Zachariiah K, Joseph SE, Kumar RK.(2010). Community reintegration of spinal cord-injured patients in rural south India. Spinal Cord, 2010, 48:628-632.

Shilling, V.; Morris, C.; Thompson-Coon, J.; Ukoumunne, O.; Rogers, M.; Logan, S. Peer.(2013). Support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. Dev. Med. Child Neurol. 2013, 602, 602–609.

Siklos, S. & Kerns, K.A.(2006).Journal of Autism and Development Disorders 36(7) 921 retrieved from https://doi.org/10.1007/s10803-006-0129-7.

Smith, Suzanne R., Hamon, Raeann R., Ingoldsby, Bron B. & Miller, Elizabeth J. (2009). Exploring Family Theories. Oxford University Press.

Snape D, Spencer L (2003).The foundations of qualitative research. In Ritchie J, Lewis J (eds.) Qualitative Research Practice. Sage Publications, London.

Spina Bifida and Hydrocephalus Association of Canada,(2010). A Guide for Educators (Fourth) Edition**.** Printed with the generous support of Ronald McDonald House Charities. Retrieved from h*ttp://sbhac.ca/wp-content/*

Spina Bifida & Hydrocephalus Association of Ontario. Spina Bifida Information. Retrieved fromhttp://www.sbhao.on.ca/spina-bifida

Spina Bifida and Hydrocephalus Association of Canada, (2015) Prenatal Diagnosis of Spina Bifida and/or Hydrocephalus. Retrieved fromhttp://sbhac.ca/wp-content/uploads/2015/06/Revised-website

Spina Bifida Association of America (2014). National Resource Center. Retrieved from http://www.spinabifidaassociation.org/

Stinnett, N., & DeFrain, J. (1985). Secrets of strong families. Boston: Little, Brown and Company.

Stone, M.B.; Botto, L.D.; Feldkamp, M.L.; Smith, K.R.; Roling, L.; Yamashiro, D.; Alder, S.C.(2010). Improving quality of life of children with oral clefts. J. Craniofacial Surg21, 1359–1361.

Strydom, H. (2005). Sampling and sampling methods. In: Research at grass roots for social sciences and human services professions, edited by De Vos, A. S., Strydom, H., Fouche, C. B. & Delport, C. S. L. Pretoria: Van Schaik: 192-204.

Talle, A. (1995). A Child is a child: Disability and equality among the Kenya Maasai. In B. Ingstad & S. R. Whyte (Eds.), Disability and Culture (pp. 56-72). Berkley, CA: University of California Press.

Taye M, Afework M, Fantaye W, Diro E, Worku A (2016). Magnitude of Birth Defects in Central and Northwest Ethiopia from 2010-2014: A Descriptive Retrospective Study. PLoS ONE 11 (10): e0161998. doi:10.1371/journal.

Taylor, S.E. & Stanton, A.L. (2007). Coping resources, coping processes, and mental health. Annual Review of Clinical Psychology, 3, 377-401. Doi:10.1146/annurev.clinpsy.3.022806.091520

Thorogood N.,Green J. (2004). Qualitative Methods for Health Research, London: Sage

Tsegazeab Laeke, Abenezer Tirsit, Hagos Biluts, Deeptha Murali, Knut Wester (2017). Pediatric Hydrocephalus in Ethiopia: Treatment Failures and Infections:A Hospital-Based, Retrospective Study World Neurosurgery. 100:30-37.

Van den Borne, H.W., van Hooren, R.H., van Gestel, M.,Rienmeijer, P., Ffyns, J.P., and Curfs, L.M.G. (1999).Psychological problems, coping strategies, and the need of information of parents of children with Praeder–Willi syndrome and Angelman syndrome. Patient Education and Counseling, 38: 205–216

Van der Lee, J., Mokkink, L., Grootenhuis, M., Heymans, H.,& Offringa, M. (2007).Definitions and measurement of chronic health conditions in childhood.

Vermaes, I.P., Janssens, J.M., Bosman, A.M.& Gerris, J.R.(2005).Parents psychological adjustment in families of children with spina bifida: A meta-analysis', BMC pediatrics 5, 32.

Vermaes, I.P.R., Gerris, J.R.M. & Janssens, J.M.(2007). Parents social adjustment in families of children with spina bifida: A theory-driven review', Journal of Pediatric Psychology 32, 1214–1226.

Vermaes, I.P.R., Janssens, J.M.A.M., Mullaart, R.A., Vinck, A. & Gerris, J.R.M., (2008).Parents personality and parenting stress in families of children with spina bifida Child: Care, Health and Development 34, 665–674.

Vijesh PV, Sukumaran PS (2007). Stress among Mothers of Children with Cerebral Palsy Attending Special Schools, Asian Pacific Disability Rehabilitation J. 18(1).

Wang, M. & Brown, R. (2009). Family Quality of Life: A framework for Policy and Social Service Provisions to Support Families of Children with Disabilities. Journal of Family Social Work, 12(2)144-167.

Willig, C. (2008). Introducing qualitative research methods in psychology: Adventures in theory and method. 2nd. Maidenhead: McGrawHill/ Open University Press.

World Health Organization.(2011).World report on disability. Geneva, World Health Organization,2011/9789240685215_eng.pdf, accessed 10 May 2017) retrieved http://whqlibdoc.who.int/publications/

Yıldırım, G., and Gökyıldız, Ş. (2004). Psychosocial Problems Parents Who Cannot Have a Healthy Baby Experienced. Journal of Anatolia Nursing and HealthSciences,7(3): 74-82.

APPENDIXES

Appendix 1

Informed Consent

My name is Admassu Sodere, I am a post graduate student at Addis Ababa University, school of social work. Currently, I am doing for partial fulfillment of my master's degree in social work on topic of challenges of parents with Spina Bifida children and coping mechanism. The purpose of this study to understand major challenges experienced by parents of children diagnosed with Spina Bifida and their coping mechanisms, additionally to understand different governmental , non- governmental ,individuals and families of psychosocial and economic support. I inviting you to participate in this research study .The researcher hopes that the information you give may possibly benefit parents who also have children with Spina Bifida disabilities .You were selected as a possible participant in this research because of your experience of caring for a child with Spina Bifida You are not forced to participate in this research study and you will not be paid to take part in the study. Duration of interview will estimate from fifty minuets up to one hour and half. The interviews will be audio-recorded and they will not be recorded without your permission. Moreover, I will ensure confidentiality by not citing your name within the study.

I sincerely appreciate your interest in my research study. Please signing after you have read and understood the above information.

Name ____________________________

Signature __________________________

Date _____________________________

Appendix 2

የስምምነት ማረጋገጫ መጠይቅ ቅጽ

እኔ አድማሱ ሶደሬ በአዲስ አበባ ዩኒቨርስቲ በማህበረሰብ አገልግሎት (ሶሻል ወርክ) ትምህርት ዘርፍ የሁለተኛ ድግሪ ተማሪ ስሆን ለመመረቂያ ይረዳኝ ዘንድ የማሟያ የጥናት ፅሁፍ በመሥራት ላይ እገኛለሁ፡፡ ይህ የጥናት ፅሁፍ በዋነኝነት የሚዳስሰው በህፃናት ላይ በሚፈጠረው የአከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ጉዳት በወላጆች ላይ ያመጣውን ተፅእኖ እና በወላጆች ላይ የተከሰተውን ተፅእኖ በምን መልኩ እንደሚቋቋሙት እንዲሁም ከተለያዩ ተቋማት ወይንም ግለሰቦች፣ ቤተሰቦች ጋር በመተጋገዝ በህፃኑ የአከርካሪ የአጥንት ክፍተት /ስፓይናቢፊዳ/ ምክንያት በወላጆች ላይ ያመጣውን ተፅእኖ ለመቅረፍ ወይንም ለመቀነስ የሚደረግ ድጋፍ ለመገንዘብ ነው፡፡ እርስዎ የዚህ ጥናት አካል መሆንዎ ለጥናቱ መሳካት እጅግ ጠቀሜታ አለው፡፡ በመሆኑም ለተዘጋጁት ጥያቄዎች ተገቢውን ምላሽ በመስጠት እንዲተባበሩኝ ስል በአክብሮ እጠይቃለሁ፡፡

በዚህ ጥናት ላይ ያሉዎትን ተሳትፎ በፍቃደኝነት የተመሠረተ በመሆኑ ምንም አይነት የገንዘብ ክፍያ አይኖረውም፡፡ የወላጅ ቃለመጠይቅ እና የቡድን ውይይቱን በምናደርግበት ጊዜ የድምፅ መቅረጫ በመጠቀም ቃለምልልስ እናደርጋለን፡፡ ይህም ቃለምልልስ ከሀምሳ ደቂቃ እስከ አንድ ሰዓት ተኩል ጊዜ ሊፈጅ እንደሚችል ይገመታል፡፡ በቃል ምልልሳችን ወቅት የሚሰጡኝ መረጃ ሙሉ በሙሉ ሚስጥራዊነቱ የተጠበቀ ሲሆን ለመመለስ የማይፈልጉትን ጥያቄዎችያ ለመመለስ መብት ያሎዎት መሆኑን እንዲሁም ከጥናቱ እራሷን ማግለል ከፈለጉ፣ ማቋረጥ ከፈለጉ መብትዎ መሆኑን እየገለፅኩ ጥያቄዎችን ባለመመለስ፣ ጥናቱን በማቋረጡት፣ ጥያቄዎችን ለመመለስ ፍቃደኛ መሆኑ ከህክምናው ሂደት እና ከተቋም ጋር ምንም አይነት ተያያዥነት የለውም፡፡ በመሆኑም ልጆት የሚያገኘው /የምታገኘው የህክምና አገልግሎትን አያስተጓጉልም፡፡

ከላይ በተጠቀሱት ነጥቦች ስለመስማማቱን እና ፍቃደኝነቶዎን እንዲገልፁልኝ ስል በትህትና እጠይቃለሁ አመሰግናለሁ፡፡

የጥናቱ ተሳታፊ

ስም ___________________________

ፊርማ ___________________________

ቀን ___________________________

Appendix 3

In depth interview guide

Part I – Socio demographic data

Age: _____ Sex _____ Marital status: ______________ Educational level: ________________

Source of Income _______________Religion: ________________ Area of residence

Part II – Information of child

Age ________ Sex ____ Diagnosed: ________________

Interview guide

Part III

1. Could you please tell me your experience or reactions when you first have been told your child has Spina Bifida?
2. Could you please tell me when your child was diagnosed with Spina Bifida?
3. Could you please tell me what you know about Spina Bifida in children?

Part IV

1. How does your child's Spina Bifida disability affect your parental life
2. How does your child's Spina Bifida disability affect your psychological including physical health?
3. How does your child's Spina Bifida disability affect your social relationship?
4. How does your child's Spina Bifida disability affect your economic?
5. How does your child's Spina Bifida disability affect your marital relationship?

Part V

1. How have you been able to cope with all the challenges you have mentioned? Please tell about anything that has been helpful to you.
2. Do you get support for you and for your child? From whom? What kind of support?
3. What do you think is the most important for governmental and non- support organization governmental to understand about you, your child, and/or your situation?

Appendix 4

ክፍልአንድ፡- የተሳታፊ ወላጆ መረጃ

ስም ______________________________ ፆታ ______________ የጋብቻ ሁኔታ ______________

የትምህርት ሁኔታ ____________________

የገቢ ምንጭ /መተዳደሪያ _________________________________

ሃይማኖት _________________________________

የመኖሪያ አድራሻ ______________________

ክፍል ሁለት፡- ስለህፃናቱ መረጃ

እድሜ ____________ ፆታ_________

የጉዳቱ አይነት __________________

በተቋሙ በህክምና የቆዩበት ጊዜ __________________

ክፍል ሶስት፡- ስለ አከርካሪ አጥንት ክፍተት ጉዳት /ስፓይናበፊዳ /

ስለአከርካሪ አጥንት ክፍተት ጉዳት /ስፓይናቢፊዳ/ ከዚህ በፊት ሰምተው ያውቃሉ? ከአወቁ የመከላከያ መንገዱን ጨምረው ይግለፁልኝ፡፡

ልጆዎት የአከርካሪ አጥንት ክፍተት ጉዳት /ስፓይናቢፊዳ/ ህመምተኛ መሆኑን ያወቁት መቼ ነው? በእርግዝና ወቅት ወይንስ ከተወለደ በኋላ?

ልጆዎት የአከርካሪ አጥንት ክፍተት ጉዳት /ስፓይናቢፊዳ/ ህመምተኛ መሆኑን ሲያውቁ ወይንም ሲገለፅሎት የተሰማዎትን ይግለፁልኝ፡፡

ክፍል አራት፡- በወላጅ ላይ ያለው ተጽእኖ

ከስነልቦናዊ ጋር ተያያዥነት ያለው ተፅእኖ /እክል/ ምን ይመስላል? ምሳሌ ድብርት፣ፍርሃት ወ.ዘ.ተ.

ከአካላዊ ጤና ላይ ያለው ተፅእኖ /እክል/ ምን ይመስላል? ለምሳሌ ክብደት መቀነስ፣እንቅልፍ ማጣትወ.ዘ.ተ.

ከማህበራዊ ህይወት ትስስር ላይ ያለው ተፅእኖ /እክል/ ምን ይመስላል? ለምሳሌ በስራ ህይወትዎ፣ በዕለት ዕለት ተግባራት ….. ወ.ዘ.ተ.

በትዳር ላይ ያለው ተፅእኖ /እክል/ ምን ይመስላል? ለምሳሌ (ባለመግባባት፣ ጊዜ ያለመስጠት ወ.ዘ.ተ

በኢኮኖሚ /በገቢና ወጪ/ ላይ ያለው ተፅእኖ /እክል/ ምን ይመስላል? ለምሳሌ ለህክምና ወጪ፣ ለትራንስፖረት ወጪ፣ ለህፃኑ እንክብካቤ ወ.ዘ.ተ.

ክፍል አምስት፡- የተፅእኖ /እክል/ መፍቻ መንገዶች

የአከርካሪ አጥንት ክፍተት /ስፓይናቢፊዳ/ ህመም ያለውን /ያለባትን/ ልጅ በመንከባከብ የደረሱበትን ተፅእኖ /እክል/ እንዴትተቋቋሙትወይንምቀነሱትይግለፁልን

አስቸጋሪ ሁኔታ ማለትም በልጆዎት ህመም ምክንያት ሲያጋጥ ሞት የድጋፍ እርዳታ የሚያገኙት ከወዴት ነው?

በልጆዎት አከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ምክንያት ከደረሰቦት ተፅእኖ /እክል/ ለመቋቋም ወይንም ለመቀነስ ምን አይነት ድጋፍ አገኙ፡፡

ያገኙት ድጋፍ /እርዳታ ምን ያህል ተጽእኖን/ እክሉን/ ለመቀነስ ጠቀሞት?

ለመንግስታዊ ሆነ መንግስታዊ ያልሆኑ ድርጅቶች፣ ግለሰቦች፣ ቤተሰቦች ለአከርካሪ አጥንት ክፍተት ጉዳት /ስፓይናቢፊዳ/ ለህመምተኛ ህፃናት እና ለወላጆች ምን መደረግ አለበት ይላሉ?

Appendix 5

Focus group discussion interview guide

Part I – Socio demographic data

Age: _____ Sex _____ Marital status: ______________ Educational level: ________________

Source of Income _______________Religion: ________________ Area of residence

Part II – Interview guide

1. Could you please tell me your experience or reactions when you first have been told your child has Spina Bifida?
2. How does your child's Spina Bifida disability affect your psychological including physical health? your social relationship? your economic? your marital relationship?
3. How have you been able to cope with all the challenges you have mentioned?
4. Do you get support for you and for your child? From whom? What kind of support?
5. What do you think is the most important for governmental and non- support organization governmental to understand about you, your child, and/or your situation?

Appendix 6

የቡድን መወያያ ጥያቄዎች

ክፍል አንድ፡- የተሳታፊ ወላጆች መረጃ

ፆታ ________________ የጋብቻ ሁኔታ ____________ የትምህርት ሁኔታ ____________

የገቢ ምንጭ /መተዳደሪያ ______________________

ሃይማኖት _____________________

የመኖሪያ አድራሻ _____________________

ክፍል ሁለት፡- ስለ አከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ልዩ ልዩ መረጃ

ህፃኑ የአከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ህመምተኛ እንደሆነ ሲነገሮት ወይም ሲያውቁት ምን አይነት ስሜት ተሰማዎት

በትዳር ህይወትዎ ፣ በስነልቦና ፣ በኢኮኖሚያዊና በማህበራዊ ህይወትዎ ላይ በአካላዊ ጤናዎት ላይ ያመጣው ተፅእኖ/እክል ካለ ይግለፁልኝ?

ቀደም ሲል የተጠቀሱትን የኢኮኖሚ ፣ የትዳር ፣ የስነልቦና ፣ የማህበራዊ ህይወትና አካላዊ ጤና ተፅእኖዎች /እክሎች እንዴት ተቋቋሙት?

እነዚህን ከላይ የተጠቀሱትን ተፅእኖዎች ለመቋቋም ወይንም ለመቀነስ ከበጎ አድራጎት ድርጅቶች፣ ከማህበረሰብ አገልግሎት ፣ ከጤና ባለሙያዎች ፣ ከበጎ አድራጎት ግለሰቦች ቤተሰቦች ጋር ምን አይነት ግንኙነት አለዎት?

መንግስታዊ ወይንም መንግስታዊ የልሆኑ አካላት ለአከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ህመም ላለባቸው ልጆች እና ወላጆች ምን አይነት እገዛ መኖር አለበት ይላሉ?

Appendix 7

Key informant interview guide

Part I – Socio demographic data

Age: _____ Sex _____ Educational level: ________________ Profession ____________

Marital status: ______________work experience ____________

Part II – Interview guide

Could you please describe psychosocial support services offered to parents with diagnosed Spina Bifida in Neurosurgical Inpatient Unit?

What are challenges you detected on parents of Spina Bifida children and how they cope those challenges from admitted in Neurosurgical Inpatient Unit?

What do you think is the most important for governmental and non- governmental support organization governmental to be aware of about parents and children with Spina Bifida ?

Appendix 8

ለባለሙያዎች የሚቀርብ ጥያቄዎች

- ዕድሜ
- የጋብቻ ሁኔታ
- የትምህርት ደረጃ
- የተሰማሩበት ሙያ

ሆስፒታሉ አከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ህመምተኛ ለሁኑ ልጆች ወላጆች ምን አይነት የድጋፍ አገልግሎት ይሰጣቸዋሃል?

አከርካሪ አጥንት ክፍተት /ስፓይና ቢፊዳ/ ህመምተኛ የሁኑ ልጆች ወላጆች ምን አይነት ተፅእኖ ይደርስባቸዋል የደረሰባቸውን ተፅእኖ /እክል/ በምን መልኩ ይፈቱታል?

መንግስታዊ ያልሆኑ ድርጅቶች፣ ግለሰቦች፣ ቤተሰቦች ለአከርካሪ አጥንት ክፍተት ጉዳት /ስፓይና ቢፊዳ/ ለህመምተኛ ህፃናት እና ለወላጆች ምንአይነት ድጋፍ ያደርጋሉ? ወደፊትስ ምን መደረግ አለበት ይላሉ?