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**KOTEBE UNIVERSITY OF EDUCATION MENELIK II HEALTH SCIENCE AND MEDICAL COLLEGE**

**DEPARMENT OF NURSING**

**KNOWLEDGE, HEALTH CARE PRACTICE AND ASSOCIATED FACTORS OF PARENTS WITH AUTISTIC CHILDREN AT SELECTED AUTISM CENTERS, ADDIS ABABA, ETHIOPIA, 2022**

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**KOTEBE UNIVERSITY OF EDUCATION MENELIK II HEALTH SCIENCE AND MEDICAL COLLEGE**

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| Total cost of the project |  |

**ASSURANCE OF PRINCIPAL INVESTIGATOR**

I the undersigned agree to accept all responsibilities for the scientific and ethical conduct of the research project and for the provision of required reports as per terms and conditions of the guideline of undergraduate studies coordination office in effect at the time after proposal defense is forwarded as the result of this application. It will provide timely progress report to our advisors and seek the necessary advice and approval from our primary advisor in the course of the research.

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# ABBREVATION AND ACRONYMS

**ASD** Autism spectrum disorder

**CI**  Confidence interval

**DSM** Diagnostic and statstical manual of mental disorder

**FMOH** Federal Ministry of Health

**NGO** Non-govermental organization

**PDD**  Pervasive developmental disorder

**QOL** Quality of life

**SES** Socioeconomic status

**SPSS** Statstical package for the social science

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# SUMMARY

**Background**: **-** Autism Spectrum Disorders (ASD) is pervasive and lifelong neurodevelopment disorders characterized by impaired socialization, impaired verbal and nonverbal communication, and restricted interests and repetitive patterns of behavior. According to epidemiological data, ASDs affect one out of every 160 people worldwide, accounting for more than 7.6 million disability-adjusted life years and 0.3 percent of the global illness burden. Nevertheless, there is a significant dearth of awareness regarding ASD among the general public and parents. A lack of understanding of autism has a negative impact on parents' awareness and behaviors, and it is a huge issue in providing health treatment.

**Objective:** to assess level of knowledge, health care practice and its associated factors among parents of autistic children at autistic centers of Addis Ababa, Ethiopia.

**Method:-** Institutional based cross sectional study will be conducted in three hospitals/centers (Yekatit 12, St Paulos, and Nehemiah autistic center). The final sample size is 422 which will be proportionally allocated to each of the institutions and systematic random sampling will be used to select study units that are part of the study. Data will be checked, cleaned and entered in to Epidata software, then will be imported to SPSS version 26.0 software for analysis. The results of the descriptive statistics will be expressed as percentage and frequency. Associations between independent variables and dependent variables will be analyzed using bivariate and multivariate analysis to identify factors which are significantly associated with knowledge; health care practice among parents of autistic children, in one of autistic centers.

**Key words: -** autism, knowledge, health care practice and factors, parents, autistic centers

# INTRODUCTION

## Background Information

Autism Spectrum Disorders (ASD) is pervasive and lifelong neurodevelopment disorders characterized by impaired socialization, impaired verbal and nonverbal communication, and restricted interests and repetitive patterns of behavior [3]. It was first described by the American child psychiatrist Kanner in the year 1943 [4]. ASD includes Autistic disorder, Asperger syndrome, Rett’s syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition [3]. This disorder is present since birth. However, its symptoms are gradually noticed after the age of 6 months and become established by age two or 3 years [5].

The most common conditions seen were learning disability, attention deficit hyperactivity disorder, mental retardation, and stuttering. Children suffering from ASD are more likely to have a variety of medical and psychiatric conditions requiring frequent physician visits for preventive, non-emergency and emergency care and are on high medication usage [6].

Autism appears to be one of the fastest growing disabilities in children [7]. Prevalence rates have been rising sharply [8]. In April 2018, the prevalence of ASD was reported by the Centers for Disease Control and Prevention to be 1 in 59 children, with a male to female ratio of 4:1, that means 1 in 37 males and 1 in 151 females have symptoms consistent with ASD [15]. The estimated prevalence of ASD increased approximately 30% from 2012 to 2013, 23% from 2006 to 2008, and 73% from 2002 to 2008 [15]. WHO stated that the worldwide prevalence of ASD was estimated to be one in 160 children (0.6%). And according to research conducted in 2014, autism affects more male than female individuals, and co morbidity is common (>70% have concurrent conditions) [37].

To date, it is still reported that there is no known medical cure of autism [7]. While specific causes of ASDs have yet to be found, many risk factors identified may contribute to their development. These risk factors include genetics, prenatal and prenatal factors, neuroanatomical abnormalities, and environmental factors [16]. It is possible to identify general risk factors, but much more difficult to pinpoint specific factors [16]. However, early diagnosis of an autism spectrum disorder is important because evidence suggests that interventions to improve functioning may be more effective in younger children and optimize long-term prognosis [7].

ASD is associated with enormous financial burdens for parents [9]. Families of people with autism are also heterogeneous, yet, as a group, they experience lower quality of life than families with a member with other neurodevelopment conditions, even before receiving the formal diagnosis [10]. Parents are typically at the Centre of this support network and carry much of the responsibility of direct care, coordination and advocacy, over and above typical parental responsibilities [11, 12]. The exact parental roles are dependent on the child’s strengths and challenges, and frequently shift over time [13]. During this process, it is important that parents maintain motivation by setting realistic goals and tracking progress to experience the many achievements that their loved one with autism can attain. Effective parents often work closely with experienced providers who can track the development of the child with autism and can provide guidance on next actions [14].

Therefore parents are considered behavior modifiers, regardless of their knowledge and training, and this comes through their interaction with their children and provides guidance and instructions to them [17].

## Statement of the problem

According to epidemiological data, ASDs affect one out of every 160 people worldwide, accounting for more than 7.6 million disability-adjusted life years and 0.3 percent of the global illness burden [18]. Nevertheless, there is a significant dearth of awareness regarding ASD among the general public and parents. Parents, who discover that their child has a developmental difficulty, even if it is not diagnosed, dismiss their child as useless and unworthy of investing money on. The majority of parents had little prior understanding of ASD and felt under-empowered by professional information on autism before or after diagnosis [19].

Lack of informal and professional support, feelings of loss of personal control, and society awareness, according to researchers, are all plausible elements linked to mothers' increased burden in families with children with autism. Lack of information caused several adverse consequences for parents and children in less developed countries, particularly in African societies, as well as a lack of assistance for children and families [25]. As a result, the loss of family income due to the need to care for family members with autism spectrum disorders exacerbates the problem [18].

Also here in Ethiopia, ASD is little understood and known. Diagnostic and educational services are scarce. Families caring for children with autism in Addis Ababa experience significant mental and practical obstacles, including stigma and social exclusion [20]. According researches, more than 80% of autistic people in Ethiopia endure societal stigma [26]. Due to social beliefs that most developmental difficulties are caused by an evil spirit, curse, or sin committed by the respective families, most parents of children with autism end up divorced and depressed [27].

A study conducted in Pakistan indicated that, significant efforts should be aimed at raising knowledge levels amongst them regarding autism, through awareness campaigns. Health professionals should also be directed to educate new parents on all details concerning autism [21].

Also four studies were conducted to further our understanding of ASD [22, 23, 28, and 29]. One assessed a social marketing campaign ("Be aware of the indications. Targeting parents, clinicians, and child care professionals, the campaign included print and Web materials, public service announcements, and a live call center open 24 hours a day, 7 days a week [29]. Changes in autism awareness, knowledge, and behaviors among parents and clinicians over time were evaluated in this study, with reported favorable changes in awareness across the 3-year study period. The effectiveness of training clinicians to recognize autism or developmental delays in children was assessed in the final three studies. Two studies used in-person didactic instruction, and the third used the Internet to offer training. [28]

As a result, parents of children with autism must not only be taught about their children's treatments, but they must also be supported and helped in the best possible way by the state, experts, and the wider community, even on an emotional level. It's also critical that professionals, relatives, friends, and others who aren't familiar with the effects of autism on children and their parents are educated [30].

According to the findings, autistic parents around the world, particularly in developing countries, have a wide range of knowledge and health-care practices, including a lack of awareness, a lack of health-care systems, a lack of support groups, economic instability, stigma, and depression. Furthermore, most people lack proper autism information and health treatment. Given the current situation and the paucity of research in this area, it is vital to analyze the general level of knowledge, health-care practice, and related issues among parents of autistic children.

## Significance of study

Communication with teaching and self-engagement of parents appear to influence their health care behavior in order to boost their knowledge and health care practice. This research is important because it aids in the early detection of autism-related characteristics in parents of autistic children due to a lack of understanding. It will assist local health officials, particularly those who deal with problem, to educate, engage, and collaborate to increase expertise. It assists parents in improving their understanding of autism and its associated issues, as well as their health-care practices. It will serve as a foundation for future research into the role of knowledge and a shift in parental attitudes toward the amount of health care provided to children with autism. It will make a significant contribution to the goal. Furthermore, this research motivates the government and other relevant stakeholders to contribute and pay attention to this issue.

## Justification of the study

Various studies have been conducted on this topic all across the world. Similarly, several Ethiopian scholars have focused their studies on autism. They did, however, bring out a limitation. It is difficult to state that the matter has been successfully raised and debated. Many of the studies conducted in Ethiopia focus on children with ASD, which is admirable, but the parents appear to be overlooked by the researchers. The significance of this research and what makes it unique is that it will not only highlight the extent of the problem, but it will also reveal how the problem is seen by people, institutions, and even the government. It will also emphasize the need of environmental awareness, family support groups, and nearby health facilities.

Because the scope of the problems is far larger than previously thought, this research will pave the way for more research. Furthermore, a small number of studies were undertaken throughout Ethiopia, demonstrating the researchers' and responsible peoples' lack of attention.

# LITERATURE REVIEW

## Introduction

Autism spectrum disorders (ASD) are a collection of life-long neurodevelopmental diseases marked by major social and communication difficulties, as well as restricting, repetitive, and ritualistic patterns of behavior, interests, or activities. [32]. Autism was originally defined by Leo Kanner in 1943 as an innate inability to create normal, biologically determined, emotional contact with others. The primacy of the social deficit is widely recognized, and lack of social reciprocity is a central part of the diagnosis [33]. Indeed, proposed revisions of the precedent edition of the manual *(DSM IV-TR)*include the combination of specific *DSM-IV-TR* diagnoses into a single broad autism spectrum disorder (ASD), and the identification of two domains of impairment (social communication and interaction, and restricted repetitive behavior) instead of three (social interaction, communication, and restricted repetitive and stereotyped patterns of behavior, interests and activities) [34]. Although genetic factors might be largely responsible for the occurrence of autism they cannot fully account for all cases and it is likely that in addition to a certain combination of autism-related genes, specific environmental factors might act as risk factors triggering the development of autism [35]. Researchers have discovered abnormalities in numerous brain regions in persons with ASD. According to previous research, patients with ASD have abnormally high levels of serotonin or other neurotransmitters in their brain. These abnormalities show that ASD may be caused by problems in genes that control brain growth and regulate how brain cells communicate with one another, possibly due to the influence of environmental variables on gene activity [31]. Autism is a heterogeneous disorder and, reflecting this heterogeneity, the term autism has been used in various ways to describe both a broader presentation as well as a specific diagnosis following its consideration as a subgroup within the general diagnostic category of ‘pervasive developmental disorders’ (PDDs) [36].

WHO stated that the worldwide prevalence of ASD was estimated to be one in 160 children (0.6%). And according to research conducted in 2014, autism affects more male than female individuals, and co morbidity is common (>70% have concurrent conditions) [37]. Although the majority of studies on ASD prevalence use figures from wealthy nations, nothing is known regarding the prevalence of ASD/PDD in low-income countries. However, estimations indicate that it is either less than or equal to that of industrialized countries [38]. According to studies undertaken by various researchers in various regions, the prevalence of all forms of autism combined is estimated to be 1 in 162 people. Autism Spectrum Disorder ASD=17/10000 and Pervasive Developmental Disorders (PDD) =62/10000, according to the global median estimate. Having children with ASD and PDD is expected to affect between 5000 and 18500 children and their parents/caregivers [39]. Although just 10% of the world's children live in these areas, a recent study of the global prevalence of autism found that 86.5 percent of cases detected in epidemiologic studies were from North America, Europe, and Japan [39].

Social relatedness, communication, and behaviors and interests are the three domains of autism disorder symptoms, with delays or aberrant functioning in at least one of these areas prior to the age of three. An individual must exhibit at least 6 of the 12 symptoms of autism disorder, with at least 2 from the social domain and 1 from each of the communication and restricted behaviors/interests categories [31]. ASD is associated with uneven distribution of cognitive skills (including splinter skills), temper tantrums, hyperactivity, short attention span, aggressive behavior, impulsivity, abnormal or exaggerated responses to sensory stimuli, self-injurious behavior, impaired mood or affect, and disruption of sleeping and eating behaviors, among other things [44].

When a parent learns that their child has been diagnosed with autism, they are often distraught. Early diagnosis, in turn, leads to early treatment, which can provide an autistic child a greater chance of living a semi-normal existence in society [40]. According to the survey, more than half of school-aged children were diagnosed with autism spectrum disorder when they were 5 years old or older. Only about 20% of children were diagnosed by the age of two. Pediatricians should screen children for autism at the age of 18 months, according to the American Academy of Pediatrics [41]. In the rural areas, where 85 percent of the population lives, there are no diagnostic or educational services. Autism is generally undetected in these places due to a lack of health care, low awareness, and stigma. Autism symptoms are frequently interpreted as a divine retribution for transgression [42].

## Knowledge of parents toward autism

Knowledge could have a detrimental impact if families lack appropriate support in navigating the needs generated by that knowledge [79]. Parents are typically at the Centre of this support network and carry much of the responsibility of direct care, coordination and advocacy, over and above typical parental responsibilities [87] [88]. Misconceptions about the causes of ASD can negatively influence families affected by ASD by serving as obstacles to proper ASD education and treatment [80] [81].  For that reason it is crucial to study parental perceptions (and potential misconceptions) of ASD etiology [82]. Understanding of the ASD etiology can help health professionals, researchers, and policymakers better educate and serve families in need [83].

An international review examining ASD knowledge has occurred in 21 different countries around the world, 52% (n=35) were conducted in North America (United States or Canada) [49], 14% (n=9) in the Eastern Mediterranean region (including, Palestine Authority, Pakistan, Saudi Arabia, Oman, Lebanon, and Iraq) [50], 12% (n=8) in Europe (including, the United Kingdom, Northern Ireland, Greece, France, Denmark, and Poland) [51], 9% (n=6) in the Western Pacific region (including Japan, China, and Australia) [52] , 9% (n=6) in Africa (Nigeria) [53], 3% (n=2) in Southeast Asia (including India and Nepal) [54], and 1% (n=1) in South America (Brazil) [55]. Between one and six different target groups were included in the analyzed research, ranging from peers/parents to experts. Only four (6%) of the targeted demographics looked at caregiver or parent viewpoints [56].

Another study looked at 83 families from Poland, Belarus, and France, with 30 families from Poland, 25 families from Belarus, and 28 families from France. When it came to determining which gender is more sensitive to autism, Polish parents gave the most wrong answers, with 53.2 percent of parents in Poland, 83.3 percent of parents in Belarus, and 78.6 percent of parents in France were convinced that the boys are mainly affected by the disease. The girls were indicated by 10% of respondents from Poland and 17.9% from France. About 10% of parents from Poland and 3.6% from France were convinced that the same percentage of both genders was concerned. 26.7% of respondents from Poland and 16.7% from Belarus did not express an unambiguous opinion on this matter. The distribution of responses differed significantly between the countries (p=0.0122\*) [53].

According to a Pakistani research, 75% of the population had heard about autism, with those who knew someone with the illness having a higher level of awareness. Parents mostly agreed upon autism being a mental disorder (n=246, 72.6%), the child becomes unsociable (n=228, 67.3%), and an autistic child has special talents/attributes (n=201, 59.3%). A significant population of parents (n=108, 31.9%) disagreed on considering an autistic child mentally retarded. Upon different opinions on autism, the parents were unsure and responded with “I don’t know,” especially in the cases of considering autism an inherited disorder (n=147, 43.4%), if autism is preventable (n=162, 47.8%), and if autism is caused due to parental negligence (n=153, 45.1%) [57].

In accordance with a study conducted by Mansoura University in Egypt, 64.7 percent of parents studied had minimal awareness of ASD. When it comes to parents' sources of information regarding ASD, 88.2 percent said they get their information from the internet. However, 76.5 percent of parents in the study had no prior experience with autistic children. Furthermore, 44.1 percent of the parents polled said society is unprepared to deal with autistic children [58].

In Tanzania, from all 29 eligible caregivers of children with ASD, 36% of participating families had never heard of ASD, 24% had heard the term ASD and could provide several words or phrases describing ASD but had little other information (e.g., affects brain, learning challenges, regression), and 40% had at least a working knowledge of ASD and could discuss the disorder's symptoms with some fluency [84].

## Health care practice of parents

The US study also showed misconceptions about the causes of ASD can negatively influence families affected by ASD by serving as obstacles to proper ASD education and treatment [80].

Families of people with autism are also heterogeneous, yet, as a group, they experience lower QOL than families with a member with other neurodevelopmental conditions, even before receiving the formal diagnosis [89]. Parents are typically at the Centre of this support network and carry much of the responsibility of direct care, coordination and advocacy, over and above typical parental responsibilities [87] [88].

Study in Pakistan shows that autism spectrum disorder (ASD) affects about 1.4% of the population in South Asia but very few have access to any form of health care service. Poor awareness of the condition in both family members and front-line health-providers leads to delay in recognition and appropriate management (27). Parents primarily view the role of their child's PCP as health maintenance only, and do not have expectations for management of ASD related issues or concerns (28).

In Ethiopian, the biggest reported unmet need was educational provision for their child (74.5 %), followed by treatment by a health professional (47.1 %), financial support (30.4 %) and expert help to support their child’s development (27.5 %). Most caregivers reported that talking to health professionals (86.3 %) and family (85.3 %) helped them to cope. Many caregivers also used support from friends (76.5 %) and prayer (57.8 %) as coping mechanisms [86].

When no other options are available, some parents resort to confining their children at home while they go out. It was emphasized that most parents believe they have no choice but to use chains to keep their children from injuring themselves when they are alone [85].

## Associated factors that affect knowledge of parents toward autism

#### Sociodemographic status

The study of autism in societies where the "scientific-medical" approach is not dominant (also known as "traditional societies" or "non-Western societies" [60] reveals diverse perceptions of disability as a specific gift from God or a punishment from God, as a temporary state [61] or as a normal development [62].

American journal indicates that in traditional societies, negative images of disability may harm the person with the disability as well as his or her family [64].

Bedouin mothers with autistic children are expected to stay in their home spaces (the family tent) and are not allowed to leave without their spouse or a close family member accompanying them. The mother is unable to go to any hospitals on her own, speak with any doctors on her own, or independently seek information on medical or community services that can assist her in caring for her child, which has a profound impact [65].

#### Socioeconomic status

A pilot study made in Hispanic culture shows: Socioeconomic status (SES), social support, language of questionnaire, spiritual attribution of child diagnosis, and religious importance predicted ASD knowledge, accounting for 43 % of variance from 64 Hispanic patients. The costs of having an autistic child are not just limited to the cost of interventions. Parents of children with autism, like parents of children with various disabilities, have larger time and financial commitments than parents of neurologically typical children [90].

A study conducted in Saudi Arabia suggested, a total of 769 participants were involved in this study. The study participants showed a weak level of knowledge about autism with a mean score of 5.9 (SD: 3.1), comprising 34.7% of the total maximum obtainable score. Binary logistic regression analysis identified that participants with a middle income category of 5000–7500 SR are less likely to be knowledgeable about autism compared to others (OR: 0.60 (95% CI: 0.39–0.92)) (p-value = 0.020) [66].

A recent report from an autism summit in which 47 delegates from 14 African countries participated highlighted the continent's lack of autistic services and the need to promote awareness and improve autism screening, training, and service plans [47].

Ethiopia, like other African countries, has a scarcity of autism services. The stigma surrounding mental health and misconceptions regarding the origins of developmental impairment and mental illness make it even more difficult to discover and care for children with autism in Ethiopia [48].

ASD affects one out of every 68 children in the United States [45]. More than 80% of their parents say they are "stressed beyond their capacity". Their capacity to parent properly, as well as handle their child's unique needs and keep their marriage together, is harmed [46].

#### Social factors

Children with disabilities are regarded as abnormal in Japan. A child with a disability is seen as a problem by the family, and the family is likely to feel ashamed [63].

Autism in the Bedouin community is perceived, according to their descriptions, as mental retardation, and people tend to push mothers of children with ‘mental retardation’ away from social events [65].

In research made in Ethiopia, when asked how many children he had, a 'educated father' of four children answered 'three' because 'he doesn't consider his child with autism as a child,' according to one autism center informant. Children with autism were sometimes forced to leave public buses, according to the same source, and taxis were not eager to take them. According to autistic center informants, it is difficult for parents to locate rental housing because landlords will compel them to leave if they disclose their child's illness [59].

### Associated factors that affect health care practice

#### Socioeconomic status

A national survey conducted in USA shows, Families of children with exceptional health care requirements, notably ASD, face considerable financial challenges in addition to navigating a complex health-care system. Because of variables relating to their child's medical care, 24 percent of families with children with special health care needs reduced their job hours or entirely quit working [74]. The lack of insurance coverage for ASD diagnosis and treatment is one reason for this financial burden. Peele and colleagues discovered that autism and intellectual disability were completely excluded from 36% of private health plans [75]. Poor coverage leads to high expenses and delayed access to services, with around 55 percent of families with ASD reporting annual out-of-pocket costs of at least $500 [76]. Similarly, lower-quality treatments have been linked to higher financial costs and dissatisfaction with care [77].

According to a study conducted in Ireland and other European nations, population socioeconomic factors such as household wealth or income, as well as parental education and occupation, are closely linked to children's health and development [91]. Following that, a number of clinical and population-based researches have found beneficial links between autism or ASD and socioeconomic factors such parental education, occupation, or income [38].

#### Psychological factors

Mothers of autistic children in Australia reported much higher levels of stress, anxiety, and depression than fathers. Mothers had a prevalence of 13.8 percent and 13.1 percent of moderate-to-severe anxiety and depression, respectively. For fathers, the comparable prevalence was 9.9% and 8.0 percent, respectively [92].

In USA of National survey of children’s health, children with ASDs were 7.3 times more likely to have a mother report a high stress level in raising her child when compared to children without ASDs (OR: 7.25, 95 % CI: 4.99–10.53, p\.001). Mothers with a child with a mild impairment were 9.4 times as likely to have a high stress level (OR: 9.41, 95 % CI: 5.24–16.89, p\.001), whereas mothers with a child with a moderate to severe impairment were 6.0 times as likely to have high stress levels (OR: 6.02, 95 % CI: 3.20–11.33, p\.001) when compared to mothers of children without an ASD [67].

Parents of children with ASD had more parenting stress symptoms than parents of generally developing children, according to a Singapore study. When compared to parents of typically developing children, parents of children with ASD reported higher depression symptoms and no significant changes in anxiety symptoms in our study [68].

#### Environmental factors

In India, caregivers indicated that they would be ashamed if people knew someone in their family had been diagnosed with autism [93].

According to a 2016 Ethiopian study, the majority of caregivers experienced stigma: 43.1 percent were concerned about being treated differently, 45.1 percent felt humiliated about their child's health, and 26.7 percent tried to keep their child's condition hidden. Caregivers offered a combination of biological and supernatural explanations for their child's condition, such as head injuries (30.4%) or birth problems (25.5%) [86].

#### Availability of health facilities

Primary care and specialty mental health clinicians must collaborate to meet the complicated symptom and behavioral treatment needs of children with ASD. Although many pediatricians agree they should check for mental health issues, they frequently remark that they lack the necessary skills to treat or manage diseases like ASD [69]. As a result, mental health treatment facilities play an important role in the provision of care for children with mental health conditions [70].

The study conducted in USA shows, of those 8,184 facilities, 66.6 percent reported that they provided behavioral health care for children, and 43.0 percent reported providing such care for children with autism spectrum disorder. Furthermore, 36.6 percent were accepting such children as new patients, 12.7 percent (1,042) reported having a provider with specialized training for such children, but only 4.3 percent (351) had a specialized treatment program for the children [71].

In particular, parent-report data from the 2011 Survey of Pathways to Service and Diagnosis (SPSD) shows that children with an ASD diagnosis who live in rural versus urban regions are more likely to report substantial challenges and delays due to a lack of available services (rural: 35 percent ; urban: 23 percent ). Because of the geographic constraints and limited availability of services in rural areas, the primary care system must rely on other entities, such as schools, to identify and treat ASD [72].

In general, poor availability and implementation of mental health services for children has been reported for rural areas however, there is little research examining the specific barriers that prevent children with ASD and their families from benefitting fully from services available in rural settings [73].

Another USA research shows, Caregivers of children with ASDs were significantly more likely to report difficulty using services as compared to caregivers of children with DDs (AOR = 1.68, 95% CI = 1.30–2.17) and MHCs (AOR = 1.56, 95% CI = 1.31–1.84). Caregivers of children with ASDs were also more likely to report lack of source of care as compared to caregivers of children with DDs (AOR = 1.53, 95% CI = 1.13–2.07), and those with both DDs/ MHCs (AOR = 1.32, 95% CI = 1.01–1.73). Taken together, these findings may highlight access difficulties of children with most complex needs such as children with ASDs due to limited supply of subspecialty care providers in the United States [78].

There are only two governmental specialized child mental health clinics, in Addis Ababa's Yekatit 12 and St. Paul's hospitals. In addition there are private clinics with some limited child mental health expertise. Each of these specialized clinics is located in the capital and therefore inaccessible to the majority (85%) of families who live in Ethiopia's rural areas [43].

Sociodemographic

Age, sex, income, educational status, religious practice

Psychological factors

Stress, depression

Knowledge about autism

Social factors

Stigma, low help seeking behavior, discrimination

Socio economic status

Income,

Figure 1: Conceptual frame work indicating factors related to Knowledge towards autism.

Knowledge about autism

Sociodemographic

Age, sex, income, educational status, religious practice,

Personal factors

Stress, depression

Health care practice

Distance of health facilities

Social factors

Stigma, low help seeking behavior, discrimination

Figure 2: Conceptual frame work indicating factors related to health care practice towards autism.

This conceptual frame work is developed after through literature review

# OBJECTIVES

## General objectives

To assess level of knowledge, health care practice and its associated factors among parents of autistic children at autistic centers of Addis Ababa, Ethiopia 2022 G.C

## Specific objectives

* To determine level of knowledge about autism among parents of autistic children at autistic centers in Addis Ababa
* To analyze health care practices among parents of autistic children at autistic centers in Addis Ababa
* To distinguish associated factors of health care practice among parents of autistic children at autistic centers in Addis Ababa
* To find out factors affecting knowledge about autism among parents of autistic children at autistic centers in Addis Ababa

# METHODS AND MATERIALS

## Study area and period

According to 2017 census, Addis Ababa has nearly 4 million populations, consisting of 1,511,000 men and 1,636,000 women, and an 8% annual growth rate. The city is a home to 23.8% of all urban dwellers in Ethiopia, and has an estimated density of 5936.2 per square kilometer. It is the 106th largest urban area in the world, according to Demographia About 82% of the population are Orthodox Christians, 12.7% Muslims, 3.9% Protestants, 0.8% Catholics while the remaining 0.6% are followers of other religions, such as Hindus, Jews and Agnostics(4). There are 125 health centers, as of 2014, Addis Ababa has 52 Hospitals, 12 of them state run and more than 40 private. This study involves the 2 public hospitals and 1 private center as they have autism centers. The study will be conducted in autistic centers of Yekatit, St. Paul and Nehemiah autism center, from May to July, 2022.

St Paul’s generalized hospital was built by the late Emperor Haile Selassie with the help of the German Evangelical Church in the year 1968 G.C. Until 2010, it used to be called St. Paul General Specialized hospital serving as a referral hospital in Addis Ababa under the Ethiopia Federal Ministry of Health (FMOH). In 2007, it started a medical school and through a decree of the council of ministers in 2010, it was established as a medical college and is currently named St Paul Hospital Millennium Medical College.

Nehemiah Autism Center has a license from Charities and Societies Agency, which is a concerned governmental office, and has rented a house to receive autistic children. The center started work on Jun 16, 2011 after they got their license on 31 August 31, 2010. At the moment they were giving training and treating Autistic children in the center. The NGO is non-profit and a non-governmental organization.

## Study design

Institutional based cross sectional will be conducted

## Source of population and study unit

All parents of autistic children in Addis Ababa, Ethiopia

All parents of autistic children who are found at autistic centers in Addis Ababa city administration, Addis Ababa Ethiopia

## Study unit

Selected parents who will fulfill the inclusion criteria and will be available at the time of data collection.

## Eligibility criteria

### Inclusion criteria

* A parent included in the study if he/she has one or more than one diagnosed autistic child and currently found at one of the autistic centers.
* The age of the child had to be <13 years

### Exclusion criteria

Parents with mental health impairments, or any other serious health problems

## Sample size determination

The sample size (n) 0 required for the study will be calculated using single population proportion formula. After comparing p – values for health-care practice, educational related factors, social factors and knowledge about autism, sample size is calculated considering a p-value of 50% (to get the largest sample size level of confidence of 95%, and margin error 5

A single population proportion formula:

n = (Z α /2) 2 p (1-p)/ d2

Where,

p - Prevalence of premarital sexual practice – 50%

d - Margin of sampling error tolerated - 5% (0.05)

z - Critical value at 95% confidence interval of certainty (1.96)

n = (1.96)2x 0.5(1-0.5)/ (0.05)2

n= 3.8416 x0.5 /0.0025

n = 384

Finally, sample size is 384 Therefore, by adding 10% non-response rate, the total sample size will be 384+38=422 parents

## Sampling procedure and techniques

There are only 2 governmental hospitals that give psychiatric services in Addis Ababa city. And there are three private autistic centers. Out of these, one private autistic center and the 2 governmental hospitals are selected. The number of study units for each unit will be proportionally allocated and that was part of the final sample size will be selected using systematic random sampling (based on the number of parents coming per month).

Where,   
 N: Total autistic children

Ni: Population size of autistic patients

ni: Sample to be drawn from each autism centers.

n: Total sample size to be drawn from total population.

Figure 3: Schematic presentation of sampling techniques used to select study subjects from autism centers in Addis Ababa, 2022

## Data collection tool

Interviewer administered structured questionnaire data collection tool will be used, it contains three parts. Part I will be used to collect socio demographic data, part II will be used to collect knowledge about autism and part III is a health care practice, which will be used to measure areas or domains of parents knowledge and health care practices: diet, medications, therapy and communication. Knowledge about autism will be assessed by requesting the respondents to answer seventeen questions. Each correct response will be scored (1) and incorrect response will be scored (0). The mean value was used to categorize study subjects as having good knowledge or poor knowledge about autism. Accordingly, the sum value less than the mean will be categorized as poor knowledge and the value greater than or equal to the mean will be categorized as good knowledge. Health care practice about autism will also assessed by requesting the respondents to answer twenty questions. Each correct response will be scored (1) and incorrect response will be scored (0). The mean value will be used to categorize study subjects as having good health care practice or poor health care practice. Accordingly, the sum value less than the mean will be categorized as poor health-care practice and the value greater than or equal to the mean will be categorized as good health-care practice.

Face to face and observation method will be used to gather both quantitative and qualitative data through institutional visits.

## Study variables

### Dependent variable

* Knowledge towards autism
* Health care practices of the parents

### Independent variables:

* Socio-demographic characteristics,
* Stigma, discrimination
* Distance of health facilities
* Educational status
* Income
* Stress , depression

## Operational definitions

* Knowledge: an idea by which parents of autistic children has about definition, risk factors, sign and symptoms, effect, diagnosis methods and treatment.
* Good knowledge-Respondents who score above or equal to the mean score of knowledge related questions.
* Poor knowledge-Respondents who score below mean score of knowledge related questions.
* Good practice - Respondents who scored more or equal to the mean score of practice related questions.
* Poor practice - Respondents who scored below mean score of practice related questions.

## Data collection procedure

Structured interviewer administered questionnaire will be used to collect data on knowledge, health care practice and associated factors. And the data will be collected by all group members after having a common ground and understanding about how the data is collected from our study population and obtaining verbal consent from our respondents.

## Data quality assurance

Both the data collectors and supervisors will be trained for half day on the objective and methodology of the research, data collection approach. The questionnaire will be translated to Amharic language and back translated into English by another person to check for consistency. Pretest will be conducted in 10% of the samples in a health care institution that will be included in the survey to see the completeness, consistency, and applicability of the instruments and will be ratify accordingly. Survey procedures will be designed to protect the patient's privacy by allowing for anonymous and voluntary participation

## Data processing and analysis

Data will be checked, cleaned and entered in to Epidata 3.1 software, then imported to SPSS version 26 software for analysis. Incomplete and inconsistent data will be excluded from the analysis. Descriptive statistics will be used to describe the sample. The results of the descriptive statistics will be expressed as percentage and frequency. Associations between independent variables and dependent variables will be analyzed first using bivariate analysis to identify factors which are significantly associated with the outcome variable. The magnitude of the association between the different independent variables in relation to dependent will be measured using odds ratios and 95% confidence interval (CI) and P values below 0.05 will be considered statistically significant.

## Ethical consideration

Ethical clearance and official letter will be obtained from the Kotebe University of Education Menelik II Health science and medical college, nursing department to the selected public health hospitals. Again permission will be obtained from respective Hospitals. At the time of data collection, the purpose of the study will be explained to the study subjects and a verbal also written consent will be taken from the participants to confirm whether they are willing to participate or not. The patients‟ privacy will be maintained by conducting the interview in a private place. Personal identifications will not be included in the data collection and throughout the research process to keep the confidentiality of the participants.

They will be informed that there is no any incentive or harm for their participation in this study.

## Dissemination plan

The finding of this study will be presented to the community of school of nursing and of Kotebe University of Education, and disseminated to the school library and respective hospitals. Finally the finding will published in peer reviewed journals for further operation.

## Expected outcomes

The expected results of this project are; improved insight about autism, among parents, and also the community, improved health care practice, publication of further studies, strengthened structural and

* Increased therapeutic centers
* Decreased number of traumatic experiences

## 

# PROJECT WORK PLAN

|  |  |  |  |
| --- | --- | --- | --- |
| Activities | May | June | July |
| Topic selection |  |  |  |
| Proposal development |  |  |  |
| Submission of final proposal |  |  |  |
| Data collection |  |  |  |
| Data Analysis |  |  |  |
| Submission of final research report |  |  |  |
| Research defense |  |  |  |

Table 1: Work plan for knowledge, health care practice and associated factors of parents with autistic children

# BUDGET PLAN

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **No** | **Budget Categories** | **Unit cost** | **Multiplying factor** | **Total Cost** |
| **1** | **Personal** |  |  |  |
|  | Data Collectors | 300/day | 300×2×3days | 1800 |
| **2** | **Material** | **Cost per item** |  |  |
|  | Paper | 2 Birr | 292×3 | 876 |
|  | Pen | 10 | 12×10 | 120 |
|  | pencil | 7birr | 7×5 | 30 |
|  | Eraser | 7 birr | 7×4 | 28 |
|  | CD | 10 Birr | 1×10 | 10 |
|  | Ruler | 10 Birr | 10×3 | 30 |
|  | Printing and binding | 5 Birr | 40×5 | 200 |
|  |  | Subtotal costs | |  |
| **3** | **Transport** | **Cost per Km** |  |  |
|  | Car | 5 birr |  | 500 |
| **4** | **TOTAL** |  |  | **3594** |

Table 2: Budget plan for knowledge, health care practice and associated factors of parents with autistic children

# REFERENCE

1. Abera M, Robbins JM and Tesfaye M (2015) Parents' perception of child and adolescent mental health problems and their choice of treatment option in southwest Ethiopia. Child and Adolescent Psychiatry and Mental Health 22(9):40.
2. Abera M, Tesfaye M, Belachew T, Hanlon C (2014) Perceived challenges and opportunities arising from integration of mental health into primary care: a cross-sectional survey of primary health care workers in south-west Ethiopia. BMC Health Services Research 14:113.
3. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders. Washington, DC; 4 1994.
4. Kanner L. Autistic disturbances of effective contact. Nerv Child 1943; 2:217-50.
5. Amaral DG, Schumann CM, Nordahl CW. Neuroanatomy of autism. Trends Neurosci 2008; 31:137-45.
6. Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National Survey of Children’s Health. Arch Pediatr Adolesc Med 2006; 160:825-30
7. Hartley-McAndrew M, Doody KR, Mertz J. Knowledge of autism spectrum disorders in potential first-contact professionals. N Am J Med Sci 2014; 7: 97-02.
8. Dillenburger K, Jordan JA, McKerr L. Autism spectrum disorder: public awareness and attitudes. [Online] 2013 [Cited 2015 May 2].
9. Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatr. 2014; 168(8):721–8.
10. Markowitz LA et al. Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. Autism 20, 832– 844 (2016). [PubMed: 26658953]
11. Ryan S & Cole KR From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. J. Appl. Res. Intellect. Disabil 22, 43–53 (2009).
12. McCann D, Bull R & Winzenberg T. The daily patterns of time use for parents of children with complex needs: a systematic review. J. Child Health Care 16, 26–52 (2012). [PubMed: 22308543]
13. Lord C, Brugha TS, Charman T, et al. Autism spectrum disorder. Nat Rev Dis Primers. 2020; 6(1):5. Published 2020 Jan 16.
14. Karst JS & Van Hecke AV Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. Clin. Child Fam. Psychol. Rev 15, 247–277 (2012).[PubMed: 22869324]
15. *"Centers for Disease Control and Prevention"* April, 2018.
16. Tager-Flusberg H (2010). *"The origins of social impairments in autism spectrum disorder: studies of infants at risk"*. *Neural Networks*. **23** (8–9):1072-6.
17. Khatib, J. (2001). Parents of children with disabilities: Strategies for working with them and training them and supporting them, a series of versions of the Special Education Academy. Riyadh, Saudi Arabia.
18. Burrell, B., Thompson, B., & Sexton, D. (1994). Predicting child abuse potential across family types. Child Abuse and Neglect, 18, 1039–1049.
19. Hodapp, R.M., Ricci, L.A., Ly,T.M., Fidler, D.J. (2003). The effects of the child with Down syndrome on maternal stress. British Journal of Developmental Psychology, 21, 1, 137– 151.
20. Ashley Hartmann (2012), Autism and its Impact on Families, St. Catherine University.
21. Anwar MS, Tahir M, Nusrat K, Khan MR. Knowledge, awareness, and perceptions regarding autism among parents in Karachi, Pakistan. Cureus. 2018 Sep 13;10(9).
22. Nalven LM, Hofkosh D, Feldman H, Kelleher K. Teaching pediatric residents about early intervention and special education. J Dev Behav Pediatr. 1997;18:371-376Harris, S. L. 1984.
23. Elmensdorp ST. Training physicians on the early behavioral characteristics of autism: the use of a brief, group didactic training module [PhD thesis]. Santa Barbara, CA: University of California Santa Barbara; 2011.17)
24. Baba, P.N., 2014. Living and dealing with autistic children: a case study of a Nigerian family in Cincinnati, Ohio, United States. Research on humanities and social sciences, 4(8).
25. Getnet D. 2013. Autism and Alzheimer’s disease in Ethiopia: A present glance. international conference on psychology. Autism and Alzheimer’s disease. Texas, USA
26. Meressa, S., 2014. Learning problems of children with autism and the challenges in the teaching process: the case of Nia Foundation Joy Center (Doctoral dissertation, Addis Ababa University).
27. Nehemiah Autism Centre. 2019. <https://www.nehemiah-autism.org/>
28. Kobak KA, Stone WL, Ousley OY, Swanson A. Web-based training in early autism screening: results from a pilot study. Telemed e-Health. 2011; 17:640-644.
29. Woodgate, R.L., Ateah, C. and Secco, L., 2008. Living in a world of our own: The experience of parents who have a child with autism. Qualitative health research, 18(8), pp.1075-
30. American Psychiatric Association. DSM 5 diagnostic and statistical manual of mental disorders. InDSM 5 Diagnostic and statistical manual of mental disorders 2013 (pp. 947-p).
31. Chaste, Pauline, and Marion Leboyer. “Autism risk factors: genes, environment, and gene-environment interactions.” *Dialogues in clinical neuroscience* vol. 14,3 (2012): 281-92. doi:10.31887/DCNS.2012.14.3/pchaste
32. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders. 4th ed. Washington, DC: American Psychiatric Association;*1994
33. WG Molecular Analysis of Synaptopathies, Neurology Department, Neurocenter of Ulm University, Ulm, Germany Psychiatry, 18 January 2013
34. Lord C, Brugha TS, Charman T, et al. Autism spectrum disorder. *Nat Rev Dis Primers*. 2020; 6(1):5. Published 2020 Jan 16
35. WHO (2013). Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders, Executive Board eb: 133/4
36. Nyoni, J., Serpell, R., n.d. The Impact on Parents of Raising a Young Child with Autism: A phenomenological Study of Parents in Lusaka, Zambia. Int. J. Disability Community Rehab
37. Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y.S., Kauchali, S., Marcín, C., et al, (2012) 39 Global Prevalence of Autism and Other Pervasive Developmental Disorders: Global Epidemiology of Autism Research .5, 160–179
38. Sonya M, Jessica V. (2012). Dynamics of Autism: Meeting the Social & Economic Challenge
39. Denise M. (2012). Most Children with Autism Diagnosed at 5 or Older Retrieved from http://www.webmd.com/brain/autism/news/20120523/most-children-withautismdiagnosed-at-5-or-older
40. Denise M. (2012). Most Children with Autism Diagnosed at 5 or Older Retrieved from http://www.webmd.com/brain/autism/news/20120523/most-children-withautismdiagnosed-at-5-or-older
41. Marquis, D., TekolaGebru, B., Baheretibeb,Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C, & Hoekstra, A. (2014). Services for Children with Autism and Their Families in Ethiopia: Service Providers perspectives. Retrieved from Mayo foundation for medical education and research 1998- 2020
42. C
43. B
44. N
45. B
46. M
47. Segall MJ and Campbell JM (2014) Factors influencing the educational placement of students with autism spectrum disorders. Research in Autism Spectrum Disorders 8(1): 31–43.
48. Muhammad Z, Al-Deen LD and Muhsin HA (2013) Knowledge about childhood autism among care providers in Baghdad. Arab Journal of Psychiatry 24(1): 27–31.
49. Suchowierska M and Walczak P (2012) Knowledge about autism among Polish pediatricians. Progress of Medical Sciences 26(1): 58–64.
50. Garg P, Lillystone D, Dossetor D, et al. (2014) An exploratory survey for understanding perceptions, knowledge and educational needs of general practitioners (GSs) regarding autistic disorders in New South Wales (NSW), Australia. Journal of Clinical and Diagnostic Research 8(7): PC01–PC09
51. Ślifirczyk A, Krajewska-Kułak E, Krukowska M, Maciorkowska E. Knowledge of parents of children with autism from Poland, Belarus and France concerning their child’s condition. Health Problems of Civilization. 2019;13(2):114-22.
52. Vijayarani M (2014) Effectiveness of the information booklet on the level of knowledge of the caregivers towards care of children with autism in the outpatient and inpatient of the child psychiatric centre at NIMHANS. International Journal of Nursing 2(2): 27–35.
53. Bordini D, Lowenthal R, Gadelha A, et al. (2015) Impact of training in autism for primary care providers: a pilot study. Revista Brasileira de Psiquiatria 37: 63–66.
54. Harrison AJ, Slane MM, Hoang L, Campbell JM. An international review of autism knowledge assessment measures. Autism. 2017 Apr;21(3):262-75
55. Anwar MS, Tahir M, Nusrat K, Khan MR. Knowledge, awareness, and perceptions regarding autism among parents in Karachi, Pakistan. Cureus. 2018 Sep 13; 10(9).)
56. Mohamed A, Mohammed B, Hassan R. KNOWLEDGE ASSESSMENT AMONG AUTISTIC CHILDREN’S PARENTS REGARDING AUTISM SPECTRUM DISORDER. Mansoura Nursing Journal. 2020 Jul 1;7(2):125-35
57. Tekola B, Baheretibeb Y, Roth I, Tilahun D, Fekadu A, Hanlon C, Hoekstra R. Challenges and opportunities to improve autism services in low-income countries: lessons from a situational analysis in Ethiopia. Global mental health. 2016;3.
58. Ha, V.S., A. Whittaker, M. Whittaker, and S. Rodger 2014 Living with of Autism Spectrum Disorder in Hanoi, Vietnam. Social Science & Medicine 120:278–285.
59. Grinker, R., and K. Cho 2013 Border Children: Interpreting Autism Spectrum Disorder in South Korea. Ethos 41(1):46–74.
60. Garcia, S.B., A.M. Perez, and A.A. Ortiz 2000 Mexican American Mothers’ Beliefs about Disabilities. Remedial and Special Education
61. Asai, M.O., and V.A. Kameoka 2005 The Influence of Sekentei on Family Caregiving and Underutilization of Social Services among Japanese Caregivers. Social Work 50(2):111–118.
62. Patka, M., C.B. Keys, D.B. Henry, and K.E. McDonald 2013 Attitudes of Pakistani Community Members and staff Toward People with Intellectual Disability. American Journal on Intellectual and Developmental Disabilities 118(1):32–43.)
63. Manor-Binyamini I, Shoshana A. Listening to Bedouin mothers of children with autism. Culture, Medicine, and Psychiatry. 2018 Jun;42(2):401-18
64. Alyami HS, Naser AY, Alyami MH, Alharethi SH, Alyami AM. Knowledge and Attitudes toward Autism Spectrum Disorder in Saudi Arabia. International Journal of Environmental Research and Public Health. 2022 Mar 19;19(6):3648
65. Zablotsky B, Bradshaw CP, Stuart EA. The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. Journal of autism and developmental disorders. 2013 Jun;43(6):1380-93
66. Lai WW, Goh TJ, Oei TP, Sung M. Coping and well-being in parents of children with autism spectrum disorders (ASD). Journal of autism and developmental disorders. 2015 Aug;45(8):2582-93.
67. Stein RE, Horwitz SM, Storfer-Isser A, Heneghan A, Olson L, Hoagwood KE. Do pediatricians think they are responsible for identification and management of child mental health problems? Results of the AAP periodic survey. Ambul Pediatr. 2008; 8(1):11–7.
68. Stroul BA, Blau GM, Friedman RM. Updating the system of care concept and philosophy. Washington (DC): Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children’s Mental Health; 2010.
69. Cantor J, McBain RK, Kofner A, Stein BD, Yu H. Fewer Than Half Of US Mental Health Treatment Facilities Provide Services For Children With Autism Spectrum Disorder: Results from a survey of US mental health treatment facilities on the availability of behavioral health care services for children with autism spectrum disorder. Health Affairs. 2020 Jun 1; 39(6):968-74.)
70. Antezana L, Scarpa A, Valdespino A, Albright J, Richey JA. Rural trends in diagnosis and services for autism spectrum disorder. Frontiers in psychology. 2017 Apr 20; 8:590.
71. Cummings, J. R., Case, B. G., Ji, X., and Marcus, S. C. (2015). Availability of youth services in U.S. mental health treatment facilities. *Adm. Policy Ment. Health* 43, 717–727.
72. Okumura MJ, Van Cleave J, Gnanasekaran S, et al.: Understanding factors associated with work loss for families caring for CSHCN. Pediatrics 124(suppl 4):S392–S398
73. Peele PB, Lave JR, Kelleher KJ: Exclusions and limitations in children’s behavioral health care coverage. **Psychiatric Services** 53:591–594
74. Parish S, Thomas K, Rose R, et al.: State insurance parity legislation for autism services and family financial burden. **Intellectual and Developmental Disabilities** 50:190–198, 2012
75. Looman WS, O’Conner-Von SK, Ferski GJ, et al.: Financial and employment problems in families of children with special health care needs: implications for research and practice. **Journal of Pediatric Health Care** 23:117–125, 2009
76. Vohra R, Madhavan S, Sambamoorthi U, St Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. Autism. 2014 Oct; 18(7):815-26.
77. Yusuf A, Peltekova I, Savion-Lemieux T, et al. Association between distress and knowledge among parents of autistic children. *PLoS One*. 2019;14(9):e0223119. Published 2019 Sep 26. doi:10.1371/journal.pone.0223119
78. Castillo A., Cohen S.R., Miguel J., Warstadt M.F. Short report: **Perceptions of causes and common beliefs of autism spectrum disorder in the U.S. *Res. Autism*** *Spectr. Disord.*2020;70 doi: 10.1016/j.rasd.2019.101472.
79. Yu L.D., Stronach S., Harrison A.J. **Public knowledge and stigma of autism spectrum disorder: Comparing China with the United States. *Autism****.*2020;24:1531–1545. doi: 10.1177/1362361319900839.
80. Goin-Kochel R.P., Mire S.S., Dempsey A.G**. Emergence of autism spectrum disorder in children from simplex families: Relations to parental perceptions of etiology**. *J. Autism Dev. Disord.*2015;45:1451–1463. doi: 10.1007/s10803-014-2310-8.
81. Hebert E.B., Koulouglioti C**. Parental beliefs about cause and course of their child’s autism and outcomes of their beliefs:** A review of the literature. *Issues Compr. Pediatric Nurs.*2010;33:149–163. doi: 10.3109/01460862.2010.498331.
82. Ashley Johnson Harrison, Kristin A. Long, Karim P. Manji, Karyn K. Blane; Development of a Brief Intervention to Improve Knowledge of Autism and Behavioral Strategies Among Parents in Tanzania. Intellect Dev Disabil 1 June 2016; 54 (3)
83. Tekola, B., Baheretibeb, Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C., & Hoekstra, R. (2016). Challenges and opportunities to improve autism services in low-income countries: Lessons from a situational analysis in Ethiopia. *Global Mental Health,* *3*, E21. doi:10.1017/gmh.2016.17
84. Tilahun, D., Hanlon, C., Fekadu, A. *et al.* Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Serv Res* **16,**152 (2016).
85. Ryan S & Cole KR From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *J. Appl. Res. Intellect. Disabil* 22, 43–53 (2009).
86. McCann D, Bull R & Winzenberg T The daily patterns of time use for parents of children with complex needs: a systematic review. *J. Child Health Care* 16, 26–52 (2012).
87. Markowitz LA et al. Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. *Autism* 20, 832–844 (2016).
88. Colbert, A.M., Webber, J. & Graham, R. Factors that Influence Autism Knowledge in Hispanic Cultures: a Pilot Study. J. Racial and Ethnic Health Disparities 4, 156–164 (2017).
89. Susser MW, Hopper K, Watson W (1985) Sociology in medicine, third edition. New York: Oxford University Press. 603 p
90. Fēi Li, Yun Tang, Fei Li, Shuanfeng Fang, Xin Liu, Minyi Tao, Danping Wu, Liping Jiang, Psychological distress in parents of children with autism spectrum disorder: A cross-sectional study based on 683 mother-father dyads,Journal of Pediatric Nursing,2022.
91. Divan G et al. Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa. India Autism Research. 2012;5:190–200.

# ANNEXES

Annex I: Subject Information Sheet (English version)

Kotebe University of Education Menelik II Health Science and Medical College, Department of Nursing Undergraduate studies.

**Dear participant!**

Here, we the undersigned, at Kotebe University of Education Menelik II Health Science And Medical College, Department of Nursing Undergraduate studies Program, currently we will be undertaking research on a topic entitled as knowledge, health care practice and associated factors of parents with autistic children in selected autism centers of Addis Ababa, Ethiopia . For this study, you will be selected as a participant and before getting your consent, you need to know all necessary information related to the study which will be detailed as follows.

**Purpose of the study**: the purpose of this study is assessment of knowledge, health care practice and associated factors among parents with autistic children in autistic centers in Addis Ababa

**Participants to be included**: all parents with autistic child sampled by systematic sampling will be included in the study

**Benefits and risks of the study**

**Benefits**: Your responses for the following questions are beneficial to you and other parents as an input in improvement of autism knowledge, health care practice and to identify the factors which affect the knowledge of health care so that recommendations will be made to responsible organizations to fill those gaps. Other than this no payment or special privilege is granted to you for your participation

**Risks**: there are no possible risks for your participation, but it might take your time as it will take 15-30 min for responding the questionnaires

**Confidentiality**: your information is 100% confidential, your name won’t be stated and your information won’t be disclosed to the third party. This study is based on your volunteer participation, and you can drop it any time you want. If you have any questions, feel free to contact one of our investigators.

Address of the principal investigator:

Kalkidan Tilahun

Cell phone: +251941238965

Are you satisfied with the information provided so far?

1. Yes………………………….. Continue to the next page

2. No …………………………… I won’t participate

# Annex II Consent form (English version)

In undersigning this document, I am giving my consent to participate in the study entitled as “knowledge, health care practice and associated factors of parents with autistic children in selected autism centers of Addis Ababa, Ethiopia.’’ I have been informed that the purpose of this study is to assess autism knowledge, health care practice and associated factors of parents in selected autism centers of Addis Ababa, Ethiopia; I have understood that participation in this study is entirely voluntarily. I have been told that my answers to the questions will not be given to anyone else and no reports of this study ever identify me in any way. I have also been informed that my participation or non-participation or my refusal to answer questions will have no effect on me. I understood that participation in this study does not involve risks. I understood that Kalkidan Tilahun is the contact person if I have questions about the study or about my rights as a study participant.

Respondent’s signature\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Interviewer Name \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Signature \_\_\_\_\_\_\_\_\_\_\_ Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_

English version questionnaire

**Part I: - Socio demographic data**

Instruction: - I request you kindly to go through each question and give your responses by circling (o) the appropriate alternative.

|  |  |  |  |
| --- | --- | --- | --- |
| No | Variable | Response | Other response |
|  | Age | 1. 20-30 2. 30-40 3. 40-50 4. >50 |  |
|  | Sex | 1. Male  2. Female |  |
|  | Relation with the child | 1. Mother 2. Father 3. Relatives 4. Care giver 5. Other (specify) |  |
|  | Place of birth | 1. Rural  2. Urban |  |
|  | Educational level | 1. Illiterate 2. Literate 3. primary 4. secondary 5. university/college graduate |  |
|  | Marital status | 1. Single 2. Married 3. Divorced 4. Widowed |  |
|  | Occupational status | 1. Civil servant 2. Farmer 3. Merchant 4. Housewife 5. Other |  |
|  | Monthly income | 1. <1000 2. 1000-5000 3. 5000-10000 4. >10000 5. Other |  |
|  | Is there family history of Autism? | 1. Yes 2. No |  |
|  | How many kids do you have? | 1. One 2. Two 3. > Two |  |
|  | How many of your kids have autism? | 1. One 2. Two 3. >two |  |
|  | Sex of the child? | 1. Male 2. Female |  |
|  | How old is the child’s age affected with autism? | 1. <2 2. 2-6 3. 6-12 4. >12 |  |
|  | How old was the child when he/she first diagnosed with autism | 1. <2 2. 2-6 3. 6-12 4. >12 |  |

Part II: - Knowledge questionnaire Instruction: - Kindly go through the questions given below and tick (o) against appropriate answer.

|  |  |  |  |
| --- | --- | --- | --- |
| No | Variable | Response |  |
| 15. | Did you have previous knowledge about autism | 1. Yes 2. No |  |
| 16. | If yes, what was your source of knowledge? | 1. Television program 2. Social media 3. Relatives or friends 4. Books or magazines 5. Other |  |
| 17. | Do you believe that a child with autism can be as effective as the normal ones if necessary support is given? | 1. Yes 2. No 3. Unsure |  |
| 18. | How common do you think autism is in our society today? Would you say … | 1. 1 in 25 2. 1 in 50 3. 1 in 100 people 4. 1 in 1,000 people 5. 1 in 10,000 people 6. Unsure 7. Prefer not to say |  |
| 19. | Which, if any, of the following statements about autism do you think are true? | 1. A child with autism will grow out of the condition 2. Autism only affects males 3. Autistic people can be over or under sensitive to stimuli like light and noise 4. Autism is a mental health condition 5. Autistic people have difficulty making friends 6. Autism is punishment from God 7. Autism is result of demonic practices 8. All are true 9. I don’t know |  |
| 20. | Could you please tell me whether you think autism is any of the following? | 1. An intellectual disability 2. A mental illness 3. A behavioral problem 4. A learning disability 5. All of the above is true 6. None of the above 7. Unsure |  |
| 21. | What do you think is  the cause of Autism? | 1. Autism is caused by vaccines 2. Autism is caused by something in the environment 3. Autism can be inherited or genetic 4. Autism is caused by poor parenting skills 5. Scientists don’t know what causes autism 6. I don’t know |  |
| 22. | Do changes in routine or transitions to new activities affect your Child’s behavior | 1. Never 2. Sometimes 3. Frequently |  |
| 23. | Do you know the signs and symptoms of Autism? | 1. Yes 2. No 3. Unsure |  |
| 24. | If yes, which signs and symptoms does your child shows | 1. Avoids or doesn’t keep eye contact 2. Doesn’t respond to name by 9 months of age 3. Repeats words or phrases over and over 4. Shows a wide range of emotion 5. Are uncoordinated and clumsy 6. Gets upset by minor changes 7. All of the above 8. I don’t know |  |
| 25. | At what age do you think the signs and symptoms started? | 1. 0-2 2. 2-6 3. >6 4. I don’t know |  |
| 26. | Which one of this do you think diagnosis of autism spectrum disorder is based on? | 1. Behavioral observation 2. Parental interviews 3. Physical appearance 4. Both 5. I don’t know |  |
| 28. | Do you think that autism can be cured? | 1. Yes 2. No 3. Unsure |  |
| 29. | Do you think there are beneficial treatments available for children with autism spectrum disorder? | 1. Yes 2. No 3. I don’t know |  |
| 30. | What kind of things do you think makes having an autistic child challenging than other problems? | 1. unable to work 2. need special care and education 3. Need special support 4. having aggressive behavior |  |

Part III: - Health care practice questionnaire Instruction: - Kindly go through the questions given below and circle (0) against appropriate answer.

|  |  |  |  |
| --- | --- | --- | --- |
| No | Variable | Response |  |
| 31. | Is your child staying with you or in the autism centers? | 1. With me 2. Autism centers |  |
| 32. | Does your child have follow up? | 1. Yes 2. No |  |
| 33. | What kind of care do you think your child needs? | 1. Nutritional therapy 2. Bathing 3. Psychological therapy 4. Cognitive behavioral therapy 5. Other(specify) |  |
| 34. | What kind of care do you give your child currently? | 1. Feeding 2. Bathing 3. Playing with him/her 4. Other(specify) |  |
| 35. | Who in the family is responsible for providing care for the child? | 1. Mother 2. Father 3. Sister and Brother 4. The whole family 5. Other |  |
| 36. | Is health institution are near to your home? | 1. Yes 2. No |  |
| 37. | If yes, do they have autism centers? | 1. Yes 2. No |  |
| 38. | Do you receive any help related to your child? | 1. Yes 2. No | --- |
| 39. | If yes, from where do you get help? | 1. Autism centers 2. NGO 3. Relatives 4. Support groups 5. Others |  |
| 40. | Do you think that caring of your child may burden all your financial status? | 1. Yes 2. No |  |
| 41. | How long did you wait to take him/her to health facilities after you saw signs and symptoms? | 1. I took him right away 2. Three months 3. Sixth months 4. >1 yr 5. I don’t recall |  |
| 42. | Do you take your child to any social gathering (wedding, to visit friends or relatives, religious places)? | 1. Yes 2. No |  |
| 43. | How do you characterize the communities’ acceptance? | 1. Good 2. Not good enough 3. The need time to approach 4. I don’t know |  |

Annex III: Amharic version questionnaire

ይህንን ሰነድ በመፈረም በአዲስ አበባ ኢትዮጵያ በተመረጡ የኦቲዝም ማዕከላት ውስጥ ያሉ የወላጆችን እውቀት፣ የጤና አጠባበቅ ልምምድ እና ተጓዳኝ ምክንያቶች በሚል ርዕስ በጥናት ላይ ለመሳተፍ ፈቃዴን እሰጣለሁኝ። ይህ ጥናት በአዲስ አበባ፣ ኢትዮጵያ በተመረጡ የኦቲዝም ማዕከላት ውስጥ ያሉ የወላጆችን የኦቲዝም እውቀት፣ የጤና አጠባበቅ ልምምድ እና ተያያዥ ሁኔታዎችን ለመገምገም ነው። በዚህ ጥናት ውስጥ ለመሳተፍ ሙሉ በሙሉ በፈቃደኝነት እንደሆነ ተረድቻለሁ። የሚሰበሰበው መረጃ ሙሉ በሙሉ በሚስጥር የሚያዝ መሆኑን እና ስሜም ሆነ መለያ አድራሻዬ እንደማይመዘገብ ተነግሮኛል። የእኔ ተሳትፎ ወይም አለመሳተፍ ወይም ለጥያቄዎች መልስ አለመስጠት በእኔ ላይ ምንም ተጽእኖ እንደሌለው ተነግሮኛል. በዚህ ጥናት ውስጥ መሳተፍ አደጋዎችን እንደማያጠቃልል ተረድቻለሁ። ስለ ጥናቱ ወይም የጥናት ተሳታፊ የመሆኔን መብት በተመለከተ ጥያቄዎች ካሉኝ ቃልኪዳን ጥላሁን ተጠሪ እንደሆነች ተረድቻለሁ።

የተጠሪ ፊርማ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

የጠያቂው ስም \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ ፊርማ \_\_\_\_\_\_\_\_\_\_\_ ቀን\_\_\_\_\_\_\_\_\_\_\_\_\_\_

ክፍል አንድ የማህበራዊ ሁኔታ ቃለ መጠይቅ መመሪያ:-

ጥያቄዉን በደንብ ከተረዱ በኋላ ከተሰጡት ምርጫዎች ዉስጥ በመልስዎ ላይ የክብ (o) ምልክት ያስቀምጡ;;

|  |  |  |  |
| --- | --- | --- | --- |
| 1 | እድሜ | 1. 20-30 2. 30-40 3. 40-50 4. >50 |  |
| 2 | ጾታ | 1. ወንድ  2. ሴት |  |
| 3 | ከልጁ ጋር ግንኙነት ያሎት ግንኙነት? | 1. እናት 2. አባት 3. ዘመድ 4. አሳዳጊ 5. ሌላ (ይግለጹ |  |
| 4 | የትውልድ ቦታ | 1.ገጠር  2. ከተማ |  |
| 5. | የትምህርት ደረጃ | 1. ማንበብ እና መጻፍ የማይችል 2. የመጀመሪያ ደረጃ 3. ሁለተኛ ደረጃ 4. ከፍተኛ ትምህርት |  |
| 7. | የጋብቻ ሁኔታ | 1. ያላገባ/ች 2. ያገባ/ች 3. የፈታ/ች 4. በሞት የተለዩ |  |
| 8. | የስራ ሁኔታ | 1. የመንግስት ሰራተኛ 2. ገበሬ 3. ነጋዴ 4. የቤት እመቤት 5. ሌላ |  |
| 9. | ወርኀዊ ገቢ | 1. <1000 2. 1000-5000 3. 5000-10000 4. >10000 5. ሌላ |  |
| 10. | ከቤተሰበዎ ዉስጥ በኦቲዝም የተያዘ ሰዉ አለ? | 1. አወ 2. የለም |  |
| 11. | ስንት ልጆች አሎት? | 1. አንድ 2. ሁለት 3. > ሁለት |  |
| 12. | ስንት ልጆችዎ በኦቲዝም ተይዘዋል? | 1. አንድ 2. ሁለት 3. > ሁለት |  |
| 13. | የልጆዎ ጾታ? | 1. ወንድ 2. ሴት |  |
| 14. | በኦቲዝም የተጠቃው የልጁ ዕድሜ ስንት ዓመት ነው? | 1. <2 2. 2-6 3. 6-12 4. >12 |  |
| 15. | ልጁ ለመጀመሪያ ጊዜ ኦቲዝም እንዳለበት ሲታወቅ ዕድሜው/ዋ ስንት ነበር? | 1. <2 2. 2-6 3. 6-12 4. >12 |  |

ክፍል ሁለት አዉቀት ቃለ መጠይቅ

|  |  |  |  |
| --- | --- | --- | --- |
| No | Variable | Response |  |
| 16. | ስለ ኦቲዝም ቀደም ብለው እውቀት ኖረዋል? | 1. አዎ 2. አይ |  |
| 17. | መረጃ አግኝተዉ ከሆነ ከማን አገኙት? | 1. ቴሌቪዥን ፕሮግራም 2. ማህበራዊ ሚዲያ 3. ዘመዶች ወይም ጓደኞች 4. መጽሐፍት ወይም መጽሔቶች 5. የጤና ባለሙያ 6. ሌላ |  |
| 18. | ኦቲዝም ያለበት ልጅ አስፈላጊ ከሆነ ድጋፍ ከተሰጠ እንደ ተለመደው ውጤታማ ሊሆን ይችላል ብለው ያምናሉ? | 1. አዎ 2. አየመስለኝም 3. እርግጠኛ አይደለሁም |  |
| 19. | ኦቲዝም በእኛ ማህበረሰብ ውስጥ ምን ያህል የተለመደ ነው ብለው ያስባሉ? ትላለህ  … | 1. ከ 25 ሰዎች 1 2. ከ 50 ሰዎች 1 3. ከ 100 ሰዎች 1 4. ከ 1,000 ሰዎች ውስጥ 1 5. ከ 10,000 ሰዎች ውስጥ 1 6. እርግጠኛ አይደለሁም 7. አላውቅም |  |
| 20. | ከሚከተሉት ስለ ኦቲዝም ከተናገሩት የትኛው እውነት ነው ብለው ያስባሉ? | 1. ኦቲዝም ያለበት ልጅ ከበሽታው ይወጣል 2. ኦቲዝም የሚያጠቃው ወንዶችን ብቻ ነው 3. ኦቲዝም ሰዎች እንደ ብርሃን እና ጫጫታ ላሉት ማነቃቂያዎች ከመጠን በላይ ወይም በታች ሊሆኑ ይችላሉ። 4. ኦቲዝም የአእምሮ ጤና ችግር ነው። 5. ኦቲዝም ሰዎች ጓደኛ ማፍራት ይቸገራሉ። 6. ኦቲዝም ከእግዚአብሔር የመጣ ቅጣት ነው። 7. ኦቲዝም የአጋንንት ድርጊቶች ውጤት ነው። 8. ሁሉም እውነት ናቸው 9. አላውቅም |  |
| 21. | እባክዎን ኦቲዝም ከሚከተሉት ውስጥ አንዱ ነው ብለው የሚያስቡ ከሆነ ሊነግሩኝ ይችላሉ? | 1. የአእምሮ ጉድለት 2. የአእምሮ ሕመም 3. የባህሪ ችግር 4. የመማር እክል 5. ከላይ ያሉት ሁሉም እውነት ናቸው 6. ከላይ ከተጠቀሱት ውስጥ አንዳቸውም አይደለም 7. እርግጠኛ አይደለሁም |  |
| 22. | የኦቲዝም መንስኤው ምንድነው ብለው ያስባሉ? | 1. ኦቲዝም በክትባቶች ይከሰታል 2. ኦቲዝም የሚከሰተው በአካባቢው በሆነ ነገር ነው። 3. ኦቲዝም በዘር የሚተላለፍ ወይም በዘር የሚተላለፍ ሊሆን ይችላል። 4. ኦቲዝም የሚከሰተው በደካማ የወላጅነት ችሎታ ነው። 5. ሳይንቲስቶች የኦቲዝም መንስኤ ምን እንደሆነ አያውቁም 6. ከላይ ከተጠቀሱት ውስጥ አንዳቸውም አይደለም 7. አላውቅም |  |
| 23. | የዕለት ተዕለት ልማዶች ላይ ድንገተኛ ለውጦች ወይም አዲስ ተግባሮች የልጅዎን ባህሪ ይጎዳሉ? | 1. በጭራሽ 2. አንዳንድ ጊዜ 3. በተደጋጋሚ |  |
| 24. | የኦቲዝም ምልክቶችን ያውቃሉ? | 1. አዎ 2. አይ 3. እርግጠኛ አይደለሁም |  |
| 25. | አዎ ከሆነ፣ ልጅዎ/ት የትኞቹን ምልክቶች ያሳያል? | 1. የዓይን ግንኙነትን ያስወግዳል/ች ወይም አይጠብቅም። 2. በ 9 ወር እድሜው/ዋ ለስም ምላሽ አይሰጥም/አትሰጥም 3. ቃላትን ወይም ሀረጎችን ደጋግሞ/ማ ይናገራል/ች 4. የተደበላለቁ ስሜቶችን ያሳያል/ች 5. በጥቃቅን ለውጦች ይበሳጫል/ች 6. ከላይ የተጠቀሱትን ሁሉንም ያሳያል/ች 7. ሌላ 8. አላውቅም |  |
| 26. | ምልክቶቹ የጀመሩት በስንተኛው ዕድሜ ላይ ነው? | 1. 0-2 2. 2-6 3. >6 4. አላቅም |  |
| 27. | ከእነዚህ ውስጥ የኦቲዝም ስፔክትረም ዲስኦርደር ምርመራው በየትኛው ላይ የተመሰረተ ይመስልዎታል? | 1. የባህሪ ምልከታ 2. የወላጅ ቃለ-መጠይቆች 3. አካላዊ ገጽታ 4. ሁለም 5. አላውቅም |  |
| 38. | ኦቲዝም ሊድን ይችላል ብለው ያስባሉ? | 1. አዎ 2. አይ 3. እርግጠኛ አይደለሁም |  |
| 39. | ኦቲዝም ስፔክትረም ዲስኦርደር ላለባቸው ልጆች ጠቃሚ ሕክምናዎች አሉ ብለው ያስባሉ? | 1. አዎ 2. አይ 3. አላውቅም |  |
| 30. | የኦቲዝም ልጅ መኖሩ ከሌሎች ችግሮች የበለጠ ፈታኝ የሚያደርገው ምን አይነት ነገሮች ይመስላችኋል? | 1. መሥራት አለመቻል; 2. ልዩ እንክብካቤ እና ትምህርት መፈለጋቸው 3. ልዩ ድጋፍ መፈለጋቸው 4. ጠበኛ ባህሪ መኖሩ 5. ሌላም |  |

ክፍል III: - የጤና አጠባበቅ ልምምድ መጠይቅ መመሪያ

|  |  |  |  |
| --- | --- | --- | --- |
| No | Variable | Response |  |
| 31. | ልጅዎ ከእርስዎ ጋር ነው ወይስ በኦቲዝም ማዕከል ውስጥ ነው የሚኖረው? | 1. ከእኔ ጋር 2. በኦቲዝም ማእከል |  |
| 32 | ልጅዎ የሀኪም ቤት ክትትል አለው? | 1. አዎ 2. አይደለም |  |
| 33. | ልጅዎ ምን ዓይነት እንክብካቤ ያስፈልገዋል ብለው ያስባሉ? | 1. የአመጋገብ ሕክምና 2. የንግግር ህክምና 3. ሳይኮሎጂካል ሕክምና 4. የግንዛቤ ባህሪ ሕክምና 5. ሌላ (ይግለጹ) |  |
| 34. | በአሁኑ ጊዜ ለልጅዎ ምን ዓይነት እንክብካቤ ይሰጣሉ? | 1. መመገብ 2. ማጠብ 3. ከእሱ/ሷ ጋር መጫወት 4. ሌላ (ይጥቀሱ) |  |
| 35. | በቤተሰቡ ውስጥ ለልጁ እንክብካቤ የመስጠት ሃላፊነት ያለው ማን ነው? | 1. እናት 2. አባት 3. ወንድሞች/እህቶች 4. መላው ቤተሰብ 5. ሌላ |  |
| 36. | የጤና ተቋም ለቤትዎ ቅርብ ነው? | 1. አዎ 2. አይደለም |  |
| 37. | አዎ ከሆነ፣ የኦቲዝም ማዕከሎች አሏቸው? | 1. አዎ 2. አይደለም |  |
| 38. | ከልጅዎ ጋር የተያያዘ ማንኛውንም እርዳታ ያገኛሉ? | 1. አዎ 2. አይደለም | --- |
| 39. | አዎ ከሆነ፣ እርዳታ ከየት ነው የሚያገኙት? | 1. የኦቲዝም ማዕከሎ 2. መንግሥታዊ ያልሆነ ድርጅት 3. ዘመዶች 4. የድጋፍ ቡድኖች 5. ሌሎች |  |
| 40. | ልጅዎን መንከባከብ ሁሉንም የገንዘብ ሁኔታዎን ሊነካ ይችላል ብለው ያስባሉ? | 1. አዎ 2. አይደለም |  |
| 41. | ምልክቶችን ካዩ በኋላ ወደ ጤና ተቋማት ለመውሰድ ምን ያህል ጊዜ ቆዩ? | 1. ወዲያው ወሰድኩት 2. ሶስት ወር 3. ስድስተኛ ወር 4. > 1 ዓመት 5. አላስታውስም። |  |
| 42. | ልጅዎን ወደ ማንኛውም ማህበራዊ ስብሰባ (ሠርግ, ጓደኞችን ወይም ዘመዶችን, የሃይማኖት ቦታዎችን ለመጎብኘት) ይወስዳሉ? | 1. አዎ 2. አይደለም |  |
| 43 | የማህበረሰቡን ተቀባይነት እንዴት ይገልፃሉ? | 1. ጥሩ ነው 2. ጥሩ አመለካከት የለም 3. ለመቅረብ ጊዜ ይፈልጋሉ 4. አላውቅም |  |