COLLEGE OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

DEPARTMENT OF NEONATAL NURSING

PREVALENCE AND PREDICTORS OF STRESS AND SOCIAL IMPACT AMONG PARENTS WITH NEURAL TUBE DEFECT CHILDREN WHO HAVE FOLLOW UP IN PUBLIC HOSPITALS, ADDIS ABABA, ETHIOPIA, 2021

PRINCIPAL INVESTIGATOR

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Approval sheet
ADDS ABABA UNIVERSITY

COLLEGE HEALTH SCIENCE SCHOOL OF ALLIED SCIENCES

DEPARTMENT OF NURSING AND MIDWIFERY

I, the undersigned MSc student, declare that I have submitted my original work on a title prevalence and predictors of stress and social impact among parents with Neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 for the examination.

Submitted by:

_____	_____	_____
Name of student	Signature	Date

This thesis work has been submitted for examination with my approval as an advisor.

Approved by:

1. _____	_____	_____
Name of Major Advisor	Signature	Date

2. _____	_____	_____
Name of Co-Advisor	Signature	Date

APPROVAL BY THE BOARD OF EXAMINATION

This thesis by Eyerusalem Tamiru is accepted in its present form by the board of examiners as satisfying thesis requirement for the degree of masters in neonatal nursing.

INTERNAL EXAMINER:

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Statement of declaration

By my signature below, I declare and affirm that this thesis is my own work. I have followed all ethical principles of scholarship in the preparation, data collection, data analysis and completion of this thesis. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this thesis.

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List of acronyms and abbreviations

ANC-	Antenatal Care
CIC-	Clean Intermittent Catheterization
ETB-	Ethiopian Birr
MOS-SSS-	Medical Outcomes Study Social Support Survey
NGOs-	Non-Governmental Organizations
NTDs-	Neural Tube Defects
PD-	Parent Distress
PSI-SF-	Parent Stress Index Short Form
SB-	Spinal Bifida
SPSS:	Statistical Package for Social Sciences
ZMH-	Zewditu Memorial Hospital

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Abstract

Background- Neural Tube Defects are congenital anomalies of the brain, spinal cord and their surrounding structures. Parents face extreme stress at the diagnosis of NTDs since they are challenged with either the misery of a termination, stillbirth or the lifelong psychological, social and financial challenges of caring for a child with NTDs.

Objective-To determine prevalence and predictors of stress and social impact among parents with Neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021.

Method- Institution based cross sectional study was implemented on 369 parents with neural tube defect children in three selected Addis Ababa public hospital by using purposive sampling technique. A structured questionnaire was used for data collection on socio-demographic characteristics and other independent variables, data on stress was collected by Parent Stress Index Short Form Likert scale and social impact data was collected using medical outcome study social support survey Likert scale tool. Data was entered and coded with Epi data v4.6 and cleaned and analyzed using SPSS 25. Level of significance was determined using $p<0.05$. Final results is presented by text, graph, and tables.

Result- All 369 respondents were participated in this study and the response rate was 100%. The mean age of the respondent was 29.38 ± 5.64. Eighty one percent of the respondents were mothers. Among the children 57.5% were male and 19.5% of children with the age of 2-5 years. 17.6% of the parents with neural tube defect children were stressed and 26.3% had social impact. Parental stress were associated with motherhood, urine incontinence, shunt insertion and use of clean intermittent catheterization, while parental social impact associated with higher parental age, bowel dysfunction, use of clean intermittent catheterization, shunt utilization and paraplegia.

Conclusion and Recommendation- There is stress and social impact among parents with neural tube defect children and its extremely under-recognized and not managed by health care professionals. Study finding recommend that stress and social impact of parents with neural tube defect children should be diagnosed early and managed appropriately.

Key Words- Neural tube defect, stress, social impact**,** parents

1. Introduction

1.1 Background

Congenital anomalies are the leading cause of death in babies under one year of age (1). Neural tube defects (NTDs) are one of the major congenital anomalies which affect the brain, spinal cord and their surrounding structures (2). It is one of the most common congenital birth defects, affecting 0.5-2 per 1000 pregnancies and 1 of every 1,000 live births worldwide (3,4).

Neural tube defects are caused by developmental malformation of the central nervous system during the embryonic period that are caused by partial or incomplete closure of the neural tube, between 21 and 28 days after conception before the women even knows she is pregnant (5,6).

Based on whether neural tissue are exposed or covered by skin NTDs are classified as open or closed. Open NTDs are more frequent and include spinal bifida (myelomeningocele), anecephaly, encephalocele, hydrocephaly, iniencephaly and schizencephaly (7).

The exact cause of NTDs is not known. However, the etiologies include both genetic and environmental factors. Maternal and paternal age, maternal socioeconomic status, education status, geographic area, occupational exposure, smoking, alcoholism, maternal use of caffeine and antiepileptic drugs during early pregnancy, maternal reproductive history, hyperthermia during early pregnancy, obesity, maternal diabetes and maternal nutrient deficiency have been associated with variations in the incidence. Yet the best known risk factor for NTDs is maternal folate deficiency (7,8). Several clinical trials concluded that periconceptional folate supplementation significantly reduces the incidence of NTDs and a declining population prevalence of NTD by 30-50% was observed following folic acid fortification of food in many countries (9–12).

NTDs can be diagnosed prenatally by imaging techniques such as ultrasound and identification of alpha-fetoprotein levels in the amniotic fluid or serum. Any malformation in the vertebral arches is starting to be visualized by twelve weeks of gestation (13).

A treatment of NTDs is puzzling and it depends on the severity of its complication. Like no treatment is available for anencephaly since the infants do not survive usually more than a few hours and surgical management has improved survival and the functions of infants with spinal bifida, meningocele and mild myelomeningoceles (14).

NTDs accounts for about 75% under five death and disabilities globally. As morbidity and mortality from infectious diseases are decreasing worldwide, the contribution of birth defects to under-five morbidity and mortality will continue to increase proportionally(15).

NTDs are the most devastating among all the structural malformations and have a grave impact upon the functioning of individuals, families and communities as a consequence (16). The consequences are predominantly seen in resource limited countries where preventative measures and long-term quality care for surviving NTDs patients are limited (17).

Children with NTDs recurrently have problems related to hydrocephalus, neurogenic bladder, kidney involvement, impaired bowel habit, pressure ulcer, orthopedic complications and psychosocial consequences. These complications can cause severe disability, which enhance significant burden to patients and as well as to their families (18). It can also be seen as a chronic disease that affect the child and his or her entire family with complex problems throughout life (19). Care of children with NTDs could exhibit mother and father with extensive physical, psychological and social demands (20,21). Parental psychological adjustment help them to deal with their infants with NTDs, siblings and the family unit (22). Most of the time parents find it very difficult to accept their child disability and they also experience a lack of support from other family members and health professionals. So it needs more emphasis since both the parents and the children are suffering.

1.2 Statement of problem

Neural tube defects (NTDs) are serious birth defects of the brain and spine which are a major yet preventable public health burden. Globally it's estimated that approximately 300,000 babies are born each year with NTDs, resulting in approximately 88,000 deaths and 8.6 million disability adjusted life years (DALYs). In low income countries, NTDs may account for 29% of neonatal deaths due to observable birth defects (15).

From 300,000 new cases of neural tube defects reported annually, 40,000 of the cases were estimated to occur in Sub-Saharan Africa. In East Africa the prevalence of neural tube defects is estimated to be 13 cases per 10,000 live births (23).

Both the birth and total prevalence of NTDs have declined during the past three decades among high income countries (24,25). Contrary to the developed world the prevalence of NTDs in developing countries is still high with reported incidence of 130 per 10,000 births (25). The difference in prevalence among countries could be due to knowledge difference of mothers about folic acid supplementation or food fortification and variation of countries health policies regarding folic acid fortification and other preventive measures (17, 25–27).

A retrospective cross-sectional study conducted in Nigeria demonstrated that the prevalence of major congenital abnormalities in Niger Delta was 20.7 per 1,000 live births, with those of the central nervous system predominating at 27% of the total (26).

In Ethiopia the incidence of NTDs is increasing petrifyingly in recent years. The burden of NTDs diverges from region to region. A recent finding in Tigray region showed the overall incidence of NTDs was 13 per 1000 births and the highest burden was reported in the Southern Zone of Tigray with the incidence of 30 per 1000 births (27) whereas, lowest prevalence was reported from a study conducted in Addis Ababa and Amhara region with the incidence of 4 per 1000 births (28).

Institution based study conducted using mixed design, cross-sectional and case control, in three Addis Ababa teaching hospitals with (n= 8677) births after the 28th week of gestation reveals among live births and stillbirths, excluding medically terminated cases the birth prevalence of NTDs was 63.4 per 10,000 births (25).

Chronic illnesses like Spinal Bifida, which is the most common type of NTDs have both sudden impact like diagnosis and high-risk surgery and chronic complication like medication consumption, incontinence and ambulation problems which have negative impressions on daily

life of the children. Children with SB have a wide range of functional impairments depending on the type of malformation, it's location on the spine and the co-morbidity of brain injuries and orthopedic deformities (19). These impairments include weakness or paralysis of the legs, bladder and bowel incontinence and cognitive deficits (29).

Parenting a child with a chronic disabling disease may have an influence on parents psychological adjustment like high parental distress because they hassle a lot for parenting their disable child (30–32). In addition to that psychological distress include a perceived inability to cope up effectively, change in emotional status, anxiety and regrets. Recent literatures identify depressive symptoms such as sadness, pessimism, loss of pleasure, changes in sleep and appetite, feelings of worthlessness, concentration difficulty, agitation and irritability which can affect work, social relationships and parenting are seen on parents with chronic illness children (33).

It is known that SB has implications not only on the affected child but also on the parents and siblings (32). Clinical symptoms of SB place considerable physical, psychological and social demands on the children and families involved. Parents of children with health conditions like SB are responsible not only for the physical care of their children but also for dealing with medical, educational and other service providers like for helping their children cope with the physical and emotional demands of their illnesses. Providing daily care to children with chronic health conditions often lead parents with a variety of burdens that can increase tension, drain energy and be accompanied by symptoms of psychological distress (4,34).

Long-term problems related to NTDs include ambulatory difficulties, bowel and bladder incontinence, hydrocephalus and shunt malfunction, skin breakdown and learning difficulties (35). Each child and family requires multidisciplinary and intensive management to their needs over time. This places considerable strain on health and social resources as well as physical, psychological and social demands on the patient and families (36).

Parenting a child with SB which accounts for two-third of NTDs may also include the challenges associated with the child's learning difficulties like impairments in working memory, verbal communication and problem-solving abilities. Significant impact on independence and social integration can be critical issues for the individual, family and community for lifelong (33).

Despite this impact there is no study conducted about its impact on parents which makes our treatment unremarkable. NTDs health care should include psychological and social support to

parents of these children. This research supposed to identify its stress and social impact on parents and fill the gap.

1.3 Significant of the study

Parents experience excessive stress at the diagnosis of NTDs. They are challenged with either the grief of a termination, stillbirth or the lifelong emotional and financial challenges of caring for a child with NTD (37). NTD is incurable congenital anomaly which has a major impact on the infant physically, psychologically and socially which leads the parent psychological, social, marital and financial crisis. The purpose of this study is to explore the stress and social challenges of parents with NTDs children. Even though aggressive surgery and extensive medical treatments are given to the infants, it has permanent consequence on the child, family, health sector, community and the government. So understanding its impact pave the way for the governments to revise ANC follow up policy which should have been started one month prior to pregnancy and put further effort on the prevention rather than the treatment, helps the health sector to be conscious on the preventive measures and counseling and the family to be meticulous for the next pregnancy. As far as my literature search, there is no similar study that has been conducted on parents of infants with NTDs in Addis Ababa. So, it can also serve as baseline for those who wish to conduct study on this area.

1.4 Justification of the study

Children with NTDs cause a severe psycho-social impact on their parents and the rest of their families. Parents encounter a significant affliction after a diagnosis of NTDs during pregnancy. In my clinical experience of caring for children with NTDs, most parents find it very difficult and challenging to accept their child disability. They will have many things to consider that leads them into distress. One of the things that make them to worry much is whether to continue or terminate the pregnancy. They will blame their self if they terminate the pregnancy or the possible future of having a disabled child make them very anxious. Giving care for a disabled child, especially without having the needed social, psychological and financial support is pretty much stressing. Parents also experience a lack of support from other family members and social groups which makes them to consider stereotype for both their child and themselves. Living in a society that frequently uses people's appearances to make judgments will hurt their emotions beyond measures. The need of financial supply to raise a child with disability is another stressful thing that affects parents. They may need to leave their job for caring their child but also parents with low income will be troubled to afford the basic needs any disabled child requires. The thought of not being able to afford their medical expenses continually is another traumatic stuff such parents have to go through. The case gets worse when there are no government sectors, volunteer groups, health and psychology professionals who gives related advices or any other institution available to assist them. I feel like both the parents and the children are neglected, so it made me curious to search relevant data on this topic. After this research result the family will be linked to psychiatric clinic for stress evaluation, psychotherapy, and treatment if needed. Governmental and nongovernmental organization will be involved to minimize the parent social burden.

2. Literature review

2.1 Prevalence of NTDs

Neural tube defects (NTDs) are congenital malformations of the central nervous system (6) and anatomically they can be classified as cranial and spinal defects. Cranial defects included anencephaly, encephalocele, and iniencephaly. On the other hand, spinal defects include meningocele, myelomeningocele and spina bifida occulta (38).

Spinal bifida and anencephaly which are the two most common forms of neural-tube defects, occurs 1 in 1000 pregnancies in the United States and an estimated 300,000 newborns worldwide (39). Among the central nervous system anomalies which are reported in 31% of newborn, myelomeningocele (MMC) is the most common of the central nervous system defects which accounts for 71% occurrence and its incidence is reported to range from 3 to 6 per 1000 live births (16).

The worldwide prevalence of NTDs ranged from 1 to 10 per 1000 (7) and its incidence in developing countries has been reported to be up to four fold higher than in developed ones (40). A systematic review on birth defects and developmental disabilities shows that there is difference in the prevalence of NTDs worldwide. According to this review the highest prevalence recorded in Eastern Mediterranean and Africa region was 124.1 and 75.4 per 10,000 births respectively while in European region it was 35.9 per 10,000 births (15).

Hospital based cross sectional descriptive study conducted in two Addis Ababa public hospitals with (n=28,961) shows the overall occurrence of NTDs was 6.1/1000 births (41).

Another study conducted using two study designs, namely, a prospective cross-sectional and a hospital-based unmatched case-control study with (n=8677) at three Addis Ababa public hospitals reveal the total prevalence for all types of NTDs was 126 per 10,000 births and the birth prevalence for all types of NTDs was 63.4 per 10,000 births. Out of the total cases of NTDs, 54.1% were cases of anencephaly, 40.5%, spinal bifida and 5.4%, encephalocele (25).

2.2 Stress of NTDs on parents

NTDs are associated with multiple medical and socioeconomic consequences. They could lead to about 50% elective terminations of pregnancies, fetal malformation or stillbirth. Out of the NTDs affected live births about 75% resulted in under five death as well as disabilities globally (42,43).

Parents face extreme distress at the diagnosis of NTDs since they are challenged with either the misery of a termination, stillbirth or the lifelong psychological and financial challenges of caring for a child with an NTDs (37).

NTDs can be seen as a chronic disease that affect the child and his or her family with complex difficulties throughout a life (44). Caregivers of children with a chronic illness like NTDs may experience poor sleep quality (45), family conflict (46), anxiety and depression (47), financial stress (48), and lower quality of life (49).

A matched case control study conducted in Chicago with (n=110) showed that mothers from the spinal bifida group had lower levels of parenting satisfaction, lower levels of perceived parental competence and higher levels of social isolation than mothers from able-bodied group. Mothers in the spinal bifida group also reported more denial, less active coping and less adaptability to change. Fathers from the spinal bifida group reported higher levels of psychological symptom and lower levels of parenting satisfaction than fathers from the able-bodied group with $p < .05$ (50).

A descriptive study conducted in Oklahoma (n=84) shows parents of pre-adolescent with spinal bifida are more tensioned than parents of healthy children. Moreover, these caregivers reports pessimism, greater doubt within their family roles and less family interrelation. Parents of children with shunt stated more anxiety (p-0.0015) and depression (p-0.0001). The level of anxiety was (p-0.027) higher in mothers than fathers (47)

Institution based study conducted in Turkish children parents (n=54) with spinal bifida reveal that the presence of SB has a negative impact on parents' psychological status and family functioning although there was no differences in depression whether they knew they are having children with SB before birth or not. Mothers depression scores were significantly higher than fathers ($p<0.001$) (51).

Institution based unmatched case control study conducted in Irbid, Jordan (n=200) showed the percentage of parents of infants with NTDs who had a clinically significant high stress was

much higher than controls group. 53.5% parents of infants with NTDs had clinically significant high stress. Being a mother (P = 0.001), Parents' lower education (P = 0.026), unemployed parents (P =0.01) and lower family income per month (P = 0.048) were significantly associated with increased parental distress (22).

Institution based cross sectional study accompanied in Malaysia, on mothers of children aged 1–18 years with (n=81) attending the spinal bifida clinics shows that more than a third of mothers of children experience clinically significant levels of parenting stress. Single-parent families were 8.6 times high likely stressed and parent using clean intermittent catheterization of bladder for their children were 3.5 times high likely to be stressed (36).

A study conducted using both quantitative and qualitative design in Uganda with 134 parents of children with spinal bifida shows 52.7% of the parents have stress. Stress outcomes were related to the inability to walk, incontinence, use of clean intermittent catheterization, bowel dysfunction, low household income, and not receiving rehabilitative care (52).

2.3 Social Impact of NTDs

NTDs are a source of high morbidity, distress, and severe physical, psychological and social handicaps (53). The impact of having a baby with spinal bifida or losing a baby born with anencephaly hurts emotionally, spiritually and financially. Most individuals who survive with NTDs have a multiple system handicaps and a limited life expectancy. Anencephaly which accounts for about one-third of cases is incompatible with life while spinal bifida, about two-thirds of NTDs, are associated with varying degrees of physical and mental disabilities even after treatment. Some of these are loss of bladder and bowel function, paralysis of the lower limbs and hydrocephalus (2). This handicap leads to huge physical, emotional, psychological, social and financial burdens on the patients, the affected families, the caregivers, the healthcare system, and the community as a whole (54,55).

A descriptive study conducted in London (n=63) parents with spinal bifida children, shows a close relationship between the adolescent's physical mobility and the social life of parents. 57.5 % of parents were able to lead a completely unrestricted social life of their own, 20% found it difficult and the remaining 22.5% had to make special arrangements (56).

A study conducted using both qualitative and quantitative study design in Canada on parents with urine and fecal incontinence revealed that both the parent and the children have social burden, isolation and caregivers also anxious about their children's self-worth (57).

A study conducted in Netherlands with 46 mothers and 37 fathers with spinal bifida shows mothers felt more restricted by their parenting role, less competent as a parent and more socially isolated than mothers in the reference group. Fathers also felt more restriction in parenting role (19).

A qualitative research conducted on neuro disable children in Malawi, indicate parents following brain injury of their children experienced barriers to care, support and social services (58).

A descriptive study conducted in Kenya (n=41) reveal that there is stigmatization on children with SB that has consequence on the quality of life of caring families. Half of mothers reported their child disability has a financial impact on the family. The disability also has adverse impact on their marriage. Three marriages had broken down as a result of the child's condition. Additionally urinary incontinence has negative impact on marriage (23).

A qualitative study conducted in Uganda on parents with hydrocephalus children revealed care givers were lack of social support either from their spouses, relatives and family members as a result of the child's condition and cultural constraints and stigma associated with hydrocephalus (59).

2.4 Conceptual framework

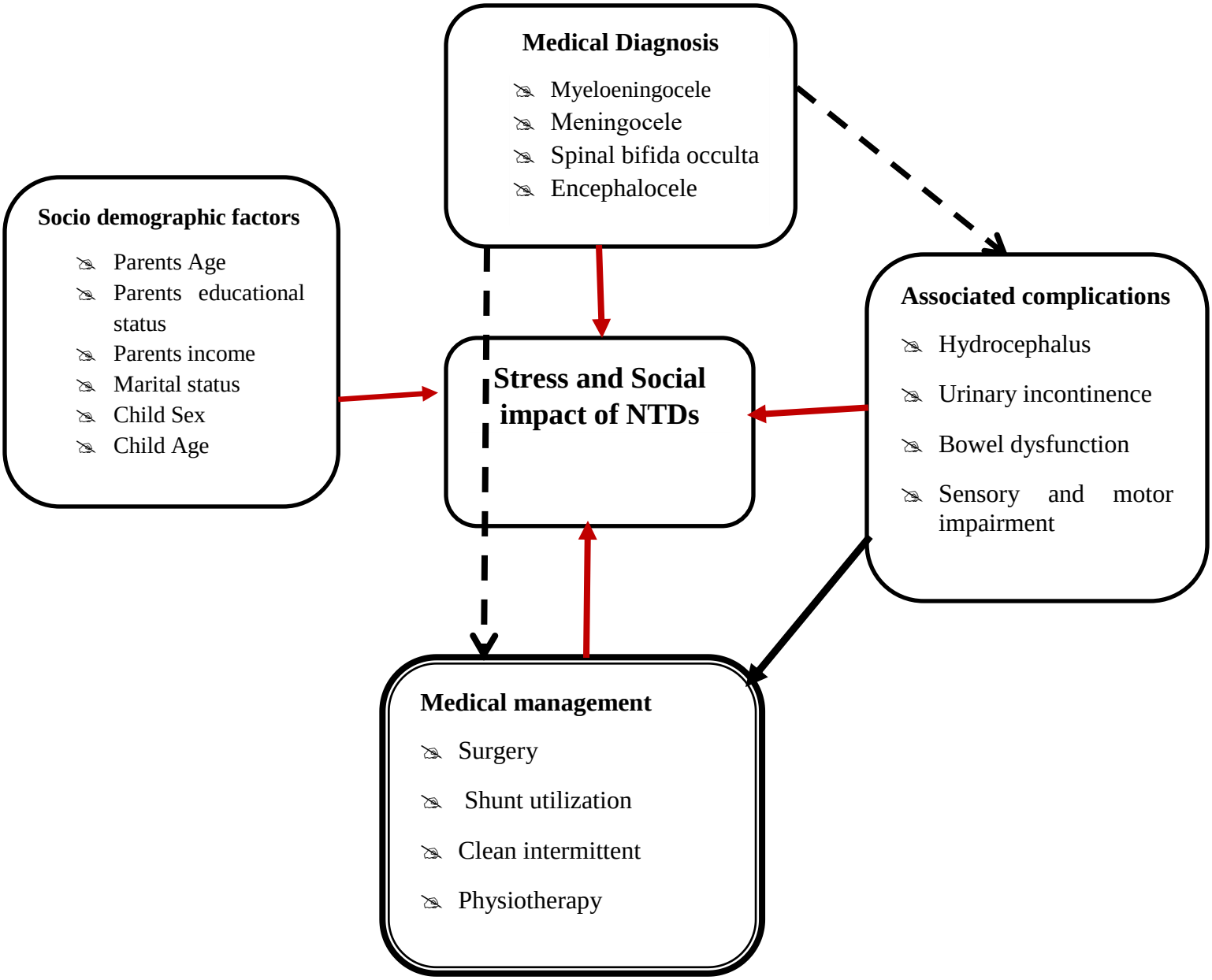

Figure 1 Conceptual framework developed after reviewing different literature on prevalence and predictors of stress and social impact among parents with Neural tube defect children who have follow up for their children in public hospitals, Addis Ababa, Ethiopia 2021 (2,7,8,18,23,52)

3. Objectives

3.1 General objective

- To assess prevalence and predictors of stress and social impact among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021.

3.2 Specific Objectives

- To determine prevalence of stress among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021.
- To determine prevalence of social impact among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021.
- To identify predictors of stress among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021.
- To identify predictors of social impact among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021.

4. Methods and materials

4.1 Study area and period

Addis Ababa is the capital city of Ethiopia. The City lies at an altitude of 7,546 feet (2,300metres). Based on 2017 population projection the total population of the city is 3,194,999. Among this 1,515,001 are men and the rest 1,679,998 are female. Addis Ababa has ten sub-cities. In this sub-cities there are 52 hospitals in which 6 are administered by Addis Ababa regional health bureau, 5 by federal ministry of health, 3 by NGO, 3 by defense and police and the remaining administered by private owners and there are 101 health centers (60). Out of 17 public hospitals NTDs treatment and follow up have been given in three hospitals namely, Zewditu memorial hospital, Yekatit 12 medical hospital and Saint Peter specialized hospital. Zewditu memorial hospital is one of AAU neurosurgical teaching hospital with 16 pediatric neurosurgical bed and an average follow up of 130 children with NTDs per month. Yekatit 12 medical college is one of the six Addis Ababa regional health bureau administered hospital. It has 10 neurosurgical inpatient bed and an average of 40 pediatrics neurosurgical follow up per month. Saint Peter hospital is one of federal ministry of health administered hospital. It has 12 neurosurgical inpatient bed and an average of 50 neurosurgical pediatric follow up per month. The study was conducted from March 9, 2021 to April 30, 2021.

4.2 Study design

An institutional-based cross sectional study was conducted.

4.3 Populations

4.3.1 Source Population

All parents who attend neurosurgical clinic for their children in selected public hospitals, Addis Ababa.

4.3.2 Study Population

Parents with NTDs children who attend neurosurgical clinic follow up during study period and who fulfill inclusion criteria in three selected public hospitals, Addis Ababa was included.

4.4 Eligibility Criteria

4.4.1 Inclusion criteria

Parents who came with age group between (1 month – 12 years) children during data collection period with diagnosis of myelomeningocele, meningocele, spinal bifida occulta and encephalocele.

4.4.2 Exclusion criteria

Parents who were diagnosed as mentally ill and unable to communicate or respond for the interview as a result of illness and children who come with relatives were excluded from this study.

4.5. Sample Size and Sampling Procedure

4.5.1. Sample Size Determination

Sample size is determined by using single population proportion formula considering the following assumptions;-

$$\boldsymbol{n = \frac{((Z\alpha/2)^2)P(1-P)}{d^2}}$$

n = minimum sample size required for the study

Z= standard normal distribution with confidence interval of 95%, Z=1.96

d = Absolute precision or tolerable margin of error d=0.05

P= is the anticipated population proportion

Sample size for stress and social impact is calculated. Since no similar study conducted previously 50% is taken for social impact and stress separately. Therefore

$$n = \frac{0.5(1-0.5)1.96^2}{(0.05)^2} = 384$$

The source population is < 10,000 so correction formula is used and by adding 10% non-response rate, the final sample size is 369.

4.5.2. Sampling technique and procedure

Three public hospitals were selected by purposive sampling technique. (Zewditu memorial hospital, Yekatit 12 hospital medical college, Saint Peter hospital) which have the only pediatrics public neurosurgical follow up clinics in Addis Ababa. Then to select the study participants from each hospital proportional allocation formula was used based on caseloads by fixing one-year total follow up prior to the survey. Simple random sampling was used to select the first participant and systematic random sampling was used for the next consecutive samples.

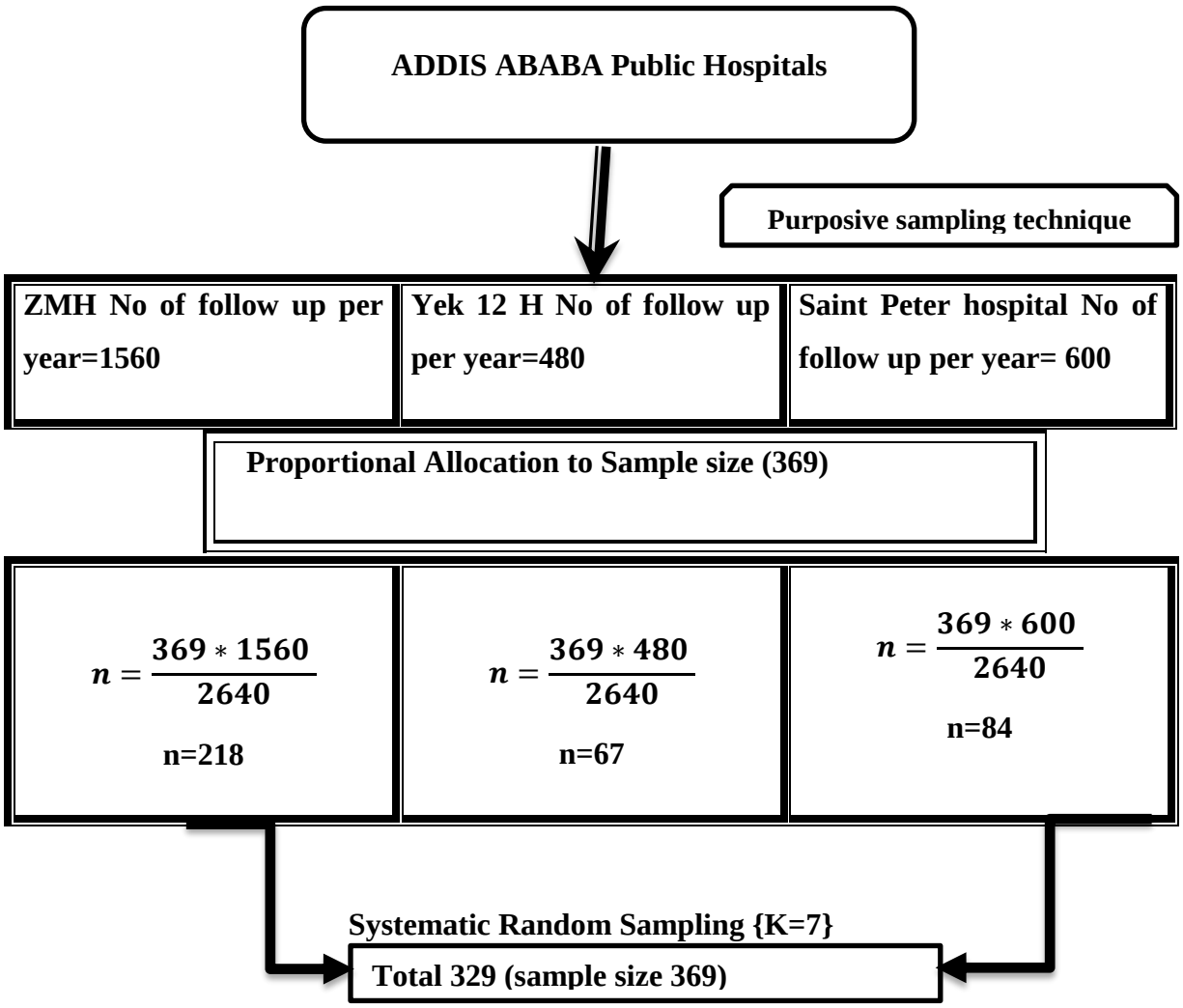

Figure 2 Schematic presentation of sampling procedure on prevalence and predictors of stress and social impact among parents with Neural tube defect children who have follow up in Addis Ababa public hospitals, Ethiopia 2021

4.6 Variables

4.6.1 Dependent Variables

- Stress among parents with neural tube defect children.
- Social impact among parents with neural tube defect children.

4.6.2 Independent Variables

- Socio-demographic characteristics like age, sex, marital Status, educational status, occupation, residency, and income.
- Medical diagnosis- myelomeningocele**,** meningocele**,** encephalocele and spinal bifida oculta.
- Associated complications- Hydrocephalus, inability to ambulate, urinary incontinence, bowel dysfunction.
- Medical management- Surgery, Shunt, physiotherapy and CIC.

4.7 Operational definitions

- NTDs- include meningocele, myelomeningocele, spinal bifida oculta and encephalocele.
- PSI- screening tool that helps providers and families identify the sources and different types of stress that come with parenting (61).
- Parental Distress (PD) - it is reflective of parents' personal adjustment to parenthood.
- Normal range of score for stress- that fall between 15 and 80 percent.
- High stress percent- scores from 81 to 89.
- Clinically significant stress percent- that falls 90-100 (61).
- Stress- high stress and clinically significant stress.
- MOS-SSS- is Social Support Survey that measures the availability of support if needed in several domain (62).
- Social impact- 'none of the time', 'a little of the time' and 'some of the time' in all scales MOS-SSS.
- No social impact- 'most of the time' and 'all of the time' in all scales of MOS-SSS.

4.8. Data Collection Procedure

4.8.1. Data collection tool and Data collection procedure

A structured questionnaire was used to collect data on socio-demographic characteristics (age, sex, education, occupation, marital status, income and residency) and other independent variables. The Amharic version of ‘‘PSI-SF ’’ was adapted to assess stress and MOS-SSS for social impact of neural tube defect on parents. The tools was translated to Amharic version for validated use in Ethiopia and retranslated to English for consistency. PSI-SF is a self-report screening tool that helps providers and families identify the sources and different types of stress that come with parenting. The scale developed in 1983 and revised to improve cultural sensitivity of language. It has three sub scales namely, Parent distress, parent-child dysfunctional interaction and difficult child. It is designed for parents of children ranging in age from 1 month to 12 years. The tool consists of child domain and parent domain. The parent domain consist of sense of competence, restriction of parental role, depression, relationship with spouse, role restriction, parent health that can be answered by means of a five-point Likert-type scale. Percentile scores that fall between 15 and 80 are considered typical stress which is normal. High stress scores for PD range from 81 to 84. Clinically significant levels of stress that need additional follow up are above 90.

Amharic version of MOS-SSS was adopted to assess social impact. It is one of the most popularly used instruments available in measuring social support which is developed by Sherbourne and Stewart in 1991. The tool have four sub scale, emotional\informational support, tangible support, affectionate support and positive social interaction support scale. Each items has a 5-point Likert response. Higher item score reflects high social support and low item score indicates low social support.

The data collection tool consists of part I socio-demographic factors, part II medical history, part III associated complication, part IV medical management, part V sense of competence, part VI restriction of parental role, part VII depression, part VIII relation of spouse, part IX parent health, part X emotional support, part XI Tangible support, part XII Affectionate support and part XIII Positive social interaction.

Three BSC nurse for data collection and two BSC nurse for supervision was recruited. Data was collected using interviewer administered technique. One day training was given to data collectors and supervisors regarding implication of the study, truthful completion of the tool and

ethical considerations to standardize the data collection. Supervision was held during data collection and each questionnaire was checked for completeness.

4.9. Data quality Assurance

To ensure quality of the data, supervisor and data collectors was trained and standardized structured questionnaire was used. Pre-test was conducted at Saint Paul hospital with 5% of sample size and Cronbach's α was used to check the reliability of the tools. The value of Cronbach's α was 0.889 PSI-SF, 0.988 for MOS-SSS and 0.787 for the entire tool. In addition to this deep discussion was conducted with data collectors to obtain honest and accurate response by assuring study units confidentiality, and also completeness and consistency of the data was cross checked during data collection and analysis.

4.10. Data processing and analysis

Collected data was entered and coded in Epi data v4.6 and transferred and cleaned using SPSS version 25 for analysis. Descriptive and inferential statistics was used to present the data. Descriptive statistics like frequency and percentage was used to summarize the socio-demographic characteristic of the study participants and also clinical characteristic. Both bivariate and multivariable logistic regression analysis was used to see the association between each independent variables and stress, and social impact of neural tube defect on parents. Those variables $p<0.25$ bivariate analysis was entered in multivariate analysis to identify independent predictors. Finally those variables which showed statistical significance at $P<0.05$ with 95% CI in the final model was reported as independently associated with stress and social impact. Final results is presented in texts, tables, chart and graphs.

4.11 Ethical Consideration

Ethical clearance was obtained from ethical review board of Addis Ababa University, College of Health Sciences and Addis Ababa health bureau. Ethical issues of the participants was addressed throughout the study. All participants of the study were provided with an informed consent, clearly stating the objectives of the study and their right to refuse and if there is any question they do not want to answer they have the right to not answer. All participants was randomly selected without any discrimination on any ground. Filled out questionnaires was carefully handled and all access to results was kept strictly to principal investigator.

4.12 Plan for dissemination of result

The findings of the study will be submitted to Addis Ababa University College of health science, school of nursing and midwifery. The findings of the thesis will be disseminated to Zewditu memorial hospital, Yekatit 12 hospital medical college and Saint Peter specialized hospital. An attempt will be made to publish the findings of this study in widely accessible national or international journals.

5. Result

Socio-demographic characteristics of Parent and children

369 Clients were contacted and 369 respondents gave a complete response with a response rate of 100 %. The mean age of the respondent was 29.38 ± 5.644. Majority of the respondents were mothers 81%. Among the respondents 95.7% were married, 70.2% had higher education, 43.6% were housewife and more than half of the respondents had average monthly income of > 2400 birr. 77.5% of the parent live in urban, among the children 57.7% were male and 19.5% of child age lies between 2-5 years.

Table 1 Socio-demographic characteristics of parents and children with neural tube defect who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Characteristics	**Frequency**	**Percent (%)**
Parent		
Mother	299	81
Father	70	19
Parent age		
18-35	324	87.8
36-55	45	12.2
Educational status of mother		
No formal education	66	17.9
Primary school	120	32.5
High school	79	21.4
Higher education	104	28.2
Educational status of father		
No formal education	43	11.7
Primary school	91	24.7
High school	80	21.6
Higher education	155	42

Occupation		
Government employee	98	26.6
Private employee	70	19
Daily labor	13	3.5
Housewife	161	43.6
Merchant	19	5.1
Other	8	2.2
Average monthly income		
<1500	47	12.7
1501-2400	30	8.1
>2400	292	79.2
Marital status		
Single	6	1.6
Married	353	95.6
Divorced	5	1.4
Widow	5	1.4
Residency		
Urban	286	77.5
Rural	83	22.5
Child sex		
Male	213	57.7
Female	156	42.3
Child age		
4 week-1 year	223	60.4
1-2 year	69	18.7
2-5 year	72	19.5
6-12 Years	5	1.4

Medical history of the children

Among the children who came for follow up 82.7% had myelomeningocele, 12.7% of them had menigocele and 4.6% had encephalocele. Only 0.3% of the parent had previous child with neural tube defect and 90.8% of the parent came for regular follow up.

Table 2 Medical history of children with neural tube defect who have follow up in public hospitals Addis Ababa Ethiopia 2021 (369)

Characteristics	Frequency	Percent (%)
Diagnosis		
Myelomeningocele	305	82.7
Menigocele	47	12.7
Encephalocele	17	4.6
Previous NTD child		
Yes	368	99.7
No	1	0.3
Regular follow up		
Yes	335	90.8
No	34	9.2

Associated complications of neural tube defect

Among the children with neural tube defect the study identified that 58.3% of the children were urine incontinent. The children who had bowel dysfunction were 42.8% and 69.9% of them were paraplegic.

Table 3 Associated complications of children with neural tube defect who have follow up in public hospitals Addis Ababa, Ethiopia 2021 (369)

Characteristics	**Frequency (N=369)**	**Percent (%)**
Urine incontinence		
Yes	215	58.3
No	154	41.7
Bowel dysfunction		
Yes	158	42.8
No	211	57.2
Unable to ambulate		
Yes	258	69.9
No	111	30.1

Medical management of neural tube defect children

Among the children who came for follow up significant majority had surgery. Shunt is inserted for only 22% of the children. 25.5% of the parent took their children to physiotherapy and 32% of the parent performs clean intermittent catheterization.

Table 4 Medical management of children with neural tube defect who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Characteristics	**Frequency (N=369)**	**Percent (%)**
Surgery		
Yes	336	91.1
No	33	8.9
Shunt		
Yes	81	22
No	288	78
Physiotherapy		
Yes	94	25.5
No	275	74.5
CIC		
Yes	118	32
No	251	68

Sense of competence among parents with neural tube defect children

This study indicates 69.1% of the parent feels their ability when they take care of their children. 38.5% face a lot of problem related to raising a disable child more than they expected and 36.6% of parents said being a parent was more difficult than they thought. 23.8% of the parent feel like they are a very good parent.

Table 5 Sense of competence of parents with neural tube defect children with follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Statement	Strongly disagree		Disagree		Not sure		Agree		Strongly agree	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
I feeling ability when I take care of my child	2	0.5	5	1.4	13	3.5	255	69.1	94	25.5
Facing a lot of problem related to raising a disable child more than I expected	3	0.8	71	19.3	16	4.3	142	38.5	137	37.1
When I become a parent, this is difficult than I thought	5	1.4	63	17.1	16	4.3	146	39.6	139	37.6
I can't make decision without help	3	0.8	81	22	21	5.7	222	60.2	42	11.3
When my child was diagnosed with this disease, I was in doubt about my ability	30	8.1	276	74.8	30	8.1	22	6	11	3

Restriction of parental Role among parents with Neural tube defect children

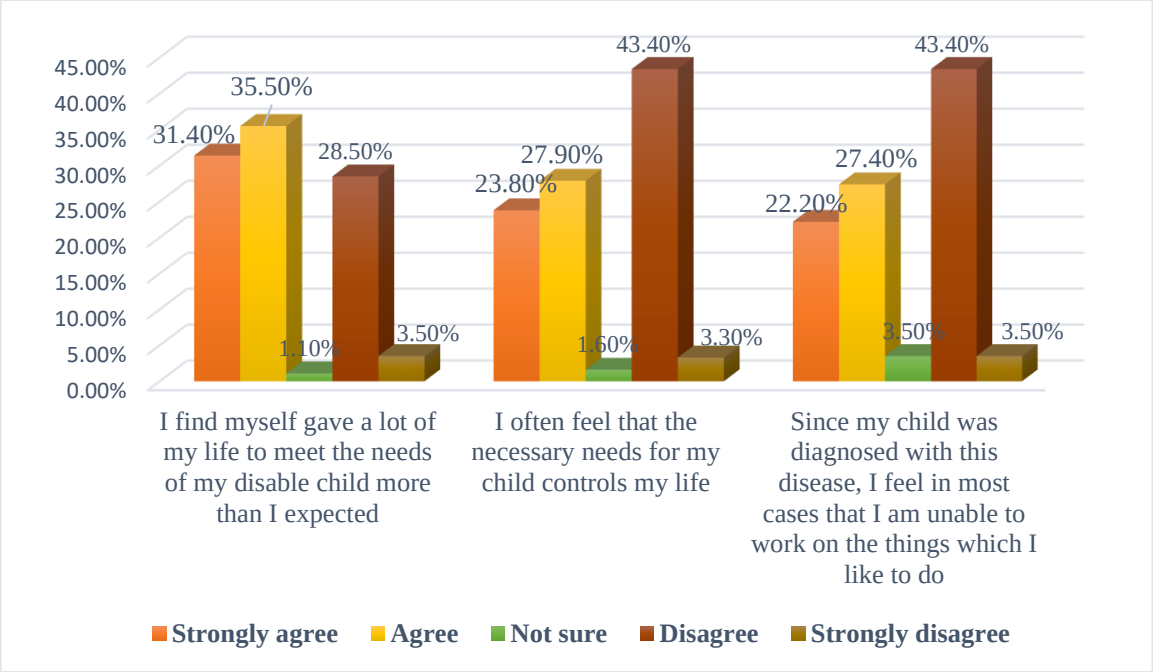

Figure 3 Restriction of parental role among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

This figure indicates 66.9% of the parent think they gave a lot of time to meet the need of their disable children, 51.7% of them also think that the necessary need of their disable children control their life and 49.6% of the parent were unable to work on things they used to after their child diagnosed with NTDs.

Depression among parents with Neural tube defect children

This study implies that 13.8% of the parent had sense of guilt about their self when they think of them self as a parent. 30.6% of the parent was not happy in recent periods. 24.9% felt sadness and depression more than they expected after knowing their children disease. 18.7% of the parent feel guilty when they get angry of their child and that bothers them.

Table 6 Depression on parents with neural tube defect children who have followed up in public hospitals, Addis Ababa, Ethiopia 2021 (n-369)

Statement	Strongly disagree		Disagree		Not sure		Agree		Strongly agree	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
When I look at myself as a parent, mostly I have sense of guilt	25	6.8	231	62.6	5	1.4	51	13.8	57	15.4
I'm not happy by anything I am doing in recent period	14	3.8	127	34.4	8	2.2	113	30.6	107	29
Every time my son does something wrong, I feel like that in fact was my fault	15	4.1	293	79.4	10	2.7	25	6.8	26	7
I often feel guilty about the way I feel about my child	14	3.8	287	77.8	7	1.9	37	10	24	6.5
I felt depression more than I expected after knowing my son's disease	11	3	166	45	2	0.5	92	24.9	98	26.6
I feel guilty when I get angry of my child and that bothers me	12	3.3	286	77.5	2	0.5	27	7.3	42	11.4

Relation of spouse among parents with Neural tube defect children

In this study 21% of the parent reported their spouse was not helping them as much as they expected since their child diagnosis and 16% said problem started to happen in their relationship. 18.2% of the parent also stopped sharing things together and they were not spending a lot of time with each other after their child diagnosis. 58.5% of the parent said their cost of living increased cause of their disable child and 36.2% of the parent had problem with their relatives since they got their diseased child.

Table 7 Relation of spouse among parent with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Statement	Strongly Disagree		Disagree		Not sure		Agree		Strongly agree	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
I have notice that since my child diagnosed with the disease my spouse doesn't give me help as much as I expected	37	10	190	51.5	0		64	17.3	78	21.2
As a consequence of my child's diseases, problems happened in my relationship with my spouse more than I expected	27	7.3	231	62.6	8	2.2	42	11.4	61	16.5
Since my child was diagnosed with the disease, I and my Husband (wife) became no longer sharing things together and no longer spend a lot of time with each other	31	8.4	199	53.9	16	4.3	56	15.2	67	18.2
It seems that the problems with relatives have been rising after we got our diseased child	23	6.2	206	55.8	5	1.4	92	24.9	43	11.7
Presence of disable child had increased the cost of living more than I expected	18	4.9	130	35.2	5	1.4	155	42	61	16.5

Parental health among parents with Neural tube defect children

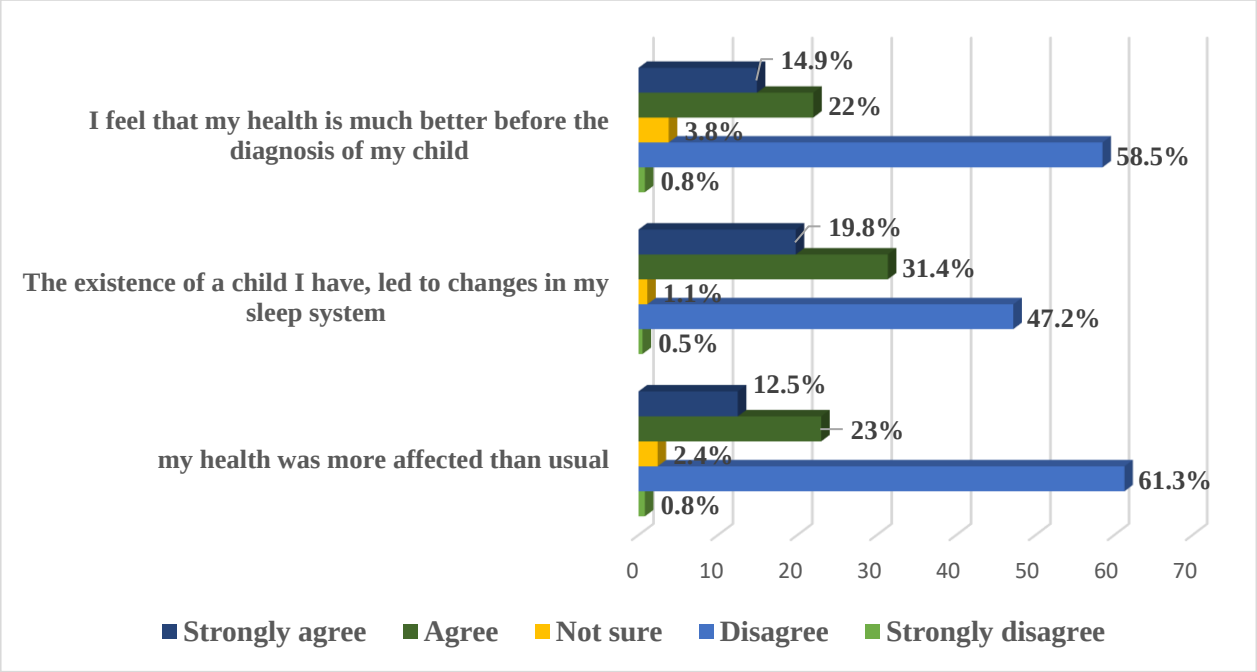

Figure 4 Parental health among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa Ethiopia

This study implies 35.5% of the parent health is more affected than usual after the diagnosis of their child and 51.2% of the respondents had change in their sleep pattern after their disabled child. 36.9% of the parent also feels their health was much better before their child diagnosed with NTDs.

Emotional support among parents with Neural tube defect children

In this study 81.3% of the respondent had no one to count on listening when they needed to talk and to give them information about the situation they are dealing with. 80.5% of the parent had no one to share their private worries with and 79.7% of the parent had no one to turn to for suggestions about how to deal with a personal problem.

Table 8 Emotional support among parents with neural tube defect children who have follow up for their children in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Statement	None of the time		A little of the time		Some of the time		Most of the time		All of the time	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Someone you can count on to listen to you when you need to talk	300	81.3	14	3.8	0		45	12.2	10	2.7
Someone to give you information to help you understand a situation	295	79.9	19	5.1	0		43	11.7	12	3.3
Someone to give you good advice about a crisis	296	80.2	17	4.6	0		41	11.1	15	4.1
Someone whose advice you really want	297	80.5	14	3.8	0		41	11.1	17	4.6
Someone to share your most private worries and fears with	297	80.5	14	3.8	0		41	11.1	17	4.6
Someone to turn to for suggestions about how to deal with a personal problem	294	79.7	17	4.6	0		38	10.3	20	5.4
Someone who understands your problem	296	80.2	15	4.1	0		37	10	21	5.7

Tangible support among parents with Neural tube defect children

In this study around 65% of the respondent had no one to help them if they were confined in bed and to take them if they need to see doctor. Despite that 33.1% of the parent sometimes had someone to deal with their daily tasks if they were sick and 54.4% of the parent had someone to prepare their meal if they were unable to do it.

Table 9 Tangible support of parents with neural tube defect children who have follow up for their children in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Statement	None of the time		A little of the time		Some of the time		Most of the time		All of the time	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Someone to help you if you were confined to bed	240	65	71	19.2	0		35	9.5	23	6.3
Someone to take you to the doctor if you needed it	237	64.2	74	20.1	0		41	11.1	17	4.6
Someone to prepare your meal if you were unable to do it yourself	239	64.8	72	19.5	0		42	11.4	16	4.3
Someone to help you with daily task if you were sick	56	15.2	104	28.2	122	33.1	44	11.9	43	11.6

Affectionate support among parents with Neural tube defect children

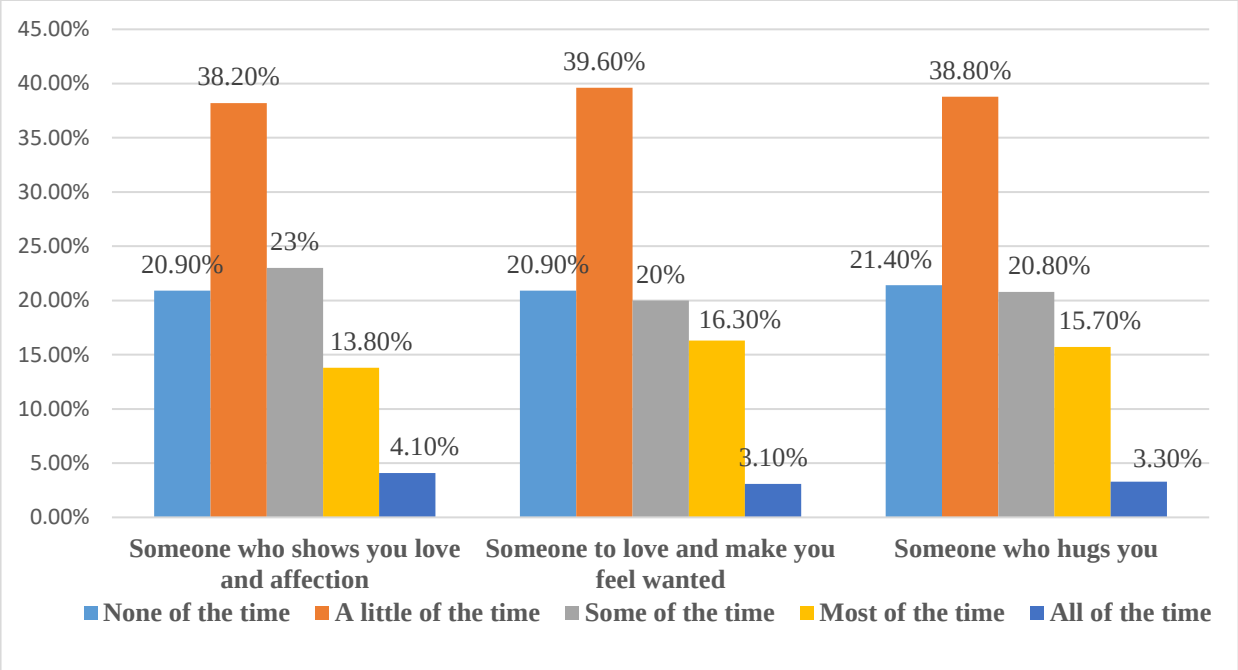

Figure 5 Affectionate support among parents with neural tube defect children who have follow up for their children in public hospitals, Addis Ababa, Ethiopia 2020 (n=369)

This figure implies 20.9% of the parent had no one to show them love and make them feel wanted. 38.8% of the respondents only had someone to hug and comfort them a little of the time.

Positive social interaction among parents with Neural tube defect children

This study identified 22% of parents had someone to have a good time with none of the time, and 38.8% of the parent had someone to do things with to get their mind off when they are in trouble and to do something enjoyable a little of the time.

Table 10 Positive social interaction among parents with neural tube defect children who have follow up for their children in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Statement	None of the time		A little of the time		Some of the time		Most of the time		All of the time	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Someone to have a good time with	81	22	147	39.8	72	19.5	56	15.2	13	3.5
Someone to do something enjoyable with	87	23.6	143	38.7	70	19	58	15.7	11	3
Someone to do things with to help you get your mind off things	88	23.8	143	38.8	70	19	59	16	9	2.4

Prevalence of stress and social impact

Out of 369 study participants 17.6% of the parent had stress and 26.3% had social impact. Among the total stressed parents 1.9% of the parent had clinically significant stress, 15.7% were highly stressed and 82.4% were typically stressed.

Predictors of stress and social impact

The result of multivariate logistic regression revealed that being mother, urine incontinence, shunt insertion and using clean intermittent catheterization had significant association with stress while higher parent age, bowel dysfunction, paraplegia, clean intermittent catheterization and shunt utilization were associated ($p<0.05$) with increased odds of social impact.

Mother with neural tube defect children had 3.28 times more likely stressed than fathers [AOR 3.28, 95% CI (3.110-9.730)].

Parents who had urine continent children were 49.7% times less likely to exhibit stress than parents who had children with urine incontinence [AOR 0.503, 95% CI (0.276-0.916)].

The likelihood of developing stress was 59.9% times less likely for parents using clean intermittent catheterization at home for their children than parents who don't [AOR 0.401, 95% CI (0.217-0.743)]. Despite that parents who use clean intermittent catheterization were 2.5 times high likely to have social impact than parents who don't use clean intermittent catheterization at home [AOR 2.565, 95% CI (1.409-4.671)].

The odds of developing stress for parents with shunt inserted babies were 0.594 times less likely than parents who had babies without shunt [AOR 0.406, 95% CI (0.211-0.779)] but 2.39 times high likely to have social impact [AOR 2.392, 95% CI (1.223-4.677)].

Parental age had a significant association with social impact. The odds of developing social impact for the age group 18-35 were 77.2% less likely compared to the age group 36-55 [AOR 0.228, 95% CI (0.1000-0.522)].

Parents with paraplegic children were 3.2 times high likely to have social impact than parents who have children who can ambulate by themselves [AOR 3.268, 95% CI (1.605-6.632)].

Parents who had bowel dysfunction children were 2.5 times high likely to have social impact than parents with stool continent babies [AOR 2.565, 95% CI (1.204-4.1023)].

Table 11 Bivariate and multivariate logistic analysis result of stress among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Variables	**STRESS**		Sig	COR (95%)	AOR (95%)
	YES	**NO**			
Parent					
Mother	61(20.4%)	238(79.6)	0.045	2.36(2.031-6.741)*****	**3.28(3.110-9.730)****
Father	4(5.7%)	66(94.3%)		1	1
Urine continent					
Yes	35(22.7%)	119(77.3%)	0.025	0.551(0.322-0.945 *****	**0.503(0.276-0.916)****
No	30(14%)	185(86%)		1	1
CIC					
Yes	35(29.7%)	83(70.3%)	0.04	0.322(0.186-0.557)*****	**0.401(0.217-0.743)****
No	30(12%)	221(88%)		1	1
Shunt					
Yes	26(32.1%)	55(67.9%)	0.007	0.331(0.186-0.589)*****	**0.406(0.211-0.779)****
No	39(13.5%)	249(86.5%)		1	1

* ($p<0.25$), ** Significant association ($p<0.05$) COR- Crudes Odds Ratio, AOR- Adjusted Odds Ratio, CI- Confidence Interval

Table 12 Bivariate and multivariate logistic analysis result of social impact among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021 (n=369)

Variables	**Social Impact**		**Sig**	**COR(95%CI)**	**AOR(95%CI)**
	Yes	**No**			
Parent age					
18-35	74(22.8%)	250(77.2%)	0.01	0.283(0.149-0.537)*****	**0.228(0.1000-0.522)****
36-55	23(51.1%)	22(48.9%)		1	1
Paraplegia					
Yes	60(23.3%)	198(76.9%)	0.001	1.650(1.012-2.691)*****	**3.268(1.605-6.632)****
No	37(33.3%)	74(66.7%)		1	1
Bowel dysfunction					
Yes	48(30.4%)	110(69.2%)	0.011	1.443(0.905-2.299)*****	**2.565(1.204-4.1023)****
No	49(23.2%)	162(76.8%)		1	1
CIC					
Yes	51(43.2%)	67(56.8%)	0.002	3.392(2.089-5.508)*****	**2.565(1.409-4.671)****
No	46(18.3%)	205(81.7%)		1	1
Shunt					
Yes	34(42%)	47(58%)	0.011	2.584(1.533-4.359)*****	**2.392(1.223-4.677)****
No	63(21.9%)	225(78.1%)		1	1

* ($p<0.25$), ** Significant association ($p<0.05$) COR- Crudes Odds Ratio, AOR- Adjusted Odds Ratio, CI- Confidence Interval

6. Discussion

Discussion on stress among parents with neural tube defect children

The overall prevalence of stress among parents with neural tube defect children were 17.6%. This result is lower than a study conducted in Uganda 52.7% (52) and Jordan 53.5% (22). The difference might be explained by, study design and sample size difference and the tool used to assess stress.

Mothers were found to be stressed than fathers. This result is supported by other studies conducted in Oklahoma (47), Turkey (51) and Malaysia (36). This could be explained by mothers are primary caregivers and they are more involved in the caring of a sick child that might increase parental stress.

Severity level and symptoms of the children go hand in hand with the stress level of the parents. For instance, parents with urine incontinent children were found to exhibit stress. This report is supported with a study conducted in Uganda (52). This could be explained by bladder dysfunctions have direct consequences for the child's participation in day-to-day activities and social relationships that bother their parents significantly (63).

Level of intervention and treatment of the children were also factors that determine how parents react to their children's situation. Parents worried less if their children get better treatment. For instance, parents with shut inserted babies were less likely to be stressed than parents without shunt inserted babies. This might be shunt surgery helps children who have hydrocephalus live full and successful lives in so many ways. Another explanation for this could be kids diagnosed and treated in early infancy from hydrocephalus have comparable head size to their peers and following the surgery, children can participate in most day-to-day activities without any major difficulties which give relief for their parents (64).

One of the home treatment that was found to alleviate parent's stress levels is the use of clean intermittent catheterization (CIC). CIC reduce leakage of urine, decreases kidney infection and maintains long-term protection of kidney which in turn reduces parental stress (65). This study negate by a research conducted in Uganda (52) and Malaysia (36).

Discussion on social impacts among parents with neural tube defect children

The overall prevalence of social impact among parents with neural tube defect children were 26.3%. These means 26.3% of the parent had no emotional, tangible and affectionate support and they also had no positive social interaction with their close ones which can leads to social impact.

Parents with paraplegic children were vulnerable to have social impact. This result is supported by a study conducted in London (56). This report could be explained by life in families of children with neural tube defect is restricted by the children needs of assistance with mobility and the length of time needed for basic activities which will have social impact for the parent (20).

Complication of neural tube defect had positive significant association with social impacts. For example, parents of children with bowel dysfunction exhibit social impact. This study is consistent with a study conducted in Canada (57). This might be explained by children with bowel incontinence are easily isolated from society and this will have social impact on parents.

Parents who use clean intermittent catheterization were prone to develop social impact. This might be explained by lack of community awareness about the disability and its's rehabilitative care, inaccessibility of suitable place for catheterization outside home, the parent should be nearby to practice catheterization and ill-managed catheterization can also cause social impact as the child would be wet and smelly.

Social impact for parents who had children with shunt was higher. This is consistent with a study conducted in Uganda (59). This might be explained by lack of community awareness about shunt that might leads to discrimination and stigma to the parent.

7. Conclusion

Prevalence of stress and social impacts among parents with neural tube defect children were 17.6% and 26.3% respectively. Stress was associated with motherhood, urine incontinence, shunt insertion and using clean intermittent catheterization while higher parent age, bowel dysfunction, paraplegia, using clean intermittent catheterization and shunt utilization were associated with social impact.

8. Recommendation

Based on this study its help full to recommend the following effort from

Ministry of health, and Regional health bureau

- NTDs prevention should be incorporated as part of ANC follow up and our ANC follow up should be revised. Even though the children have been treated vigorously, the parents are still suffering from stress and social impact. So we should be meticulous on prevention, early detection and early management of neural tube defect.
- Reusable catheters, enema equipment and shunt should be available in neuro-surgical treatment centers with adequate amount.
- Emphasis should be given in creating community awareness by broadcasting and press about neural tube defect, its complication and its impact on parents, community and on the country.
- Neural tube defect management should incorporate psychological support to the parents. Until then our treatment of neural tube defect children will be unremarkable.

Health care providers

- Health care worker should inform parents who have children with neural tube defect as early as possible and in detail of the difficulties that their children will experience in the future during ANC visit. So they can make informed decision by analyzing the risk and benefit.
- Health care providers who are working in neuro-surgical unit should detect stress and link the parent to psychiatry clinic for evaluation, psychotherapy and treatment if needed.
- Clean Intermittent Catheterization and enema training should be given to parents so that stress and social impact will decline.

NGO

- Nongovernmental organizations should establish and mobilize peer association of parents with neural tube defect children for experience sharing, creating community awareness to reduce their stress and social burden.
- Nongovernmental organization should be involved in ambulatory device, catheterization and enema equipment donation.

Researchers

- This topic is not well investigated in our country, so researchers should give high emphasis on doing both qualitative and quantitative research with including of those factors which are not addressed in this study such as, knowledge of having children with neural tube defect before birth, access to ambulatory device, enema utility, learning disabilities in the children needs to be studied.
- Further research should be conducted on family functioning, marital and financial impacts, anxiety, depression and other mental illness among parents with neural tube defect children that will help to revise our ANC follow up policy.

9. Strength of the study

- It is new area of study; since there is no documented data available on this topic.
- The study had high response rate.

10. Limitation of the Study

- Since it is a hospital based study it makes it difficult to conclude for the general population.
- If it was qualitative study rather than quantitative deep information will be collected.

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12. Annexes

Annex 1: Information Sheet (English version)

Hello

My name is Eyerusalem Tamiru; I am MSc student at Addis Ababa university collage of health science, department of nursing and midwifery. I am conducting a research on prevalence and predictors of stress and social impact among parents with neural tube defect children in Zewditu Memorial hospital, Yekatit 12 medical college hospital and Saint Peter hospital. The aim of the study is to collect information regarding prevalence and predictors of stress and social impact among parents with Neural tube defect children who have follow up for their children in public hospitals, Addis Ababa, Ethiopia 2021. The study will not give any direct benefits to the participants but the information which will be obtained from you will help the researcher to recommend the government and other NGOs to design appropriate interventions to address the problems. The study will not impose any risk and participation is based on your consent and you can quit from giving answers to the questions any time you want. The information's that you give us will not be accessed by anyone other than the study team and will be confidential. If you are willing the interview may take 20-30 minute and we can proceed. If you have any questions regarding the study, you can contact the following individual.

1. Eyerusalem Tamiru- Phone Number;- +251910421282

Do I have your permission to continue?

Yes ____

No ____

Interviewer: Name_____ signature: _____date: _____

Annex 2 English Versions Questionnaire prevalence and predictors of stress and social impact among parents with neural tube defect children who have follow up in public hospitals, Addis Ababa, Ethiopia 2021

PART I: - Socio-demographic factors			
No	**Socio-demographic information**	**Possible answers**	**Remark**
101	Parent	1. Mother 2. Father	
102	Age of the parent	____Years	
103	Educational status of the mother	1) No formal education 2) Primary Education 3) Secondary Education 4) Higher education	
104	Educational status of the father	1) No formal education 2) Primary Education 3) Secondary Education 4) Higher education	
105	Occupation of mother\father	1) Government Employee 2) Private employee 3) Merchant 4) Daily labor 5) House Wife 6) Other, Specify _____	
106	Average Monthly income	_____ ETB	
106	Marital status	1. Single 2. Married 3. Divorced 4. Widow	
107	Residency	1) Urban 2) Rural	
108	Child sex	1. Male 2. Female	
109	Child Age	_____ months _____ years	
PART II: - Medical history			
201	Do you have history of previous NTDs child?	1) Yes 2) No	
201	Diagnosis	1. Myelomeningocele 2. Meningocele 3. Spinal bifida occulta 4. Encephalocele 5. Other specify, _____	

201	Are you coming for a regular checkup?	1) Yes 2) No	

PART III Associated complications			
No		**Possible Answer**	**Remark**
301	Does your child have urinary incontinence?	1) Yes 2) No	
302	Does your child have bowel dysfunction?	1) Yes 2) No	
303	Does your child ambulate by himself\herself?	1) Yes 2) No	

PART IV Medical Management			
No		**Possible Answer**	**Remark**
401	Is surgery done	1) Yes 2) No	
402	Is shunt inserted?	1) Yes 2) No	
405	Do you use Clean Intermittent catheterization for your child?	1) Yes 2) No	
406	Do you take your child for physiotherapy?	1) Yes 2) No	

PSI-SF (Stress questionnaire)

Part V: Sense of Competence

No	Questions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
501	When my child was diagnosed with this disease, I was in doubt about my ability to perform my duties and my obligations as a parent					
502	When I became a parent, this was more difficult than I thought					
503	I feel my ability when I take care of my child					
504	I cannot make decisions without help					
505	I have lot of problems related to raising a disable child more than I expected					
506	I feel like I am: 1. A Very good mother (father) 2. Better than most mothers (fathers) 3. Like most mothers (fathers) 4. Worse than others					

Part VI: Restrictions of parental role

No		Strongly agree	Agree	Not sure	Disagree	Strongly Disagree
601	I find myself gave a lot of my life to meet the needs of my disable child more than I expected					
602	I often feel that the necessary needs for my child controls my life					
603	Since my child was diagnosed with this disease, I feel in most cases that I am unable to work on the things which I like to do					

Part VII: Depression

No		Strongly agree	Agree	Not sure	Disagree	Strongly disagree
701	When I look at myself as a mother (father), I mostly have a sense of guilt or feeling bad about myself					
702	I'm not happy by anything I am doing in recent period					
703	When my child acts improperly or overly induces a state of agitation or chaos, I feel my responsibility for that as if I did not do anything properly					
704	Every time my son does something wrong, I feel like that in fact was my fault					
705	I often feel guilty about the way I feel about my son					
706	I felt sadness and depression more than I expected after knowing my son's disease					
707	I feel guilty when I get angry of my son and that's what bothers me					
708	One month after my son was diagnosed with the disease, I noticed that I felt sad and depressed more than I expected					

Part VIII: Relation of Spouse

No		Strongly agree	Agree	Not sure	Disagree	Strongly disagree
801	I've noticed that since my child was diagnosed with the disease, My husband (wife) does not give me help as much as I expected					
802	As a consequence of my child's diseases, problems happened in my relationship with my husband (wife) more than I expected					
803	Since my child was diagnosed with the disease, I and my Husband (wife) became no longer sharing things together and no longer spend a lot of time with each other					
804	It seems that the problems with relatives have been rising after we got our diseased child					
805	The presence of disable child had increased the cost of living more than I expected					

Part IX Parent health						
No		**Strongly agree**	**Agree**	**Not sure**	**Disagree**	**Strongly disagree**
901	During the past six months, my health was more affected than usual or I had more aches and pains than I have under normal circumstances					
902	The existence of a child I have, led to changes in my sleep system					
903	I feel that my health is much better before the diagnosis of my child					
904	Since my child was diagnosed with the disease 1. I became significantly ill 2. I never felt that my health is good 3. I didn't notice any changes in my health					

No	MOS-SSS (Social impact questionnaire) **PART X Emotional\ informational support**					
		None of the time	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
1001	Someone you can count on to listen to you when you need to talk					
1002	Someone to give you information to help you understand a situation					
1003	Someone to give you good advice about a crisis					
1004	Someone to confide in or talk to about yourself or your problems					
1005	Someone whose advice you really want					
1006	Someone to share your most private worries and fears with					
1007	Someone to turn to for suggestions about how to deal with a personal problem					
1008	Someone who understands your problems					

No	PART XI Tangible support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1101	Someone to help you if you were confined to bed					
1102	Someone to take you to the doctor if you needed it					
1103	Someone to prepare your meals if you were unable to do it yourself					
1104	Someone to help with daily tasks if you were sick					

No	PART XII Affectionate support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1201	Someone who shows you love and affection					
1202	Someone to love and make you feel wanted					
1203	Someone who hugs you					

No	PART XIII Positive social interaction					
		None of the time	A little of the time	Some of the time	Most of the time	All of the time
1301	Someone to have a good time with					
1302	Someone to do something enjoyable with					
1304	Someone to do things with to help you get your mind off things					

Annex 3: Information Sheet (Amharic version)

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ሰላም

ስሜ እየሩሣሌም ታምሩ ይባላል፡፡በአዲስ አበባ ዩኒቨርስቲ፣የነርሲንግ እና አዋላጅነት ትምህርት ክፍል ውስጥ የድህረ ምረቃ ተማሪ ስሆን በዘውዲቱ መታሰቢያ ሆስፒታል፤ በ የካቲት 12 ሆስፒታል እና ሆስፒታል እና ቅዱስ ጴጥሮስ ስፔሻላይዝድ ሆስፒታል አዲስ አበባ ኢትዮጵያ ውስጥ በ 2021 የህብለሰረሰር ትቦ አለመግጠም በቤተሰብ ላይ የሚስከትለውን ጭንቀት እና ማህበራዊ ተፅዕኖ በማጥናት ላይ እገኛለሁ፡

የጥናቱ አላማም በህብለሰረሰር ትቦ አለመግጠም ምክንያት የሚመጣውን ጭንቀት እና ማህበራው ጫና አስመለክቶ መረጃ መሰብሰብ ሲሆን ከዚህም በተጨማሪ የጥናት ውጤት ለሚመለከታቸው አካላት ደርሶ የህብለሰረሰር ቱቦ አለመግጠም ችግር ላለባቸው ህፃናት ቤተሰቦች የስነ ልቦና እና ማህበራዊ ድጋፍ ለማድረግ ይጠቅማል፡፡ ጥናቱም ለተሳታፊዎቹ ቀጥተኛ የሆነ ጠቀሜታ የማይኖረው ሲሆን ከእናንተ የሚገኘው መረጃ ግን ተመራማሪው የመንግስት እና ሌሎች መንግስታዊ ያልሆኑ አካላት ችግሩን ለመፍታት የሚያስችል ተገቢ የሆነ እርምጃ እንዲወስዱ ምክረ ሀሳብ ለመስጠት ይረዳዋል፡፡ ጥናቱ በተሳታፊዎች ላይ ምንም አይነት አደጋ የማያስከትል ሲሆን የሚከናወነው በተሳታፊዎች ፈቃደኝነት ተመስርቶ በመሆኑ በማንኛውም አይነት ጊዜ ለጥያቄዎቹ ምላሽ አልሰጥም ብለው ማቋረጥ ይችላሉ፡፡ የሚሰጡንን መረጃ ከአጥኚው ቡድን ውጭ ማንም ሰው የማያየው ሲሆን በሚስጢር ይያዛል እንዲሁም ፈቃደኛ ከሆኑ ቃለመጠየቁ ከ 20-30 ደቂቃዎች ውስጥ ሊከናወን ይችላል፡፡ ስለሆነም መቀጠል እንችላለን፡፡የመረጃ ሰነድ ስለጥናቱ በቂ የሆነ መረጃ መረዳት በምችለው ቋንቋ ተሰጥቶኝ በፈቃደኝነት በጥናቱ ለመሳተፍ ተስማምቻለሁ፡፡በተጨማሪም በማንኛውም ጊዜ ቃለ መጠይቁን ማቋረጥ እንደምችል እና በዚሁም ምንም አይነት ጉዳትእንደማይደርስብኝ ወይም ጥቅም እንደማያጎልብኝ ተረድቻለሁ፡፡

1. አዎ ከሆነ ወደ ሚቀጥለው ጥያቄ ሂድ

2.አይደለም ከሆነ ተሳትፊውን በማመስገን ወደ ሚቀጥለው ተሳተፊ ሂድ

የመረጃ ሰብሳቢው ስም ፊርማ _____

መረጃው የተሰጠበት ቀን _____

Annex 4: Questionnaire (Amharic Version)

መጠየቅ

ክፍል ፩ የወላጆች እና የህጻናት ማህበራዊ እና ሥነ-ህዝብ መጠይቆች		
101	ወላጅ	1. እናት 2. አባት
102	የወላጅ እድሜ	_____ አመት
103	የእናት የትምህርት ደረጃ	1. ያልተማረች 2. የመጀመርያ ደረጃ 3. ሁለተኛ ደረጃ 4. ኮሌጅና ከዚያ በላይ
104	የአባት የትምህርት ደረጃ	1. ያልተማረ 2. የመጀመርያ ደረጃ 3. ሁለተኛ ደረጃ 4. ኮሌጅና ከዚያ በላይ
105	የወላጅ ስራ	1. የመንግስት ሰራተኛ 2. የግል ሰራተኛ 3. ነጋዴ 4. የቀን ሰራተኛ 5. የቤት እመቤት 6. ሌላ ካለ _____
106	ወርሀዊ አማካይ ገቢ	_____
107	የትዳር ሁኔታ	1. ያላገባ 2. ያገባ 3. የፈታ 4. የሞተበት
108	የመኖርያ ቦታ	1. ከተማ 2. ገጠር
109	የህፃኑ ጾታ	1. ወንድ 2. ሴት

110	የህፃኑ እድሜ	_____
ክፍል ፪ የህክምና ታሪክ		
201	ከዚህ በፊት የህብለ-ሰረሰር ቱቦ አለመግጠም ችግር ያለበት ልጅ አለዎት?	1. አዎ 2. አይ
202	የአጉኑ ልጆት የህመም አይነት	1. ማይሎሜኔንጎ ሴሌ 2. ሜኔንጎ ሴሌ 3. ስፓይናል ባይፊዳ ኦኩላታ 4. ኢንሴፋሎሴል 5. ሌላ _____
203	ሁልግዜ ለክትትል ይመጣሉ	1.አዎ 2. አይ
ክፍል ፫ ተያያዥ ችግሮች		
301	ልጅዎ ሽንቱን መቆጣጠር ይችላል?	1. አዎ 2. አይ
302	ልጅዎ ሰገራውን መቆጣጠር ይችላል?	1. አዎ 2. አይ
303	ልጅዎ በራሱ መንቀሳቀስ ይችላል?	1. አዎ 2. አይ

ክፍል ፬ የህክምና እርዳታ

401	የቀዶ ህክምና ለልጆ ተሰርቶለታል?	1. አዎ 2. አይ
402	ቀጭን ቱቦ በልጆ ጭንቅላት ዉስጥ ገብቶለታል?	1. አዎ 2. አይ
405	በቤት ዉስጥ ልጆን ለማሸናት የሽንት ማሸኛ ቱቦ ይጠቀማሉ?	1. አዎ 2. አይ
406	ልጅዎን የአካል እንቅስቃሴ ህክምና የሚሰጥበት ቦታ ይወስዳሉ?	1. አዎ 2. አይ

ክፍል ፭ የብቁነት ስሜት						
	ጥያቄ	በጣም እስማማለሁ	እስማማለሁ	እርግጠኛ አይደለሁም	አልስማማም	በጣም አልስማማም
501	ልጄን ስንከባከብ ብቁ እንደሆንኩ ይሰማኛል					
502	ከልጄ ህመም ጋር ተያይዞ ከጠበቅኩት በላይ ብዙ ችግር ገጥሞኛል					
503	ቤተሰብ መሆን ካሰበኩት በላይ ከባድ ነው					
504	ያለሰው እርዳታ ውሳኔ መወሰን አልችልም					
505	ልጄ ይዤ ህመም ከገጠመው በኃላ የቤተሰብ ኃላፊነቴንና ግዴታዬን በትክክል መወጣቴን እጠራጠራለሁ					
506	እኔ የሚሰማኝ 1. በጣም ጥሩ ወላጅ እንደሆንኩኝ ነው 2. ከሌሎቹ የተሻልኩ ወላጅ እንደሆንኩኝ 3. እንደ አብዛኛዎቹ ወላጅ እንደሆንኩኝ 4. ከሌሎች የከፋሁ ወላጅ እንደሆንኩኝ					

ክፍል ፮ የቤተሰባዊ ሚና ክልከላ						
	ጥያቄ	በጣም እስማማለው	እስማማለው	እርግጠኛ አይደለሁም	አልስማማም	በጣም አልስማማም
601	ካሰብኩት በላይ እራሴን ህመም የገጠመውን ልጄን ፍላጎት ለማሟላት ብዙ ጊዜዬን ሰጥ አገኘዋለሁ					
602	ብዙ ጊዜ የልጄ አስፈላጊ ነገሮች ህይወቴን እንደተቆጣጠሩት ይሰማኛል					
603	ልጄ ይዤ ህመም ከገጠመው በኋላ በአብዛኛው ጉዳይ መስራት የምፈልጋቸውን ነገሮች መስራት አልቻልኩም					

ክፍል ፯ ድባቴ						
	ጥያቄ	በጣም እስማማለው	እስማማለው	እርግጠኛ አይደለሁም	አልስማማም	በጣም አልስማማም
701	እራሴን እነደቤተሰብ ሳየው ብዙ ጊዜ የጥፋተኝነት ስሜት ይሰማኛል					
702	በቅርብ ጊዜ በማደርጋቸው ነገሮች ሁሉ ደስተኛ አይደለሁም					
703	ልጄ ጥፋት ሲያጠፋ የኔ ጥፋት እንደሆነ ይሰማኛል					
704	ብዙ ጊዜ ስለ ልጄ በማስበው ነገር ራሴን ወቅሳለው					
705	የልጄን ህመም ካወቅኩኝ በኋላ ካሰብኩት በላይ ንዴት እና ድብርት ይሰማኛል					
706	በልጄ ስለምናደድበት ጥፋተኝነት ይሰማኛል ፤ እና ይዤ ነገር ያሳስበኛል					

ክፍል ፰ ከትዳር አጋርዎ ጋር ያሎት ግንኙነት						
	ጥያቄ	በጭራሽ	አልፎ አልፎ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ
801	ልጄ ይህ ህመም ከገጠመው በኋላ የትዳር አጋሬ ያሰብኩትን ያህል እያገዘኝ አይደለም					
802	ከልጄ ህመም በኋላ ካሰብኩት በላይ ከትዳር አጋሬ ጋር ባለኝ ግንኙነት ችግር መፈጠር ጀምሯል					
803	ልጄ ህመም ከገጠመው በኋላ ከትዳር አጋሬ ጋር ብዙ ጊዜ ማሳለፍ እና ነገሮችን መጋራት አቁመናል					
804	ከልጄ ህመም በኋላ ከዘመዶቻችን ጋር ያለን ግንኙነት ችግር ላይ ወድቋል					
805	የልጄ ህመም ካሰብኩት በላይ የኑሮ ወጪያችንን ጨምሮታል					

ክፍል ፱ የቤተሰብ ጤንነት						
	ጥያቄ	በጭራሽ	አልፎ አልፎ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ
901	ባለፉት ስድስት ወራት ጤንነቴ ከሌላው ጊዜ በበለጠ ተቃውሷል					
902	የልጄ ህመም የእንቅልፍ ሁኔታዬን ቀይሮታል					
903	ጤንነቴ ከልጄ ህመም በፊት ጥሩ እንደሆነ ይሰማኛል					

904	ከልጄ ህመም በኋላ; 1. በጣም መታመም ጀምሬያለው 2. ጤናዬ ጥሩ እንደሆነ አይሰማኝም 3. በጠናዬ ላይ ምንም ለውጥ አልመጣም					

ክፍል ፤ የመረጃ እርዳታ						
	ጥያቄ	ምንም ጊዜ	ትንሽ ጊዜ	አንዳንድ ጊዜ	አብዛኛውን ጊዜ	ሁል ጊዜ
1001	ማውራት ስትፈልጉ የሚሰማችሁ ሰው አለ					
1002	አሁን ያላችሁበትን ሁኔታ ለመረዳት መረጃ የሚሰጣችሁ ሰው አለ					
1003	ችግር ላይ ስትሆኑ ጥሩ ምክር የሚሰጣችሁ ሰው አለ					
1004	ምክሩን በጣም የምትፈልጉት ሰው አለ					
1005	የግል ጭንቀታችሁን እና ፍረሃታችሁን የምታካፍሉት ሰው አለ					
1006	የግል ችግራችሁን ሃሳብ እና መፍትሄ ለማግኘት የምትሄዱበት ሰው አለ					
1007	ችግራችሁን የሚረዳችሁ ሰው አለ					

ክፍል ፲፩ የሚጨበጥ ድጋፍ						
	ጥያቄ	ምንም ጊዜ	ትንሽ ጊዜ	አንዳንድ ጊዜ	አብዛኛውን ጊዜ	ሁል ጊዜ
1101	ታማችሁ አልጋ ላይ ብትሆን የሚያግዛችሁ ሰው አለ					
1102	ህክምና ቢያስፈልጋችሁ ወደ ሀኪም የሚወስዳችሁ ሰው አለ					
1103	ምግብ ማዘጋጀት ባይችሉ የሚያበስልልዎት ሰው አለ					
1104	ቢታመሙ የእለት ተእለት ተግባሮትን ለማድረግ የሚያግዝዎት ሰው አለ					

ክፍል ፲፪ የፍቅር ድጋፍ						
	ጥያቄ	ምንም ጊዜ	ትንሽ ጊዜ	አንዳንድ ጊዜ	አብዛኛውን ጊዜ	ሁል ጊዜ
1201	ፍቅር እና ወዳጅነት የሚያሳይዎት ሰው አለ					
1202	የሚወዱት እና ተፈላጊነት እናዳልዎት እንዲሰማዎ የሚያደርግ ሰው አለ					
1203	ሲከፋዎት አቅፎ የሚያፅናና ሰው አለ					

ክፍል ፲፫ የተሟላ ማህበራዊ ግንኙነት						
	ጥያቄ	ምንም ጊዜ	ትንሽ ጊዜ	አንዳንድ ጊዜ	አብዛኛውን ጊዜ	ሁል ጊዜ
1301	ጥሩ ጊዜ አብረው የሚያሳልፉት እና የሚዝናኑት ሰው አለ					
1302	ደስ የሚያሰኝዎትን ነገር አብረው የሚያደርጉት ሰው አለ					
1303	አዕምሮትን ለማሳረፍ ሲያስቡ አብሮት የሚሆን ሰው አለ					