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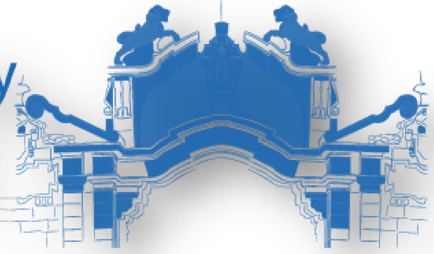

ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCES

SCHOOL OF MEDICINE

DEPARTMENT OF PEDIATRICS AND CHILD HEALTH

KNOWLDEGE, ATTITUDE AND PRACTISE OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY ATTENDING FOLLOW UP AT NEUROLOGIC CLINIC IN TIKUR ANBESSA SPECILIZED HOSPITAL.

ADDISABEBA, ETHIOPIA

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THESIS SUBMITTED TO THE DEPARTMENT OF PEDIATRICS AND CHILD HEALTH, SCHOOL OF MEDICINE, COLLEGE OF HEALTH SCIENCES, ADDIS ABABA UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR SPECIALTY CERTIFICATE IN PEDIATRICS AND CHILD HEALTH

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Declaration

I, the undersigned, Pediatrics and Child Health final year resident declare that this thesis done is my original work in partial fulfillment for the certificate of Pediatrics and Child Health.

Title: - Knowledge, Attitude and Practice of Caregivers of Children with Cerebral Palsy attending Follow up at Neurology Clinic in TASH, Addis Ababa, Ethiopia

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Acronyms

AAU	Addis Ababa University
ADL's	Activity of daily living
AOR	Adjusted odd ratio
BDI	Beck Depression inventory scale
CHS	College of Health Science
CP	Cerebral Palsy
DPCH	Department of Pediatrics and Child Health
GDD	Global Developmental Delay
NICU	Neonatal Intensive Care Unit
PICU	Pediatrics Intensive Care Unit
PNC	Pediatrics Neurology Clinic
PWD	Patients with disability
ROPD	Regular Out Patient Department
SCPE	Surveillance of Cerebral Palsy in Europe
STIA	State-Trait Anxiety Inventory (STAI)
TASH	Tikur Anbessa Specialized Hospital
UNCRPDs	United Nation Convention Rights Persons With disability ()
WHO	World Health Organization

Summary

Background:

Cerebral palsy (CP) is one of the most severe disabilities in childhood and makes heavy demands on health, educational, and social services as well as on families and children themselves. The complex and chronic nature of the multiple impairments that contribute to the diagnosis of CP has a substantial impact on the functional level and quality of life of the child, which, in turn, can result in a significant physical, financial, and psychological health burden on the family. Most parents of children with CP lack basic knowledge of the disease, its cause, prognosis, treatment modality, and outcome. There are also a limited number of studies Carrying out any intervention and evaluating the response of that intervention to parental knowledge of CP. The overall point of this study is to depict and analyze the knowledge, attitude, and practice of parents and guardians with CP in, Ethiopia where children who require neurologist assessment get referred to from all over the nation

Methods:

A hospital based descriptive cross-sectional study conducted on 144 Primary care givers of children with CP who are attending on follow-up at pediatrics neurology clinic. Every patient coming for follow up during the study period fulfilling the inclusion criteria were asked to be included in the study. The diagnosis of CP confirmed using the SCPE decision tree before inclusion to the study. The data obtained from the questionnaire was entered into the computer and analyzed using statistical package of social sciences (SPSS) 25. Binary logistic regression was used in assessing the effect of general characteristics on attaining the required knowledge, attitude and practice of care givers.

Result

In this study among 144 participant,137 were willing, making a response rate of 95.1% and 56.2% of the primary caregiver were mother and half of the participants were in the age group of 30-40 years and more than three-fourth of the participants were married and 28.6% of caregiver learned up to collage level and 51.1% caregiver had inadequate income and the overall Knowledge, Attitude and Practice of Caregivers of Children with Cerebral Palsy attending Follow up at Neurology Clinic in TASH is (66%,64% and 34%) respectively.

Conclusion

Caring for a child with cerebral palsy is a big task requiring mental fortitude and physical vitality as well as community involvement. In order to improve outcomes for children with CP and to maintain the health of caregivers, necessary support systems must be in place. Social welfare and other organizations should support mothers with cerebral palsy children to help lift the huge financial burden required for care of their children. Governments should also create an enabling and supportive environment through the establishment of rehabilitation centers and social protection policies for cerebral palsy children. A multi approach is needed to assist caregivers on all fronts to deal with day-to-day challenges.

Key Words: Cerebral Palsy; primary care giver; knowledge; attitude; practice; Ethiopia

1. INTRODUCTION

Cerebral Palsy (CP) is a group disorders involving movement and posture and of motor function; it is permanent, but not unchanging; it is due to a non-progressive interference, lesion, or abnormality of the developing/immature brain. (1)

Cerebral palsy (CP) is one of the most severe disabilities in childhood and makes heavy demands on health, educational, and social services as well as on families and children themselves. The complex and chronic nature of the multiple impairments that contribute to the diagnosis of CP has a substantial impact on the functional level and quality of life of the child, which, in turn, can result in a significant physical, financial, and psychological health burden on the family. (2)

1.1. Background

A child with CP suffers from several problems such as spastic paralysis, cognitive impairment, chronic pain, speech and visual impairment, and gastrointestinal and feeding problems. They also have several limitations in self-care functions such as feeding, dressing, bathing, and mobility. These limitations can result in requirement for long-term care that far exceed the usual needs of normal children. The difficulties faced by children with CP result in their parents experiencing a higher level of stress which has an adverse effect on their physical health and social well-being. Changes in healthcare systems and societal attitudes have resulted in most children staying at home in the care of family rather than in an institution. The ideal management of CP is comprehensive and effective physical rehabilitation which is unfortunately expensive for the average Ethiopian family. (3)

Numerous obstacles for mother of children with cerebral palsy and creates its own deep sorrow and trauma, "psychological, physical health and socio-economic challenges" throughout her life. Even though, mother plays essential role in taking care their children. Furthermore, a mother has many hindrances in life such as maternal problems, lack of job opportunities on top of these nurturing and supporting children with disability. Therefore, it negatively touches the life cycle a mother of children with cerebral palsy. (4)

Disability may mean impairment, participation restriction; active limitation and different organization and even communities may have their own explanation. According to United Nation United Nation Convention Rights Persons With disability (UNCRPDs) considers "those who have long- term physical, mental, intellectual, or sensory impairments which cause with

various barriers that may hinder their full and effective participation in society on an equal basis with others". (5)

In this regard, there is no single mostly agreed explanation given to the concept of disabilities. There is also small piece of information and concepts on the „occurrence‟, distribution and experience of disability. For instance, World Health Organization pointed out that disability is "complex, dynamic, and multidimensional". (6) As a concept and definition disability is widely different. In Ethiopia Persons with disability are perceived as "weak", "hopeless", "dependent", and "unable to learn" and "subject of charity". The misunderstandings and miscalculations of the abilities of persons with disabilities have contributed to experience low social and economic status. (7) The meaning of disability is different and its category is also different. Physical disability is one of the most common types of disability. It's associated with disorder such as, musculoskeletal, Nero-muscular disability, circulatory, respiratory and nervous system. In this group of classification there are primarily two groups of physical disability musculoskeletal disability and Nero-muscular disability. (5)

Musculoskeletal disability is incapability only one of its kinds of movement of the body parts due to bone deformity, which affect ligaments, joints, muscles, tendons, peripheral nerves, degeneration. But Nero-muscular disability is motor neuron diseases injury have an effect on body part due to diseases without controlled movement of degeneration disorder of the nervous 22system. (4)

Cerebral palsy may begin in the early childhood extended throughout one's life. It is mainly associated with "disorder of sensation, behaviour, motor speech, and "other cognitive impairments perception, cognition, communication, and behaviour" by epilepsy, and by secondary musculoskeletal problems" (4). Rehabilitation is important that the rehabilitation centers ought to care children's with living cerebral palsy. It may take short- or long-term procedure. In addition, it depends according to the severity, to sustain empowering persons with disabilities and "optimal physical, sensory, intellectual, psychiatric and / or social functioning levels, providing them with the tools to change their lives towards a higher level of independence" (7) Children with CP demand more intense care from their parents compared to normal children at their age. Therefore, family especially parents as their caregiver plays a crucial role in CP development milestone. Moreover, socioeconomic condition, marital conflicts, and other parental responsibilities give additional burden to parents. Knowledge of the parents about CP may worsen these conditions. Poor knowledge will impact the attitude of the parents and their daily behavior, leading to failure in their children's development. Good

knowledge develops a supportive and cooperative attitude, resulting in proper daily behavior and indirectly supporting the development of their children. (8)

1.2. Statement of the problem

CP is a clinical syndrome that encompasses a wide range of brain disorders associated with impaired motor function. (9) It occurs in 1.2–3.6 children per 1000 live births. Numerous cerebral palsy registries exist throughout the world and population prevalence rates from four continents have remained consistent over several decades. (10)

There are many problems suffered by children with cerebral palsy like chronic pain, spastic paralysis, and perceptive impairment, impaired vision and speech problems, as well as digestive problems and malnutrition. Also, they have many obstacles in doing self-care tasks, for example, eating, changing clothes, moving as well as bathing, can lead to the need for long-term care that goes far beyond the usual needs of normal children. (11)

Most parents of children with CP lack basic knowledge of the disease, its cause, prognosis, treatment modality, and outcome. There are also a limited number of studies

Carrying out any intervention and evaluating the response of that intervention to parental knowledge of CP. (12)

Parental stress and adaptation depend on the type of impairment, family management resources, and formal and informal community support. The stress of parenting depends on the severity, type of disability, behavior and development. Higher parental stress was associated with behavioral and developmental disability. (13) Lower socio-economic status of the family is associated with more stress due to fewer resources. Proximate spousal and immediate family support were established to facilitate family adaptation and reduce stress. Religious coping has been reported to reduce parental stress by two types of social support systems in terms of group support. Formal social support includes services provided by health workers such as school programs, parent education teachers, and physical therapist and family support agencies. Informal social support includes family members, family members, neighbors, friends and community groups. (14)

Mother of children living with cerebral palsy has different responsibilities with difficulties for their day-to-day life expectancy to facilitate several needs of a child. In fact, both parents (mother and father) of a child living with disability share household tasks, burdens to protect their child. Mothers are exposed to numerous challenges besides their life to allow their children to continue clinical services and therapies, possible intervention of skill training and educational settings. Despite the fact that mothers who are regularly pretty close and sensitive for their

children, how much more the proximity is quite crucial for a mother of a child with CP since the child needs her full day special treatment in addition to the regular household management. The mother certainly confers time, energy, empathy, a psychological wellbeing, financial strength, flexibility and readiness to cope up the challenges. (4)

Consequently, Discrimination and labelling can cause trauma and foster negative attitude for the mother. However, Rehabilitation centers, other stakeholder and vast community members need to ensure a great deal of involvement in order to pay attention for mothers and for their children. If not, the conscience is imposed to put mothers to hide their children at home. Studies have pointed out the impact and significant role played by mothers of children with cerebral palsy are limited, especially with regard to care of infants shortly after birth and the role played in the occupational therapy interventions. Thus, there should be study to find out the role of mothers in rehabilitation center to treat children with cerebral palsy. The role of mothers of children with cerebral palsy participate in the physical therapy in rehabilitation center for their children with cerebral palsy are likely to develop more understanding into the impairments and abilities of their children, resulting in more realistic view of their child's potential in relations of daily functioning. Moreover, by participating in therapy, mother can become more skilled at taking care of their children. Eventually, this increases mothers' confidence in their own competence and reduces maternal stress. (4)

Researchers also found that disability is viewed differently in every culture. Cultural beliefs play an important role in deciding how the family perceives disability, and the kind of prevention, treatment and rehabilitation initiatives it takes. Families of certain cultural backgrounds have double clinical and conventional beliefs about the existence, cause and treatment of disability. (14) Environmental risk factors including lack of services and negative attitudes can also adversely affect the prognosis of the disabled child. (15)

1.3. Rationale of the study

There is plentiful data on the knowledge, attitude, and practice of parents and guardians of CP patients in created nations. The circumstance is switched in creating nations particularly in Africa.

Recognizing the critical role that family plays in the integration and provision of care for children living with complex disabilities such as CP has resulted in shifting from focusing on the child to considering the needs of the whole family. Therefore, family-centered care has become a cornerstone of rehabilitation services. Family-centered practice encompasses collaboration with families on child-related goals as well as the evaluation of family values, beliefs, and needs to design interventions targeted at positive family outcomes

This means that each family can choose its own, optimal service delivery and should, for example, be given options with respect to their level of involvement.

Different families will have different preferences when it comes to their involvement in their child's care. This may be influenced by culture, and how parents think about their children and different disability diagnoses is likely to have different meanings for parents from different cultural backgrounds. Moreover, the concept of "disability," and what it means to live with a disability, is multifaceted, including social and cultural influences, traditional practices, and personal experiences. (16)

Parents of children with cerebral palsy need to know and treat the disorder. This would help in the study of treatment in order to attain efficient abilities and improve quality of life. No two mothers and no two children are exactly the same thing.

The overall point of this study was to depict and analyze the knowledge, attitude, and practice of caregivers with CP in, Ethiopia where children who require neurologist assessment get referred to from all over the nation. It endeavors to address a few of the holes by improving parents and guardians' information with respect to CP in TASH and to Provide way better administration and restoration of this vulnerable population and their guardians. It is trusted that the comes about from this investigate work will help to shed more light on this ignored theme by expanding the information of guardians on CP and serve as the premise for setting up bigger epidemiological and community-based intervention studies to progress the quality of life of children with CP and their caregivers in Ethiopia.

2. Literature review

CP is benign, not progressive condition and the brain insult has already happened, but it can be changing in nature. Parents have the lifelong task of accepting their child's developmental disability. Parents frequently experience varying periods of denial, anger, and sorrow once disability is diagnosed in their child. (17)

I attempt to review the related literature which has more stressed on, the knowledge, attitude, and practise that primary care givers of children with cerebral palsy. The literature that focused on the knowledge, attitude and practise of primary care givers to treat their children with cerebral palsy is rarely available. So i mainly focused on those available literatures. There are some attempts of review by some researchers in relation to parental role for children with cerebral palsy in Ethiopia, which are too general and do not show the specific knowledge, attitude and practise of parents.

2.1 Historical background of the of disability

Even if there is no exact agreement on the "definitions of disabilities", but there are little internationally comparable information on the incidence, distribution and trends of disability. According to world health organization, disability is "complexes, dynamic, and multidimensional".(6)

However, in Ethiopian contexts disability is defined as any person unable to ensure by himself or herself a normal life, because of deficiency in his or her physical or mental capabilities. Nayarit Gazeta of the Emperor Haile Selassie I, in the Order No. 70 of 1970, described the disabled as, people who is unable to earn his livelihood and do not have anyone to support him because of limitations of normal physical or mental health. In addition, shall include any persons who are unable to earn their livelihood because they are too young or too old.

In Negarit Gazeta the Transitional Government of Ethiopia, Proclamation No. 101 of 1994 referred a disabled person as, a person who is unable to see, hear or speak or is suffering from mental retardation or from injuries that limit him or her due to natural or manmade causes. However, the term does not include persons who are alcoholic, drug addicts and those with psychological problems due to socially deviant behaviours. (18)

From all types of disability as the researcher mentioned before the main focus of this study was it's all about cerebral palsy. Cerebral palsy is one of the most mutual developmental disabilities. A condition is started early in childhood and continuing throughout the lifetime. The definition and classification of cerebral palsy, according to the Executive Committee for the Definition of Cerebral Palsy, states that: "Cerebral palsy describes a group of permanent disorders of the development of movement and posture that are attributed to non-progressive disturbances that occurred in the developing fatal or infant brain. The motor disorders of cerebral palsy are often

accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems" (2)

2.2 Disability in Ethiopia

According to WHO, 10% of the population of any developing country is estimated to be people with disabilities estimate of ten per cent (10%) is applied to indicate the scope of disability in Ethiopia, the figure will be as big as 17.6million. (6)But this figure has not been confirmed by the National Population and Housing Census conducted by the Central Statistics Authority (2007). Rather the census report designated that there were 864,218 PWDs of which 464,202 are Male and 400, 016 Female. Out of the total PWDs, 31.18% have leg, hand and body movement problems, 28.77% seeing problems and total blindness, 19.74% hearing and speech difficulties, 4.8% people with intellectual disabilities, 6.8% persons with mental problem and 8.78% with other disabilities. This data shows how much the issue of disabilities needs concern. But as the data shows person with cerebral palsy even they are not counted in their category as a one of independent disability types. For this reason, the researcher desperately needs to thoroughly scrutinize the knowledge, attitude, and practise of primary care givers of children with cerebral palsy.

2.3. Families of Children with Disabilities.

Families are the main source of support for children with disabilities. "Family members absorb the added demands on time, emotional resources, and financial resources" (19)

The condition of successful support is a challenge, particularly mother of children living with Cerebral palsy and children with cerebral palsy involves suitable sustainable rehabilitation intervention which should efficiently meet to achieve of children and Caregivers/Family. Families are one of the main supports of life-threatening for children with disabilities. "Family members absorb the added demands on time, emotional resources, and financial resources" (19). Non family members sometimes do not offer extensive care for children with disability as a family of children with disability. (20)

In Ethiopia there was no study done on our specific topic on knowledge, attitude and practise of primary care givers of children with cerebral palsy. But there is one study done on the role of mother with CP children CHESHIRE Ethiopia. In their study 40 parents were randomly selected and interviewed and Findings of the study indicated that mother of children living with cerebral palsy involved in the rehabilitation centre. They were challenged by lack of financial support, transport and physical treatment training for mother of children with cerebral palsy. Results also pointed out that the effects of those challenges in mothers of children with cerebral palsy life such as psychological injurers, emotional disturbance, and financial problem.(4)

In Africa, I found three studies done regarding the knowledge, attitude and practise of primary care givers of children with cerebral palsy.

The first study it was conducted in Khartoum pediatric hospitals and Khartoum Cheshire Home for rehabilitation of disabled children. The objectives of the study were to assess knowledge, attitude and practices of mothers of children with CP and to study the psychological impact on them. Two hundred and four children were enrolled in the study. The finding was half of mothers 50.5% had good knowledge about CP. Mother's educational level; age of the mother had significant correlation with the knowledge score. Some aspects of attitudes are influenced by educational level of the mothers e.g., the link between CP and mental retardation, believe in traditional medicine and expectation of special treatment. Anxiety was moderate in less than half 40.7% of the mothers when assessed by (STAI). There was a significant correlation between the severity of anxiety and the degree of disability in the child. Depression was diagnosed in more than two thirds of the mothers when assessed by (BDI).(17)

In Ghana there was another research done on the perceptions and experiences of cerebral palsy among caregivers of children with Cerebral Palsy in a low resource setting. 15 caregivers were purposively selected and interviewed face to face. Results of Study revealed that caregivers had different perceptions regarding the causes of cerebral palsy with most of them linked to spiritual reasons. Caregivers faced physical, emotional, financial, marital and social challenges. The study also found that the external network available to the Caregivers were mainly NGO's with limited governmental support.(21)

In Nigeria also there was study done on psychosocial problems among mothers of children with cerebral palsy attending physiotherapy outpatient department of two selected tertiary health centres in Ogun state: seven mothers of children with CP were included in the study and the result showed the psychosocial challenges encountered by the mothers were associated with nine common sub-themes. These are: (i) stress of caring for over dependent child; (ii) mothers' restricted participation in the society; (iii) financial constraint experienced by the mothers of children with CP; (iv) health problems experienced by mothers of children with CP; (v) feelings of uncertainty about the child's future; (vi) society's negative perception of child's problems; (vii) support obtained by the caregivers from others; (viii) availability of support from healthcare facilities; and (ix) Personal belief about condition.(3)

Nationwide there are few studies done on knowledge, attitude, and practise of primary care givers of children with CP.

In Indonesia there was a study aimed to explore the knowledge, attitude, and behaviour among parents with CP children. This study was descriptive quantitative study and conducted at the

Physical Medicine and 31 parents were asked to complete a questionnaire that was specifically designed. Finding was 51.6% had good knowledge about CP; 58.1% had good attitude toward CP children, and 51.6% had good behaviour while taking care of their children.(8)

In India they did a study is to check the perception of mothers of cerebral palsy children with disabilities. It explored mother's knowledge, social well-being and awareness of treatment rendered. 220 mothers, averaged 33.44 + 6.14years, of children with CP were randomly selected for this study. Data was collected from mothers attending rehabilitation centres from different institution and special schools in Tamil Nadu. Mothers can hold both a fatalistic view of disability and a belief in the course of disability. The results showed there is significance difference with in the mother's perception towards types of disability in Parental stress, child's ability, mother's confidence, improvement, health status, benefits and belief. Mothers should be motivated to maximize rehabilitation services in order to improve their children's functional capacity. (14)

In Bangladeshi they did a study to find out the parent's perception of the cerebral palsy child after confirming the diagnosis. 14 parents were purposively selected and in-depth interview was conducted with a semi-structured open-ended questionnaire. Parents are experiencing great emotional stress during the diagnostic process and dissatisfaction with disclosure is widespread. It also found that most of the participants have lack of knowledge about the condition of cerebral palsy and the general public has lack of knowledge about the disorder too. Also, mothers get less time to perform their own self-care activities, as the literature has indicated. This is due to continuous care-giving demands and mothers leave their own daily life needs, and become unconscious about their own self-care activities and how it impacts on their quality of life.(22)

In Saudi Arabia there was study done on the Perception of Disability among Mothers Living with a child with Cerebral Palsy. The findings of this study suggest that mothers had various cultural and religious explanations for the cause of their children's disabilities, with some placing great emphasis on the role of the evil spirit. Mothers also expressed feelings of shame and of receiving negative attitudes from their extended family. Importantly, they also reported stigma and a lack of support from their extended families and community. This finding is consistent with numerous other studies that have suggested that disabled children and their families are subjected to discrimination and stigmatization and that the discrimination experienced by disabled children and their families is persistent. This may tend to have an isolating effect on the mother and child.(16)

In American study Feldman studied public perception of cerebral palsy, he selected randomly adult population from the waiting room of a suburban pediatrics office in New Jersey school of osteopathic medicine. 5% of his study group were at the lowest education which was found to be high school. He reported that about 40% believe that CP has a genetic ethology, and affected children can't speak in 20%,die earlier in 57% and can't hold jobs as an adults in 20%. A small percentage 4% believes that CP is infectious.(23)

In Finland studied public awareness and attitudes towards cerebral palsy; he found that CP was known to 95.4% and its meaning to 60.7% and 88.4% would let their children play with cerebral palsy patients .He found that knowledge about CP was independently related to good basic education, but a good knowledge of CP fostered a positive attitude towards people with this disease. (24)

3. Objective

3.1. General objective

1. To analyze the knowledge, attitude and practice of parents and guardians of children with CP in TASH, Ethiopia

3.2. Specific objective

1. To identify caregivers' knowledge about the condition of cerebral palsy.
2. To assess the family role of caring for a child with cerebral palsy.
3. To explore the attitudes of care giver of children with CP, family and to their own lives.
4. To identify the amount of time care givers can spend to perform their ADL's (self-care, productivity, leisure) along with taking care of their cerebral palsy child.

4. Material and methodology.

4.1.Study setting

The study was conducted in TASH, Department of Pediatrics and Child Health, Addis Ababa, Ethiopia. TASH was established in 1974. It is the teaching hospital of School of Medicine, School of Pharmacy, School of Public Health and School of Allied Health Sciences. It is also the largest referral hospital in Ethiopia with over 700 beds and serves as a training centre for undergraduate and postgraduate medical students, dentists, midwives, pharmacists, medical laboratory technologists and radiology technologists.

The Department of Pediatrics and Child health is one of the oldest departments in CHS. It consists of one pediatrics emergency ward, four admission wards including pediatrics orthopaedics ward, one NICU, one PICU, one ROPD and different referral clinics.

The Pediatrics Neurology clinic is a follow up clinic for outpatient follow up of pediatric patients with neurologic disorders. A total of 500 to 700 patients are seen in this clinic each month (clinical audit of pediatrics department 2013 E.C). The clinic works in all of the five working days serving 25 – 35 patients per day. It is run by pediatric neurologist, pediatric residents, and nurses. The monthly audit report of PNC indicates that most of the children on follow-up are with the diagnosis of seizure disorders followed by developmental delay and the majority of these cases are accounted by children with CP.

4.2.Study Population

Primary care giver of children with CP who are attending on follow-up at pediatrics neurology clinic will be subjected to the study.

4.3.Study Design and Study Period

It is a prospective hospital based descriptive cross-sectional study to be conducted between June 8 and September 8,2021G.C.

4.4.Sample size determination

Sample size is calculated using Cochran's formula of cross-sectional study. The predicted Prevalence of CP in Africa is less precise with limited information depicting wide ranging figures (14). A study done by Ayalew et al describing the patterns of neurologic morbidities

among patients attending the pediatric neurology clinic of TASH showed that cerebral palsy was the most common pediatric neurologic problem excluding patients with seizure disorder as there was separate seizure clinic during the study period (35). From clinical audit of pediatrics department done over the past one year overall 100 to 130 children with GDD are seen each month and among these the majority is contributed by CP patients. On the HMIS log book 20 to 30 children are registered with the diagnosis of CP in addition to those registered with the diagnosis of GDD. Overall, there are no available data as to the prevalence of CP in Ethiopia. Taking an assumption of P value of 50% to obtain a confidence level of 95% and a power of 80%, a total of 384 children will be taken. Taking additional 10% non-responders mean at least 426 children will be recruited.

$$n = Z^2 P(1-P)/d^2$$

N =Sample size

Z =Statistical certainty =1.96 (at 95% level of confidence)

P =Prevalence = 50%

D =Desired margin of error = 0.05

Finite population corrector.

Sample size correction for finite population is valid to be used for sample sizes with proportion greater than 5% of the source population (i.e., $n/N>0.05$) (36). As the above sample size is more than 5% of the source population the corrected sample for 3 months study period taking source population of 204 (maximum 68 patients per month) and using correction formula for finite population will be 133. Taking additional 10% non-responders 144 children was the final sample.

$$n' = \frac{NZ^2P(1-P)}{d^2(N-1) + Z^2P(1-P)}$$

4.5. Sampling Technique

Every patient coming for follow up during the study period fulfilling the inclusion criteria will be asked to be included in the study. Willing study subjects were included in the study until the minimum sample size is attained.

4.6. Inclusion and Exclusion Criteria

Inclusion criteria

a) Children who fulfill the criteria for definition of CP.

b) Children aged eighteen years or less.

c) Children who presented with their caregivers.

d) Primary caregivers who has cared for the child for more than 6 months.

Exclusion criteria:

a) A child with intellectual disability without physical disability.

b) A child with blindness, deafness without physical disability.

c) A child with physical disability of progressive nature.

d) A child who presented without his or her primary caregiver.

e) A child whose primary care givers refuse to participate in the study.

4.7. Data collection

Questionnaire pre- test

Piloting of the questionnaire was done in a sample of five children attending TASH. These subjects were not be included in the study results. Findings from the pilot study were utilized in modifying any questions on the standard questionnaire. The pretest helped to determine the duration it would take one to complete the questioner. If by any means the questioner is found to be time consuming and compromising patient care then specific data collector were allocated for each day as per the agreement among the residents.

Data Collection Procedure and Questionnaire

Every primary care giver of child coming for follow up during the study period fulfilling the inclusion criteria will be asked to be included in the study. The diagnosis of CP was confirmed using the SCPE decision tree before inclusion to the study and Willing study subjects were included in the study until the minimum sample size is attained.

Data collection was by the two GPs and principal investigator. The data collectors were given training on how to abstract the data using the questionnaires and how to do the clinical assessment by the principal investigator.

The mothers were contacted and informed about the purpose of the study, then consented and personally interviewed by the responsible doctor with the help of a pretested and pre-coded questionnaire to interview the caregiver

The questionnaire is composed of five parts.

The first and second parts are concerned about personal data of the child and his care giver.

The third part of the questionnaire assesses the knowledge of the primary care giver toward cerebral palsy. The knowledge is about the nature of the disease, possible causes, associated disabilities and probably the fate and prognosis.
The forth part of the questionnaire assesses the attitude of the mothers toward cerebral palsy patients. The fifth part obtains data about practices toward cerebral palsy children, including feeding, physiotherapy and schooling if the child's age is appropriate.
The data obtained from the questionnaire was entered into the computer and analyzed using statistical package of social sciences (SPSS). Descriptive and comparative statistics was performed. Binary logistic regression was used in assessing the effect of general characteristics on attaining the required knowledge.
Scoring system: A scoring system was used to assess the general knowledge of mothers of CP children whom were included in the study. Using scores of one and zero for correct and incorrect responses respectively. The total of responses was analyzed a cut-off point of 50% were used to divide the responses to good and poor knowledge. Scores of more than 50% were considered as good knowledge and scores equal to or below 50% were considered as poor knowledge.

4.8. Study variables

- **Independent variables**
  - Socio-demographic data –Age, sex, address, religion, primary caregiver age, marital status of parents, primary caregiver's highest level of education, Primary caregiver's monthly income
  - Health related data – anthropometry, functional severity, co morbidities

- **Dependent variables**
- Knowledge, attitude and practice of primary care givers of children with CP.

4.9. Data Quality Assurance

During the data collection, regular and periodic supervision were made for quality and completeness by the primary investigator.

4.10. Data analysis and Interpretation

The data obtained from the questionnaire were entered into the computer and analyzed using statistical package of social sciences (SPSS) version 25. Binary logistic regression was performed. P value less than 0.05 is considered significant. Bivariate analysis was done to see crude association followed by multivariate analysis for significantly associated factors.

4.11. Operational definitions

Cerebral palsy is defined as a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.

Primary care giver- refers to the parents and guardians who have the greatest responsibility for the daily care and rearing of a child.

SCPE decision tree; children suspected to have CP will be assessed based on the following decision tree to confirm inclusion to the study. See fig 1

Good knowledge –respondents who scored above or equal to the mean score (50%) of the knowledge related questions.

Poor knowledge- respondents who scored below the mean score (50%) knowledge relate questions.

Favorable attitude- respondents who scored above or equal to the mean score (50%) of the attitude related questions.

Unfavorable attitude- respondents who scored below the mean score (50%) of the attitude related questions.

Good practice- respondents who scored above or equal to the mean score (50%) of the practice related questions.

Poor practice- respondents who scored below the mean score (50%) of the practice related questions.

4.12. Ethical considerations

Ethical clearance was obtained from the Pediatrics and Child Health Department's Research and Publications Committee of the School of Medicine, College of Health Sciences, and Addis Ababa University. Respondents were clearly informed about the purpose of the study and the information required from them. There won't be any risk or harm on the participants associated with the study. They were told that they have the full right of non-involvement and the right to

stop the interview at any point in time. Informed, written consents from primary care takers and verbal assent was obtained from all the study participant children aged above 12 years who are capable of making informed and voluntary decision. Participant confidentiality were assured. Patients who refuse to take part in the study was receive the same quality of health care service as the participants. All participants included in the study were kept anonymous during subsequent analysis and dissemination.

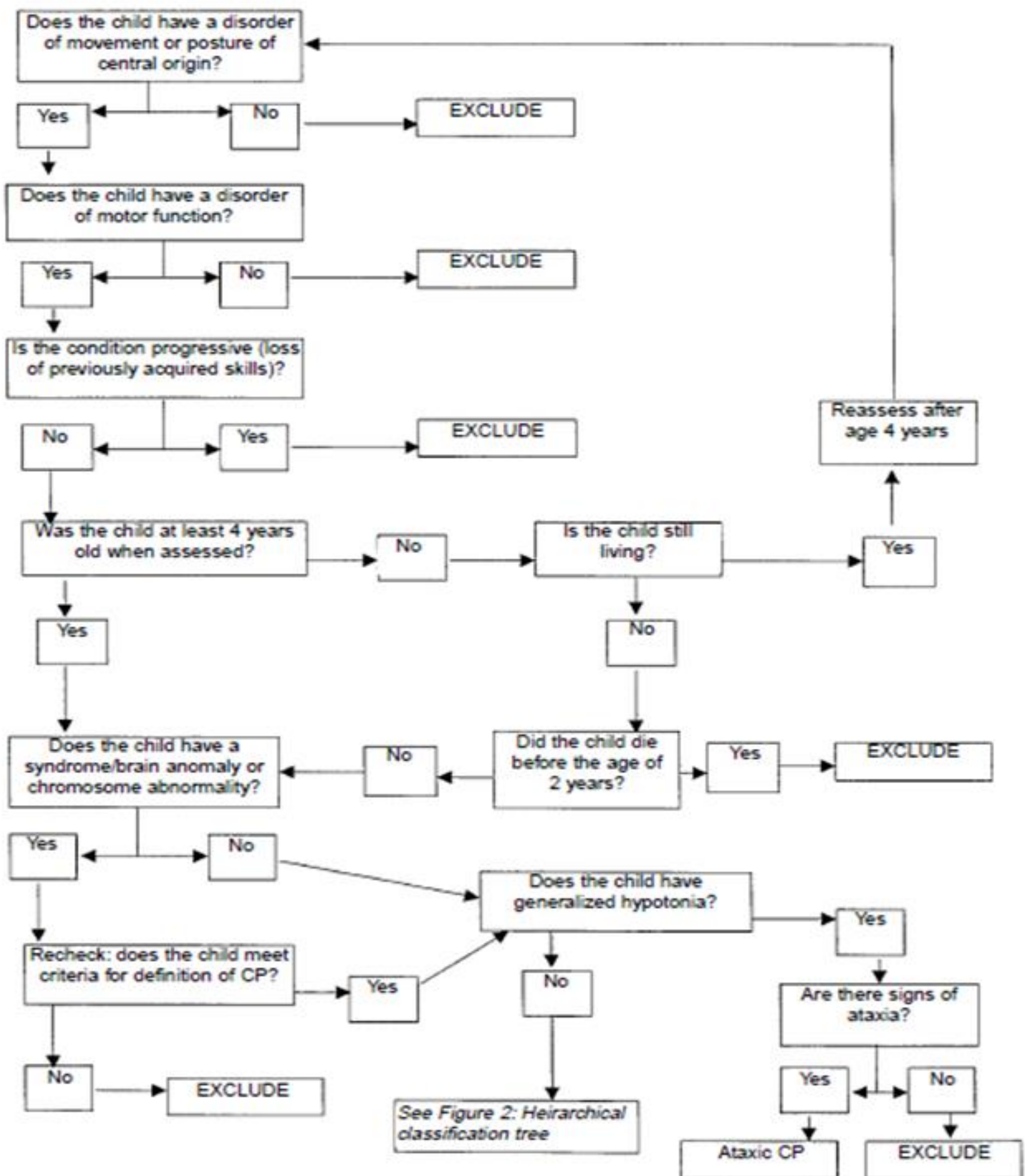

Figure 1. Decision tree for inclusion/exclusion of cases of cerebral palsy

4.13. Dissemination of findings

The result of the study was presented on the research defense day and a formal report was submitted to the DPCH. The research output will also be published on local or international peer reviewed scientific journals.

5. Result

5.1. Sociodemographic characteristics of cerebral palsy caregiver

In this study 137 participants were involved, making a response rate of 95.1% and 56.2% of the primary caregiver were mother and half of the participants were in the age group of 30-40 years and more than three-fourth of the participants were married and 28.6% of caregiver learned up to collage level and 51.1% caregiver had inadequate income.

Table 1. the sociodemographic characteristics of primary caregiver of cerebral palsy children having neurology follow-up in Tikur Anbessa Specialized hospital Addis Ababa, Ethiopia, 2021

Variable	frequency	Percent
Relationship of primary care giver		
Mother	77	56.2
Father	3	2.2
both parents	32	23.4
adult relatives	4	2.9
non relative	16	11.7
Orphanage	5	3.6
Age of primary caregiver		
<20	4	2.9
20-30	58	42.3
30-40	69	50.4
40-50	1	.7
Marital status of caregiver		
Single	4	2.9
Married	107	78.1
Divorced	17	12.4
Widowed	4	2.9
Care griever education level		
Illiterate	10	7.3
can read and write	13	9.5
Primary	34	24.8

Secondary	36	26.3
College	39	28.5
Primary caregiver occupation		
Housewife	55	40.1
Student	3	2.2
Merchant	34	24.8
daily laborer	3	2.2
government employee	37	27.0
Monthly income of caregiver		
<3000	6	4.4
3000-6000	32	23.4
6000-10000	43	31.4
10000-15000	37	27.0
>15000	14	10.2
Monthly income		
partially adequate	67	48.9
Inadequate	70	51.1

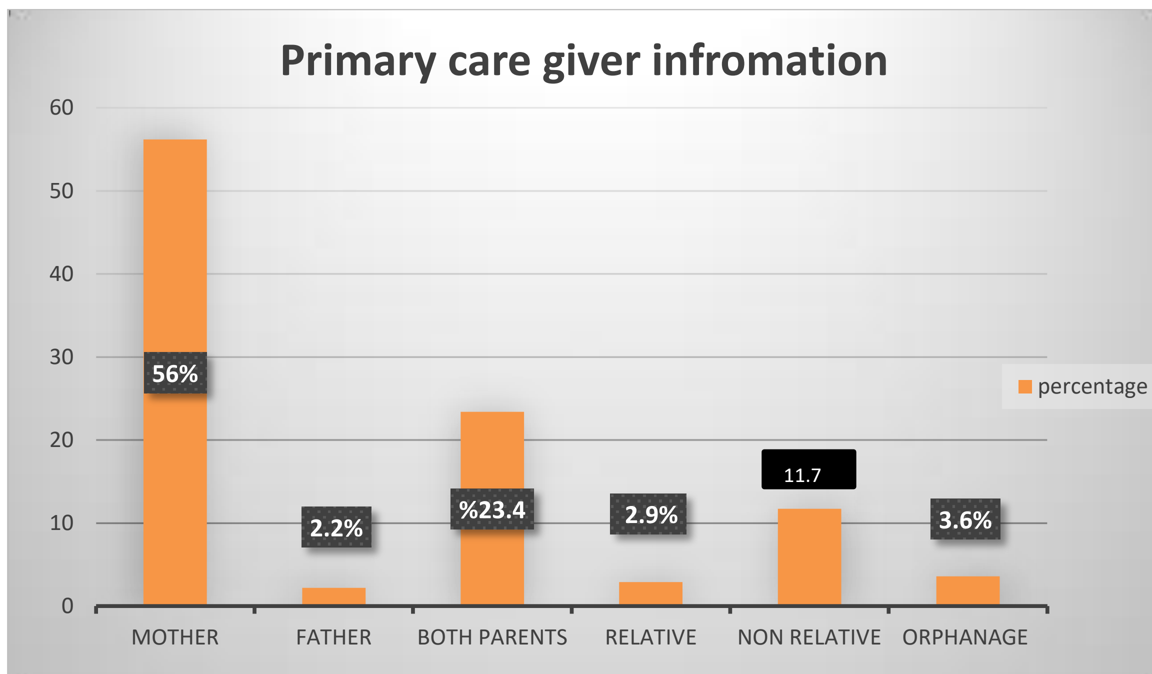

Figure 2

5.2.Sociodemographic characteristics of children having cerebral palsy

Four-fifth of the children having cerebral palsy were in the age group of 1-5 years and 44.5% were the first birth and 59.9% of the participants had ≤ 4 family size and 73.7% were from Addis Ababa and 86.1% of children had no schooling and 92% completed immunization as shown in the table below.

Table 2. the child characteristics of having cerebral palsy

Variable	frequency	Percent
Age of children in years		
<1	9	6.6
1- 5	109	79.6
>5	19	13.9
Sex		
Male	94	68.6
Female	43	31.4
Birth order		
First	61	44.5
Second	44	32.1
Third	29	21.2
More than tree	3	2.2
Family size		
≤4	82	59.9
≥5	55	40.1
Address		
Addis Ababa	101	73.7
Out of Addis Ababa	36	26.3
Religion		
Orthodox	68	49.6
Muslim	40	29.2
Protestant	24	17.5
Catholic	5	3.6
Children education		
no schooling	118	86.1
Nursery	15	10.9
Primary	4	2.9
Immunization completed		
YES	126	92.0
NO	11	8.0
If no, what doses are missing		
One	3	27.3
Two	8	72.7

5.3. Primary caregivers' knowledge on children cerebral palsy

Mean value was used to determine the level of knowledge and 66% of the participants scored above the mean value as shown in the figure below

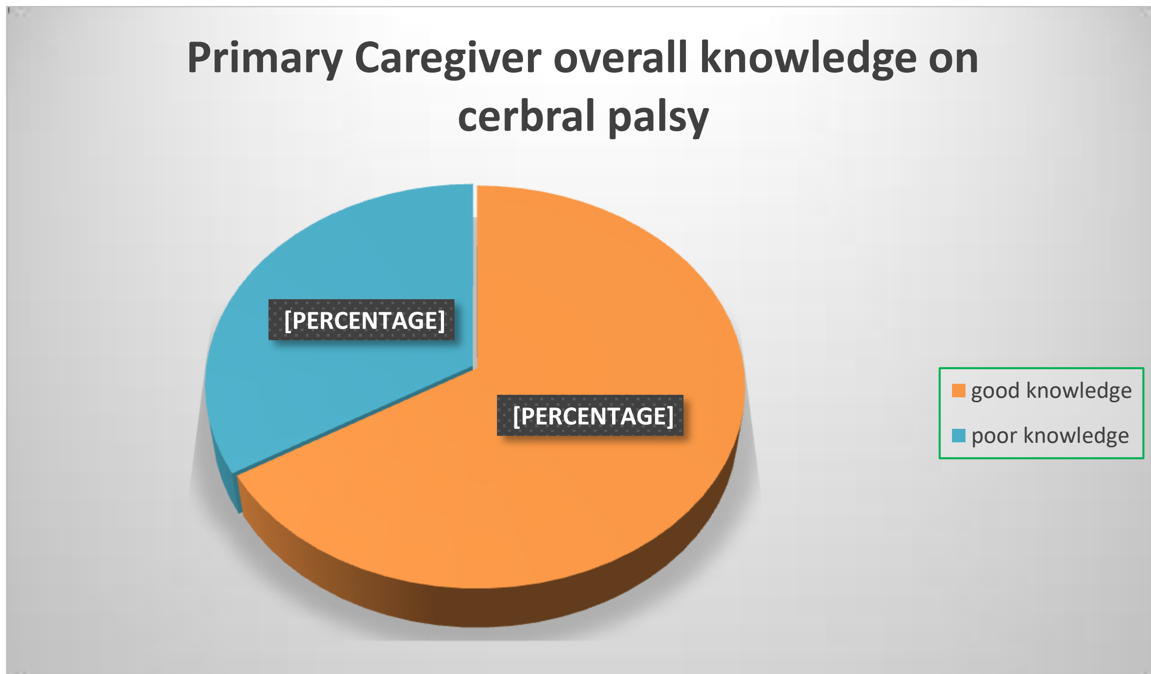

Figure 3. The overall knowledge of primary caregiver on cerebral palsy

87.6% the study participants were aware about cerebral palsy after the diagnosis of the children and 49.6% participants know that the risk of CP by perinatal event and 67.9% know about the relationship between CP and brain insult and 50.4% of the participants know about PNA as cause for brain damage and 39.4% about the strong relation of CP and physical disability.

Table 3. Knowledge of study participants about children cerebral palsy

Variable	frequency	Percent
Time to aware about Cerebral palsy		
prior to dx of child	17	12.4
after the dx of child	120	87.6
possible risk factors that can cause CP		
perinatal event	68	49.6
witch craft	3	2.2

evil eye	5	3.6
underline brain abnormality	5	3.6
preterm labour	32	23.4
no cause blame	24	17.5
direct relationship between brain insult and CP		
yes, there should be	93	67.9
no, that not necessary	6	4.4
don't care	38	27.7
What do you think the cause of brain damage		
Perinatal asphyxia	69	50.4
Meningitis	6	4.4
difficult labour	3	2.2
neonatal jaundice	9	6.6
don't know cause	6	4.4
What do you think CP is		
benign condition	52	38.0
progressive diseases	75	54.7
run in certain families	9	6.6
hereditary of infectious	1	.7
Do you think there is increased chance to have another affected child		
Yes	35	25.5
No	28	20.4
don't know	74	54.0
Do you think CP has strong association with other physical disabilities		
Yes	54	39.4
No	70	51.1
can't tell	13	9.5
Do you think Immunization should be delayed or ceased I CP patients		
Yes	39	28.5
No	98	71.5
Who is your source of information		
medical personnel & health workers	127	92.7
Media	10	7.3

5.4. Primary caregivers' Attitude on Cerebral palsy

The overall attitude of children primary caregiver on cerebral palsy were as shown in the figure below

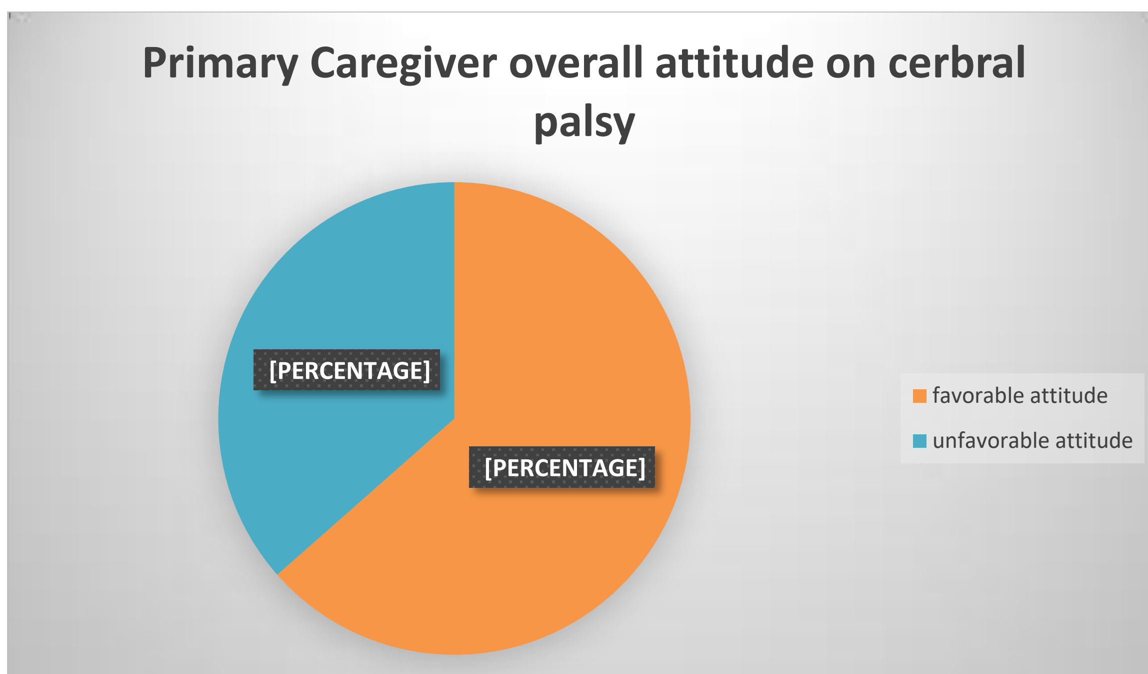

Figure 4. The overall attitude of primary caregiver on cerebral palsy

From all participants, 56.2% think about the association of CP and mental retardation and 92% aware bout What do you think the effect of CP on the need of the child special schools and lives in special communities' special treatment owing to their disability for CP children and 48.2% of participants don't think about the use of traditional medicine for CP management as shown in the table below.

Table 4. the attitude of study participants on children cerebral palsy

Variable	frequency	Percent
Do you think that CP is associated with later development of mental retardation?		
Yes	77	56.2
No	60	43.8
What do you think the effect of CP on the need of the child		
special schools and lives in special communities	126	92.0
special treatment owing to their disability	11	8.0
think traditional medicine can be used in the management of CP		
Yes	71	51.8
No	66	48.2
Are you able to perform your house-hold/official activities properly with taking care of your child in the home		
can perform	57	41.6
can't perform	80	58.4
How much time you can give to perform those activities please explain		
too much time	95	69.3
not too much time	42	30.7

Do you think it is enough for you if not then why not		
Enough	46	33.6
not enough	91	66.4
You have to spend lots of time and have to give special care to your child.		
feel fine	46	33.6
feel tired	91	66.4
Do you face any extra stress or impact on your family relationship due to your child		
Yes	98	71.5
No	39	28.5
Do you think that your other family members are supportive and sympathetic towards your child		
Yes	80	58.4
No	57	41.6
Do you think that your neighbours are supportive and sympathetic towards your child		
Yes	80	58.4
No	57	41.6
Have you face any stigma due to having a child with cerebral palsy		
Yes	65	47.4
No	72	52.6
Do you think that you are only responsible for your child's cerebral palsy		
Yes	67	48.9
No	70	51.1
Do you feel frustration because of having a child with cerebral palsy		
Yes	39	28.5
No	98	71.5

5.5. Primary caregivers' Practice on cerebral palsy child

The overall practice of study participants for caring cerebral palsy children were as shown the figure below

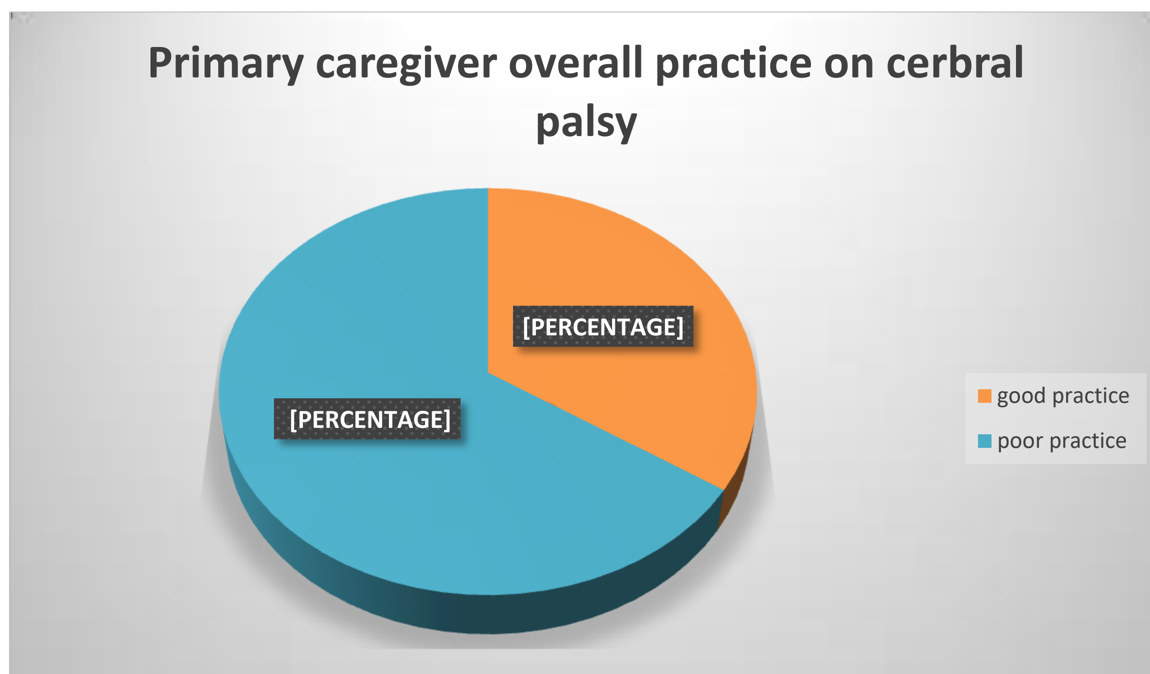

Figure 5. the overall practice of primary caregiver giving a care for cerebral palsy children

Concerning to the specific practice-based question, 77.4% children having CP feed by mouth, 15.3% feed independently and 67.2% of children start physiotherapy and from those 42.4% were started in the physiotherapy centre and only 4.4% took physiatry in daily base as shown in the table below

Table 5. The practice-based characteristics of study participants on CP

Variable	frequency	Percent
How are you feeding your child		
breast feeding	3	2.2
bottle feeding	28	20.4
feed by mouth	106	77.4
Does he/she feed himself		
Independently	21	15.3
Dependently	116	84.7
Did your child started physiotherapy		
Yes	92	67.2
No	45	32.8
If ‘yes’ specify place (92)		
Home	53	57.6
physiotherapy centre	39	42.4
How many times per week does your child do physiotherapy		
once per week	14	10.2
twice per week	49	35.8
three times per week	8	5.8

every day	6	4.4
Sometimes	14	10.2
Does your child go to school		
Yes	26	19.0
No	111	81.0
Is your child on medication		
Yes	78	57.4
No	59	42.6
type of medication		
Clonazepam	25	32
Phenobarbital	14	18
Phenytoin	1	1.3
sodium valproate	38	48.7

5.6. Determinant factor affecting caregiver practice on cerebral palsy

The strength of association was measured using odd ratio and 95% CI by using binary logistic regression model. Accordingly, sex, relation of primary caregiver was an association with practice on CP by bivariate logistic regression and the finding of multivariable logistic regression showed that, the odds of male caregiver had 60% less likely in practice of CP than female caregiver (AOR=0.4, 95%CI=0.17, 0.99) and participant having partially adequate income had 2.6 times increase in practice than having inadequate income (AOR=2.6, 95%CI=1.05, 6.46) and having good knowledge had increase their practice by 1.9 folds than participant having poor practice (AOR=1.9, 95%CI=1.76, 4.87)

Table 6. the Dependent and independent variable relation using bivariate and multivariate regression on cerebral palsy children caregiver practice in TASH, Addis Ababa

Variable	Practice on cerebral palsy		p-value	COR (95%CI)	P-value	AOR (95% CI)
	Good	Poor				
Sex of caregiver						
male	26	68	0.017	0.4(0.19, 0.85)	0.047	**0.4(0.17, 0.99)**
female	21	22	1		1	
Birth order						
1st	22	39	1		1	
2nd	10	34	0.146	0.5(0.23, 1.25)	0.086	0.42(.156, 1.129
3rd	12	17	0.627	1.3(0.51, 3.09)	0.685	1.2(.435, 3.547
>3	3	0	**		**	
Primary caregiver						
mother	30	47	1		1	
father	1	2	0.845	0.8(0.07, 9.02)	0.739	0.65(0.05, 8.20)
both parents	7	25	0.0910	0.4(0.17, 1.14)	0.103	0.39(0.13, 1.21)
adult relatives	2	2	0.662	1.6(0.21,	0.569	1.9(0.22, 15.52)

				11.73)		
non relative	7	9	0.722	1.2(0.41, 3.62)	0.516	1.5(0.44, 5.24)
orphanage	0	5	**		**	
Adequacy of income						
partially adequate	26	41	0.279	1.5(0.74, 3.01)	0.039	**2.6(1.05, 6.46)**
inadequate	21	49	1		1	
Knowledge						
poor knowledge on cp	10	36	1		1	
Good knowledge on CP	37	54	0.030	2.5(1.09, 5.58)	0.017	**1.9(1.76, 4.87)**
Attitude on CP						
unfavorable	15	35	1		1	
favorable	32	55	0.422	1.4(0.64, 2.86)	0.321	1.6(.64, 3.88)

6. Discussion

cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood. it is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles. The symptoms of CP vary from person to person. Parents with CP children play a significant role in taking care of their CP children as these children demand more intense care. Good knowledge, attitude, and behavior may give these parents an aid to handle their situation.

Socio demographic characteristic of the study group:

The male to female ratio in our study is 2.1: 1 which is found higher than that was reported previously by a study done at Khartoum (1.37: 1) (17), and Bangladesh (1.5:1) (22). Our findings, suggests CP have a significant male predominance as also found in literature. Among care givers of children in the study were illiterate (7.3%), which is a low percentage, in comparing to the results reported by Dr. Sheima (22.1%) (17) only 24.8% and 26.3% were in primary and secondary education respectively, which reflects that still education is a big problem in Ethiopia. Mothers account more than half of the primary caregiver amongst this (40.1%) of them are house wives. Regarding the monthly income; almost all the population in the study had restricted income, which was less than 10,000 birr.

66% of our participants have good knowledge about cerebral palsy. This finding was higher than the previous study which was conducted in Khartoum pediatric hospitals (17) and Indonesia (8), which is 51.6%. This can be explained among our study group the number of illiterates were smaller and majority of our study group also attended college. The other reasoning can be difference in study population, it might be also difference in study area and that may lead to difference in awareness of the population.

Concerning to the specific knowledge assessment of the participant, 87.6% the study participants were aware about cerebral palsy after the diagnosis of the children compering this to the study conducted in

Khartoum paediatrics hospital (17) 93.6% of the study participant were aware about CP after the diagnosis and shows a slightly higher number of participants were aware about cp prior to diagnosis, which can be explained by educational level difference of the study population.

In our study we tried to identify the risk factors of CP, the major risk factor was perinatal asphyxia 50.4% which is higher to what was found by Ibrahim & Muneer 27% followed by meningitis in post neonatal period 4.4% which is less than what found by Dr sheima (17) 17.3%. Neonatal jaundice was found in (6.6%) of our study group which is comparable to what's reported in literature. 67.9% know about the relationship between CP and brain insult and half of the participants know about PNA as cause for brain damage and 39.4% about the strong relation of CP and physical disability.

28.5% of the caregivers consider that a child with CP had a reason to postpone the immunization schedule, which is higher than study done by Dr Sharma in Khartoum (7.4%) (17) which reflects we have a lot work to do on educating our population about immunization.

We observed in our study the great role that health institutes, medical personnel play to provide health education 92.7% the media play a small part 7.3% to provide health education.

CP challenging and impose a burden on their parents; in this way, they experience significantly poorer satisfaction with life and psychosocial well-being compared to the parents of children with typical development. Reports also indicate that parenting these children involves more stress, anxiety, and depression and anxious parents are more likely to have anxious children. Since the emotional well-being of parents may influence their parenting attitudes toward their children. Therefore, the report of this study showed that the attitude of primary caregiver on child's cerebral palsy was 64%. But the possible reason for the increment of the attitude of the participants were increased awareness about the characteristics and possible outcomes of CP.

Regarding some aspects of attitudes of the caregivers included in the study we found that 51.8% believes in traditional medicine which is less than that found by Dr Sharma (17). Despite the fact that almost all mothers admitted that the CP child needs more attention and care 92%, and the family was in great discomfort due to his or her disability, also confessed that it is shameful to have a child with CP; almost all caregivers strongly refused the idea of putting the child in an institute which was similar to what was found in literature.

On the other hand, the practice of study participants on cerebral palsy were low (34%). This may be due to the socio-economic status of the participants, in which most of the material to manage and treat cerebral palsy were costly. This finding reasoning was supported by the statistically significant variable.

So, determinant variable that determine the practice of study participants were sex (male caregiver had 60% less practice of CP than female caregiver) and participant having partially adequate income had 2.6 times increase in practice than having inadequate income and having good knowledge had increase their practice by 1.9 folds than participant having poor practice.

Knowledge and practices of the physiotherapy methods by caregivers was high in 67.2%, more than half conduct the exercises of physiotherapy at home, besides what the child have in the physiotherapy clinics. Schooling was deficient in 81% of children at school age due to unavailability special need school and transportation problems, the remainder were in ordinary schools.

7. Conclusion

Cerebral palsy is the commonest physical disability and the majority of cerebral palsy cases were related to preventable causes. It is was not known to, almost, all mothers before they had an affected child. So, health institutes and workers play a major role in providing health education to the community. To conclude, caring for a child with cerebral palsy is a big task requiring mental fortitude and physical vitality as well as community involvement. In order to improve outcomes for children with CP and to maintain the health of caregivers, necessary support systems must be in place. Social welfare and other organizations should support mothers with cerebral palsy children to help lift the huge financial burden required for care of their children. Government should also create an enabling and supportive environment through the establishment of rehabilitation centres and social protection policies for cerebral palsy children. A multi-disciplinary approach is needed to assist caregivers on all fronts to deal with day-to-day challenges.

8. Limitation of study

The study though it is done in on the biggest specialized hospital of Ethiopia where patients are referred from all over the country, it is not representative of the general population. The children included in our study are referred mostly from Addis Ababa they were probably referred due to the severity of their case. This can affect our result by depicting higher numbers of severe cases. Though the study has more than adequate sample size and is adequately powered, causal relationships cannot be determined from our study as it is a cross sectional study done at a point in time.

9. Recommendation

There is a need to know more facts about CP among children, so we recommended that:

1- Conducting community based prospective studies to know the actual incidence of CP among our children.

2- Neonatal resuscitation programs should be one of the priorities in our health programs.

3- There is a need to establish a comprehensive program that can improve emergency obstetric and neonatal care and also promote fetal survival.

4- There is a need to multidisciplinary centers in order to take care of children with CP and counsel their parents.

5- Doctors and other medical personnel should give time to parents especially the mothers of children with cerebral palsy and make it one of their tasks to:

• Identify factors that predispose to CP.

• Inform them about nature of CP and the methods of management.

• Incorporate knowledge of CP in the curriculum of health visitors and nursery schools.

• Assess the psychological impact of disability on parents and offer counseling

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11. Annexes

Annex I**; selection of cases to be included on the study**

Code number _____________ Date ____/___/___

Please use the following SCPE decision tree to decide on inclusion of the child to the study

NB; if the child was already diagnosed with CP but excluded according to this decision tree please notify the consultant neurologist and the primary investigator.

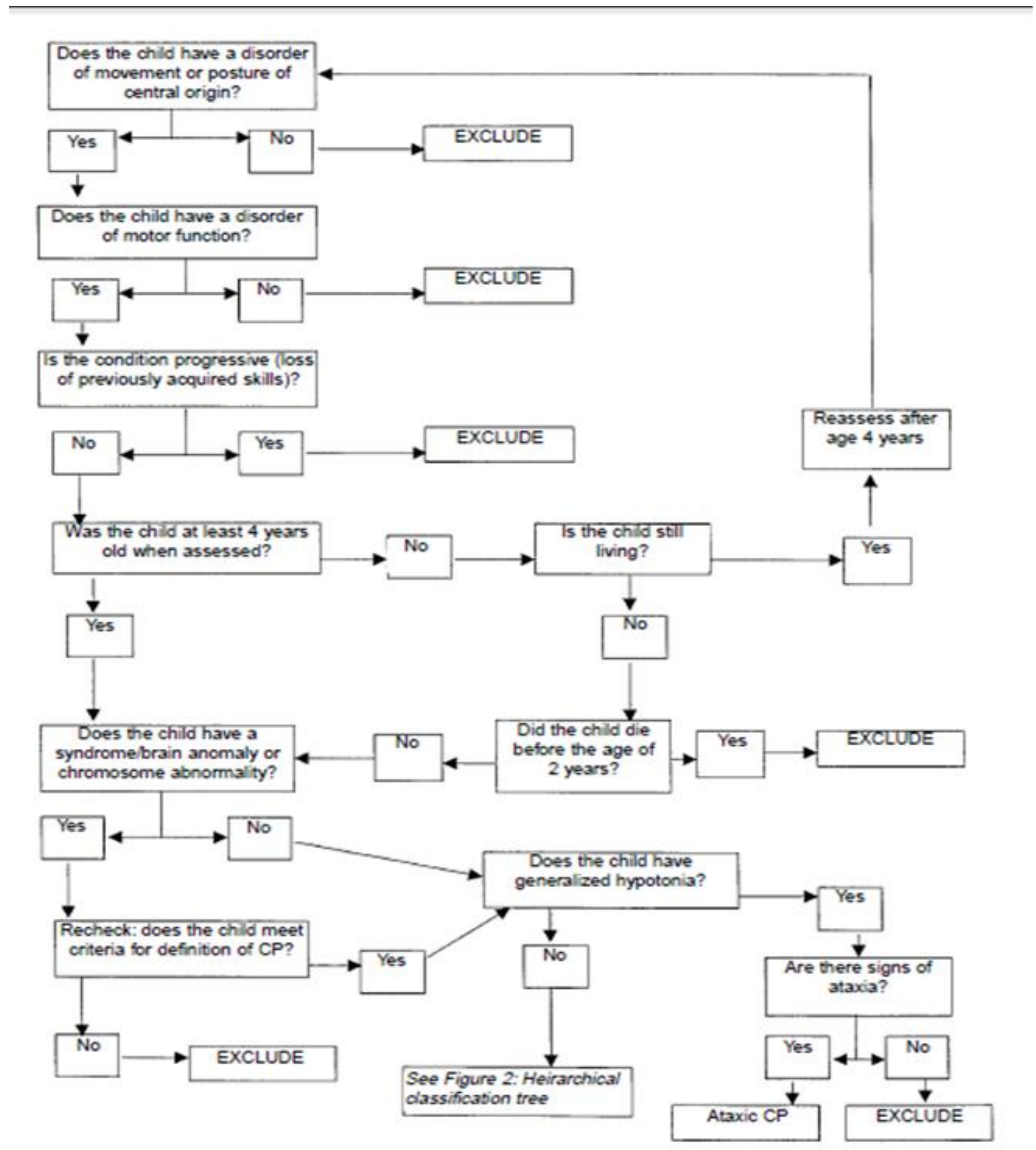

Fig I. Decision tree for inclusion/exclusion of cases of cerebral palsy

Annex II: Primary Caregiver's Information sheet and Consent Form

CONSENT FORM

(Please read out to the participant)

My name is Dr Firehiwot; I am conducting a study for partial fulfillment of the requirements for specialty certificate in Pediatrics and child health, titled on

"Knowledge, Attitude and Practice of caregivers of Children with Cerebral Palsy attending follow up at Neurology Clinic in Tikur Anbessa Specialized Hospital"

From the Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University.

The purpose of this study is to describe and analyze the knowledge, attitude and practice of parents and guardians with CP in Ethiopia; it attempts to address some of the gaps by enhancing parents and guardians knowledge regarding CP, and to provide better management and rehabilitation of this vulnerable population and their parents. It is hoped that the results from this research work will assist to shed more light on this neglected topic by increasing the knowledge of parents on CP and serve as the basis for setting up larger epidemiological and community based intervention studies to improve the quality of life of children with CP and their caregivers in Ethiopia. I would like to know some information related to my study.

I would like to inform you that this is a purely academic study and obtain information will not be used for any other purpose. All information provided by you will be kept confidential and also the source of information will remain anonymous.

Your participation in his study voluntarily and also have the right not to answer a particular question that you don't like or do not want to answer during interview .

Do you have any questions before I start?

So may I have your consent to proceed with the interview?

Yes ☐ No ☐

Signature of the witness…………………. Date……………….

Signature of the participants……………… Date………………

Informed Consent Form for care givers of children with CP (Amharic Version)

<u>የ ጥናቱ የ ሚረጃ እና ስምምነ ት ሰነ ድ</u>

ይህ የሚደኝ እና የስምምነት ሰነድ በጥቁር አንበሳ ሆስፒታል የሚታከሙ በእርግዝና ወቅት ወይም በወሊድ ጊዜ በተከሰተ የአእምሮ ጉዳት ምክንያት ሰውነታቸውን የማዘዝ ችግር ያለባቸው ህፃናት ተንከባካቢዎች ዕውቀት ፣ አመለካከትና ተግባር በተመለከተ ለሚደረገ ውጥናት የተዘጋጀ ነው።

የዚህ ጥናት ዓላማ የወላጆችን እና የአሳዳጊዎችን ዕውቀት ፣ አመለካከት እና አሠራር በኢትዮጵያ ከሲፒ ጋር ለመግለፅ እና ለመተንተን ነው፣ ሲፒን በተመለከተ የወላጆችን እና የአሳዳጊዎችን ዕውቀት በማሻሻል በትአንዳንድ ክፍተቶችን ለመቅረፍ እንዲሁም የተሻለ አያያዝ እና ተሃድሶ ለማስጠት ነው፡ ፡

ከዚህ የምርምር ሥራ የተገኘው ውጤት በዚህ ችላ በተባለው ርዕስ ላይ የወላጆችን እውቀት በመጨመር በሲፒ ላይ የበለጠ ብርሃን ለማብራራት ይረዳል እንዲሁም የኑሮ ጥራትን ለማሻሻል ትልቅ ኤፒዲሚዮሎጂያዊ እና ህብረተሰብን መሠረት ያደረጉ ጣልቃ ገብነት ጥናቶችን ለማቋቋም መሠረት ሆኖ ያገለግላል ፡ ፡ ይህ ሙሉ በሙሉ የአካዳሚክ ጥናት መሆኑን ለማሳወቅ እና መረጃ ለማግኘት ለሌላ ዓላማ አይውልም፡ ፡ በአንተ የቀረቡት መረጃዎች በሙሉ በሚስጥራዊነት ይቀመጣሉ እንዲሁም የመረጃው ምንጭ የማይታወቅ ይሆናል፡ ፡ የጥናቱ የተሳታፊዎችን መረጃም ሆነ ማንነት በሚስጥር የሚጠበቅ ይሆናል በሚሆኑም የተሳተፊዉስም በጥናቱ ማጠይቅ ላይ አይካተትም።

በጥናቱ ውስጥ ያለዎት ተሳትፎ በፈቃደኝነት እንዲሁም በቃለ ማጠይቅ ወቅት የማይወዱትን ወይም የማይፈልጉትን የተወሰነ ጥያቄ ላለመመለስ መብት አለው፡ ፡

ልጁ/ልጅቱ በጥናቱ እንዲሳተፍ ከፈቀዱስለ የማህበራዊ እና ጤና ሁኔታ መረጃ ይሰጣሉ።

ከመጀመሬ በፊት ጥያቄዎች አሉዎት?

ስለዚህ ቃለ ማጠይቁን ለመቀጠል የእርስዎ ፈቃድ ሊኖርኝ ይችላል?

አዎ □ አይ □

የምስክሩ ፊርማ………………….. ቀን ……………….

የተሳታፊዎቹ ፊርማ……………… ቀን ………………

Annex III: Study Questionnaire

Title of the Research – Knowledge, Attitude and Practice of caregivers of Children with Cerebral Palsy attending Follow up at Neurology Clinic in Tikur Anbssa Specialized Hospital, Addis Ababa, Ethiopia.

Instructions – Please take your time to carefully complete the information below.

Code number ______________ Date ____/___/___

Part I – Socio-demographic Data of child

1. Date of birth ______/_____/________
2. Age in completed years and months |___|___|
3. Sex:
   a. Male b. Female
4. Birth order
   a. First b. Second c. Third d. More(specify)
5. Family size |___|___|
6. Address (region)
   a. AA b. Oromia c. Amhara d. SSNPR e.Others (specify)_______
7. Religion:
   a. Orthodox Christian b. Muslim c. Protestant d. Catholic e.Other, specify_________________
8. Immunization History:
   a. Is immunization completed? ________________________________
   b. If no, what doses are missing?

   1.____________ 2.____________ 3.____________4.________________
9. Child's level of education
   a. . No schooling b. Nursery c. Primary School (grades 1-8) d. Secondary school (grades 9-12)

Part II–Family and Primary caregivers' information

1. Who is the primary caregiver?
2. If not parents, state why____

   a. Mother b. Father c. Both parents

   d. Adult relative e. Non relative adult f. Orphanage
3. Primary care giver's age

   a. under 20 yr. b. b/n 20 -30 yr. c. b/n 30 -40yr.

d. b/n 40 -50yr. e. b/n 50-60 yr. f. above 60 yr.

4. What is the marital status of parents?
   a. Single parent b. Married c. Divorced
   d. Widowed (specify the deceased) ________________
5. Primary caregiver's highest level of education **(Mother)**
   a. Illiterate b. Can read and write c. Primary education (attended grades 1-8)
   d. Secondary education (attended grades 9-12)
   e. College level education (certificate/diploma/1st degree/Master/MD/PhD)
6. Primary caregiver's occupation (**Mother**) ______________________
7. Primary caregiver's highest level of education (**Father**)
   a. Illiterate b. Can read and write c. Primary education (attended grades 1-8)
   d. Secondary education (attended grades 9-12)
   e. College level education (certificate/diploma/1st degree/Master/MD/PhD)
8. Primary caregiver's occupation **(Father)** ______________________
9. Primary caregiver's highest level of education (**Other**)
   a. Illiterate b. Can read and write c. Primary education (attended grades 1-8)
   d. Secondary education (attended grades 9-12)
   e. College level education (certificate/diploma/1st degree/Master/MD/PhD)
10. Primary caregiver's occupation (**Other**) ______________________
11. What is your household income per month?
    a. Under 3000 birr B. b/n 3000 – 6000 birr c. b/n 6000- 10,000 birr
    d) 10,000 -15,000 e. Above 15,000
12. Monthly income (as perceived by primary care giver to support the family):
    1. Partially Adequate income 2. Inadequate income

Part III–Primary caregivers' knowledge

1. When were you aware about CP?
   a) Prior to the diagnosis of your child
   b) After the diagnosis of your child
   c) Not aware at all
2. What possible risk factors can cause CP?
   a) Perinatal event b) Witch craft c) Evil eye
   d) Underlying brain abnormality e) preterm labor
   f) Can't find any cause to blame g) other causes like febrile illness

3. Do you think there is direct relationship between brain insult and CP?
   a) Yes, there should be
   b) No, that is not necessary
   c) I don't know

if 'Yes" proceed with question number 4

4. What do you think the cause of brain damage?
   a) Perinatal asphyxia b) meningitis c) difficult labor
   d) Neonatal jaundice e) febrile illnesses
   f) Do not know the cause
5. What do you think CP is?
   a) It is benign condition.
   b) It is a progressive disease.
   c) Run in certain families.
   d) It is hereditary or infectious disease.
6. Do you think there is increased chance to have another affected child?
   a) Yes, it has increased risk
   b) No, there is no increased chance
   c) I don't know.
7. Do you think CP has strong association with other physical disabilities?
   a) Yes b) No c) I can't tell
8. Do you think Immunization should be delayed or ceased I CP patients?

   Yes ☐ No ☐
9. Who is your source of information?
   a) Medical personnel and health workers
   b) Media (television &radio)
   c) Friends or neighbors

Part IV– Primary caregivers' Attitude.

1. CP is associated with later development of mental retardation.

   Yes ☐ No ☐

2. What do you think the effect of CP on the need of the child?
   a) They should have special schools and live in special communities that affords their needs
   b) They need special treatment owing to their disability.
3. Do you think traditional medicine can be used in the management of CP?

Yes ☐ No ☐

If yes what type ______________________

4. Are you able to perform your house-hold/official activities properly with taking care of your child in the home?

-How much time you can give to perform those activities please explain?

-Do you think it is enough for you if not then why not?

5. You have to spend lots of time and have to give special care to your child. By maintaining this entire things how you feel physically?
    1. I feel fine
    2. I feel tired and exhausted
6. Do you face any extra stress or impact on your family relationship due to your child?

   Yes ☐ No ☐
7. Do you think that your other family members are supportive and sympathetic towards your child? Yes ☐ No ☐
8. Do you think that your neighbors are supportive and sympathetic towards your child?

   Yes ☐ No ☐
9. Have you face any stigma due to having a child with cerebral palsy?

   Yes ☐ No ☐
10. Do you think that you are only responsible for your child's cerebral palsy?

   Yes ☐ No ☐
11. Do you feel frustration because of having a child with cerebral palsy?

   Yes ☐ No ☐

Part V– Primary caregivers' Practice.

1. How are you feeding your child?
   a) breast feeding
   b) Bottle feeding
   c) Mouth feeding
2. Does he/she feed himself independently? Or with help of the care giver?
3. Did your child started physiotherapy?

   Yes ☐ No ☐
4. If 'yes' specify where? a) home b) physiotherapy center
5. How many times per week does your child do physiotherapy?
   a) Once per week
   b) Twice per week
   c) Three times per week
   d) Everyday
   e) Sometimes

Questions no 6 is for school age CP children.

6. Does your child go to school? Yes ☐ No ☐
7. If 'No' specify the reason. ______________________________

    a. Is your child on medication? Yes ☐ No ☐ what type specify __________

8. Who will give the medication? ______________

Thank you!!!

የ ጥና ት ማጠይቅ

የ ምር ምር ውር ዕ ስ - በ ጥቁር አ ን በ ሳ ሆስ ፒ ታል የ ሚታከ ሙበ እ ር ግዝና ወቅት ወይምበ ወሊድ ጊ ዜ በ ተከ ሰ ተ የ አ እ ምሮ ጉዳት ምክ ን ያ ት ሰ ውነ ታቸውን ማዘ ዝ ችግር ያ ለ ባ ቸውህ ፃ ና ት ተን ከ በ ካ ቢዎች ዕ ውቀት ፣ አ መለ ካ ከ ትና ተግባር በ ተመለ ከ ተ ለ ሚደረ ገ ውጥና ት የ ተዘ ጋጀ ነ ው፡፡

መመሪ ያ ዎች - እ ባ ክ ዎን ከ ዚህ በ ታች ያ ሉትን ሚ ጃዎች በ ጥን ቃቄ ለ ማጠና ቀቅ ጊ ዜ ይውሰ ዱ፡ ፡

የ ኮድ ቁጥር _____________ ቀን ____ / ___ / ___

ክ ፍል I - የ ልጁ ማህበ ራዊ-ስ ነ -ህዝብ ሚ ጃ

1. የ ትውል ድ ቀን ______ / _____ / ________

2. ዕ ድሜበ ተጠና ቀቁ ዓ መታትና ወሮች ውስ ጥ|||

3. ፆ ታ:

ሀ. ወን ድ ለ . ሴት

4. የ ልደት ቅደምተከ ተል

ሀ. መጀመሪ ያ ለ . ሁለ ተኛ ሐ. ሦስ ተኛ ው መ. ተጨማሪ (ይግለ ጹ)

5. የ ቤተሰ ብ ብዛ ት |||

6. አ ድራሻ (ክ ልል)

ሀ. AA ለ . ኦ ሮሚያ ሐ. አ ማራ መ. SSNPR e. ሌሎች (ይግለ ጹ) _______

7. ሃ ይማኖ ት

ሀ. ኦ ር ቶዶክ ስ ክ ር ስ ቲያ ን ለ . ሙስ ሊም ሐ. የ ፕሮ ቴስ ታን ት መ. ካ ቶሊክ

ሌላ ፣ ይግለ ጹ________________

8. የ ክ ትባ ት ታሪ ክ

ሀ. ክ ትባ ት ተጠና ቋል ? ______________________________

ለ . ካ ልሆነ ፣ ምን ዓ ይነ ት ማጠኖች ይጎ ድላ ሉ?

1 .____________ 2 .____________ 3 .____________ 4 .________________

9. የ ልጆች የ ትምህር ት ደረ ጃ

ሀ. . አ ል ተማሪ ም ለ . የ ህጻ ና ት መዋያ

ሐ. አ ን ደኛ ደረ ጃ ትምህር ት ቤት (ኛ 1-8) መ. ሁለ ተኛ ደረ ጃ ትምህር ት ቤት (ከ 9 ኛ እ ስ ከ 12 ኛ ክ ፍል)

ክፍል II – የቤተሰብእና የመጀመሪያ ደረጃ ተንከባካቢዎች ሚጃ

1. ዋና ተንከባካቢ ማን ነው?

2. ወላጆች ካልሆኑ ለምን እንደሆነ ይግለጹ____

ሀ. እናት　　ለ. አባት　　ሐ. ሁለቱምወላጆች

መ. ጎልማሳ　　ሠ. ዘመድ ያልሆነ　　ረ. የሕፃናት ማሳደጊያ

3. የመጀመሪያ ደረጃ እንክብካቤ ሰጪዕድሜ

ሀ. ከ 20 ዓመት በታች　　ለ. 20 -30 ዓመት.　　ሐ. 30 -40yr.

መ. 40 -50yr.　　ሠ. 50-60 ዓመት.　　ረ. ከ 60 ዓመት በላይ

4. የወላጆች የጋብቻ ሁኔታ ምንድነ ው?

ሀ. ነ ጠላ ወላጅ　　ለ. ያገባች　　ሐ. የተፋታች

መ. ማጣለት (ማዱን ይጥቀሱ) ________________

5. የመጀመሪያ ደረጃ ተንከባካቢ ከፍተኛ የትምህርት ደረጃ (እናት)

ሀ. የተማረ አይደለም

ለ. ማንበብእና መጻፍ ይችላል

ሐ. የመጀመሪያ ደረጃ ትምህርት (ከ 1ኛ እስከ 8ኛ ክፍል የተማሩ)

መ. የሁለተኛ ደረጃ ትምህርት (ከ 9ኛ እስከ 12ኛ ክፍል የተማሩ)

ሠ. የኮሌጅ ደረጃ ትምህርት (የምስክር ወረቀት / ዲፕሎማ/ 1ኛ ዲግሪ / ማስተር / ኤምዲ / ፒኤችዲ)

6. የመጀመሪያ ደረጃ ተንከባካቢ ሥራ (እናት) _______________________

7. የመጀመሪያ ደረጃ ተንከባካቢ ከፍተኛ የትምህርት ደረጃ (አባት)

ሀ. የተማረ አይደለም

ለ. ማንበብእና መጻፍ ይችላል

ሐ. የመጀመሪያ ደረጃ ትምህርት (ከ 1ኛ እስከ 8ኛ ክፍል የተማሩ)

መ. የሁለተኛ ደረጃ ትምህርት (ከ 9ኛ እስከ 12ኛ ክፍል የተማሩ)

ሠ. የኮሌጅ ደረጃ ትምህርት (የምስክር ወረቀት / ዲፕሎማ/ 1ኛ ዲግሪ / ማስተር / ኤምዲ / ፒኤችዲ)

8. የመጀመሪያ ደረጃ ተንከባካቢ ሥራ (አባት) _______________________

9. የመጀመሪያ ደረጃ ተንከባካቢ ከፍተኛ የትምህርት ደረጃ (ሌላ)

ሀ. የተማረ አይደለም

ለ. ማንበብ እና መጻፍ ይችላል

ሐ. የመጀመሪያ ደረጃ ትምህርት (ከ 1ኛ እስከ 8ኛ ክፍል የተማሩ)

መ. የሁለተኛ ደረጃ ትምህርት (ከ 9ኛ እስከ 12ኛ ክፍል የተማሩ)

ሠ. የኮሌጅ ደረጃ ትምህርት (የምስክር ወረቀት / ዲፕሎማ/ 1ኛ ዲግሪ / ማስተር / ኤምዲ / ፒኤችዲ)

10. የመጀመሪያ ደረጃ ተንከባካቢ ሙያ (ሌላ) ________________________

11. በወር የቤተሰብዎ ገቢ ምን ያህል ነው?

ሀ. ከ 3000 ብር ለ. 3000 በታች - 6000 ብር ሐ. 6000-10,000 ብር

መ) 10,000 -15,000 ሠ. ከ 15,000 በላይ

12. ወርሃዊ ገቢ

ሀ. በከፊል በቂ ገቢ ለ. በቂ ያልሆነ ገቢ

ክፍል III – የመጀመሪያ ደረጃ ተንከባካቢዎች እውቀት

1. ስለ ሲፒ መቼ ያውቁ ነበር?

ሀ) ልጅዎ ምርመራ ከማድረግዎ በፊት

ለ) ከልጅዎ ምርመራ በኋላ

ሐ) በጭራሽ ግንዛቤ የለኝም

2. ምን አደጋ ሊያስከትሉ የሚችሉ ምክንያቶች ለ CP መንስኤ ሊሆኑ ይችላሉ?

ሀ) የቅድመወሊድ ክስተት ለ) ጥንቆላ ሐ) ክፉ ዓይን

መ) የአእምሮ ያልተለመደ ሁኔታ ሠ) የቅድመወሊድ ምጥ

ረ) ለመውቀስ ምንምምክንያት ማግኘት አይቻልምሰ) እንደ ትኩሳት በሽታ ያሉ ሌሎች ምክንያቶች

3. በአንጎል ችግር እና ሲፒ መካከል ቀጥተኛ ግንኙነት አለ ብለውያስባሉ?

ሀ) አዎ መኖር አለበት

ለ) የለም፣ አስፈላጊ አይደለም

ሐ) አላውቅም

አዎ ከሆነ በጥያቄ ቁጥር 4 ከቀጠለ

4. የአንጎል ጉዳት መንስኤ ምን ይመስልዎታል?

ሀ) የ ፔርናታል አስፐክሲያ ለ) የ ሜጅራት ገ ትር በሽታ

ሐ) አስቸጋሪ ዌልድ

ማ) በተወለዱ ሕፃናት ዕድሜላይ ቢጫመሆን e) የ ትኩሳት በሽታዎች

ረ) ማንስኤውን አያውቁም

5. ሲፒ ምን ድን ነ ውብለውያስባሉ?

ሀ) ጥሩ ያልሆነ ሁኔ ታ ነ ው፡ ፡

ለ) የ ማያቋርጥበሽታ ነ ው፡ ፡

ሐ) በተወሰኑ ቤተሰቦች ውስጥመኖር ፡ ፡

ማ) በዘ ር የ ሚተላለፍ ወይምተላላፊ በሽታ ነ ው

6. ሌላ የ ተጠቂ ልጅ ለመውለድ እድሉ የ ጨምሪ ይማስልዎታል?

ሀ) አዎ ዕድሉን ጨምሯል

ለ) የ ለም፣ የ ጨምሪ ውዕድል የ ለም

ሐ) አላውቅም

7. ሲፒ ከሌሎች የ አካል ጉዳተኞች ጋር ጠንካራ ትስስር አለውብለውያስባሉ?

ሀ) አዎ ለ) አይ ሐ) መናገ ር አልችልም

8. ክትባት በሲፒ ህሙማተኞች ማዘ ግየ ት ወይምማቆምአለበት ብለውያስባሉ?

አዎ □ አይ □

9. የ ሚረጃ ምን ጭዎ ማን ነ ው?

ሀ) የ ህክምና ሰራተኞች እና የ ጤና ሰራተኞች

ለ) ሚዲያ (ቴሌቪዥን እና ሬዲዮ)

ሐ) ጓደኞች ወይምጎረቤቶች

ክፍል IV - የ መጀመሪያ ደረጃ ተንከባካቢዎች አማለካከት.

1. ሲፒ ከጊዜ በኋላ የ አእምሮ ዝግመት እድገ ት ጋር የ ተቆራኘ ነ ው፡ ፡

አዎ □ አይ □

2. ሲፒ በልጁ ፍላጎ ት ላይ የ ሚያሳድረውተጽዕኖ ምን ይማስልዎታል?

ሀ) ልዩ ትምህርት ቤቶች ሊኖሯቸውእና ፍላጎ ታቸውን በሚከመልዩ ማህበረሰቦች ውስጥመኖር አለባቸው

ለ) በአካለ ስንኩልነ ታቸውልዩ ህክምና ይፈልጋሉ፡ ፡

3. ባህላዊ ሕክምና ለ Cp ሕክምና ሲባል ሊያገለግል ይችላል ብለው ያስባሉ?

አዎ □ አይ □

አዎ ከሆነ ምን ዓይነት

4. በቤት ውስጥ ልጅዎን ከመንከባከብ ጋር የቤት-ማቆያ /ኦፊሴላዊ እንቅስቃሴዎን በትክክል ማከናወን ይችላሉ?

- እነዚያን ተግባራት ለማከናወን ምን ያህል ጊዜ ማስጠት ይችላሉ እባክዎን ያስረዱ?

- ለእርስዎ በቂ ነው ብለው ያስባሉ ታዲያ ካልሆነ ለምን?

5. ብዙ ጊዜ ማሳለፍ እና ለልጅዎ ልዩ እንክብካቤ ማስጠት አለብዎት፡፡ ስለዚህ በአካል ምን ይሰማዎታል?

1. ጥሩ ስሜት ይሰማኛል

2. ድካም እና ድካም ይሰማኛል

6. በልጅዎ ምክንያት በቤተሰብዎ ግንኙነት ላይ ተጨማሪ ጭንቀት ወይም ተጽዕኖ ይገጥማዎታል?

አዎ □ አይ □

7. ሌሎች የቤተሰብዎ አባላት ለልጅዎ ደጋፊ እና ርህሩህ ናቸው ብለው ያስባሉ?

አዎ □ አይ □

8. ጎረቤቶችዎ ለልጅዎ ደጋፊ እና ርህሩህ ናቸው ብለው ያስባሉ?

አዎ □ አይ □

9. ሴሬብራል ፓልሲ ያለበት ልጅ በመውለድዎ መገለል አጋጥሞዎታልን?

አዎ □ አይ □

10. ለልጅዎ ሴሬብራል ፓልሲ ብቻ ተጠያቂው እርስዎ ይመስሉዎታል?

አዎ □ አይ □

11. ሴሬብራል ፓልሲ ያለበት ልጅ በመውለዱ ምክንያት ብስጭት ይሰማዎታል?

አዎ □ አይ □

ክፍል V– የመጀመሪያ ደረጃ ተንከባካቢዎች ተግባር።

1. ልጅዎን እንዴት እየመገቡ ነው?

ሀ) ጡት ማጥባት

ለ) ቱቦ መመገብ

ሐ) በአፍ መመገብ

2. ራሱን ችሎ ራሱን ይመገባል? ወይስ በእንክብካቤ ሰጪው እርዳታ ይመገባል?

3. ልጅዎ ፊዚዮቴራፒን ጀምሯል?

አዎ □ አይ □

4)'አዎ' ከሆነ እባክዎን የት ይግለጹ? ሀ) ቤት ለ) የፊዚዮቴራፒ ማዕከል

5. ልጅዎ በሳምንት ስንት ጊዜ የፊዚዮቴራፒ ሕክምና ያደርጋል?

ሀ) በሳምንት አንድ ጊዜ ለ) በሳምንት ሁለት ጊዜ ሐ) በሳምንት ሦስት ጊዜ

መ) በየቀኑ ሠ) አንዳንድ ጊዜ

ጥያቄዎች ቁጥር 6 በትምህርት ቤት ዕድሜ ላይ ለሚገኙ ልጆች ነው፡፡

6, ልጅዎ ትምህርት ቤት ይሄዳል?

አዎ □ አይ □

7. ‹አይ› ከሆነ ምክንያቱን ይግለጹ፡፡ ________________________________

ሀ. ልጅዎ መድሃኒት ላይ ነው?

አዎ □ አይ □ ምን ዓይነት ይጥቀሱ________________________________

8. መድኃኒቱን ማን ይሰጣል?

አመሰግናለሁ!!!