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AUTISM: PARENTS' EXPERIENCE AND CARE PRACTICE IN ADDIS ABABA

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Declaration

I hereby declare that the dissertation entitled *"Autism: Parents' Experiences and Care Practices in Addis Ababa"* submitted by me for the partial fulfillment of the Master Degree in Social Work to Indira Gandhi National Open University (IGNOU). This thesis is my own original work and has not been submitted earlier either to IGNOU or to any other institution for the fulfillment of the requirement for any course of study or published in any media. To my knowledge all the references used for the thesis have been fully acknowledged.

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Certificate

This is to certify that Mrs. MIRAF DEMISSIE KEBEDE student of MSW from Indira Gandhi National Open University, (IGNOU) New Delhi was working under my supervision and guidance for her project work for the course MSWP-001.

Her project work entitled *"Autism: Parents' Experiences and Care Practices in Addis Ababa"* Which she is submitting, her genuine and original work.

Place: Addis Ababa, Ethiopia

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Dedication

This research paper is dedicated to all third world mothers who have a child with autism and suffer that the enormous challenges.

Acronym

ASD	Autism Spectrum Disorders
A.A	Addis Ababa
C/S	Caesarean Section
FMOH	Federal Ministry of Health
HEWs	Health Exestation Workers
PDD	Pervasive Developmental Disorder
WHO	World Health Organization

Table of contents

Abstract

Introduction Autism is a complex neurobehavioral disorder that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviours. There is critical lack of awarness among the community and parents about ASD. Commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves by burdened with the full responsibility of care and likely having very little income. Thus this study aims to understand the pscycological, social and economic experiences of parents/caregivers from having or parenting a child with ASD.

Methods : This was a phenomenological qualitative study conducted in Addis Ababa, Ethiopia. Seventeen caregivers of autistic children from 15 families were purposively selected. Semi structured in depth interview guide that include participants' views to ASD, its challenges and their overall experiences was used to collect the data. Analysis was done using themes emerged from the data.

Result: Initially all study participants' does not have any awareness about the problem of their child with autism. Most of them noticed their child's problems and heard about it from health professionals. In-depth interview had also indicated that: All parents of children with autism require intensive care and always need somebody to follow up the child with autism and 13(81.25%) child spent the day and night at home. In addition having a child with autism has not only extra expense but also effects on generating income to support their family. In this study, it is found that parents having child with autism expressed their feeling of being isolated from social life due to perceive a lack of understanding what autism is and what was involved in caring by the community

Conclusion: Autistic disorder imposes a huge emotional/psychosocial and economic burden on families and communities. Existence of autism training centers, lack of funding and resources are among the challenges that were faced by the families/care takers of Autistic children.

Chapter One

1. Introduction

1.1 .Background

Autism is a complex neurobehavioral disorder that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. A child with autism who is very sensitive may be greatly troubled sometimes even pained by sounds, touches, smells, or sights that seem normal to others. Many people with autism are cognitively impaired to some degree. In contrast to more typical cognitive impairment, which is characterized by relatively even delays in all areas of development, people with autism show uneven skill development. Autism is four times more common in boys than in girls. Autism typically appears during the first three years of life. It knows no racial, ethnic, or social boundaries. Family income, lifestyle, or educational levels do not affect a child's chance of being autistic (http://www.webmd.com/brain/autism/understanding-autism-basics).

Studies found out that even in high income countries, raising a developmentally different child is a unique emotional and psychological challenging experience for most parents (Freedman, 2011; Pottie, Cohen, & Ingram, 2008). This situation is likely worse in most low-income countries including Ethiopia. Having/parenting a child with any developmental disorder has significant socioeconomic and cultural implications. This is reflected by complete lack of awareness, attention and support from the community as well as the government, and parents are exposed to stigmatization, which contributes for economic, social, emotional and psychological challenges and experiences.

Autism Spectrum Disorders (ASD), characterized by abnormalities in social functioning, language and communication, and unusual behavioral interests, are a collection of five developmental disorders, namely Autistic disorder, Asperger's syndrome, Rett's disorder, Childhood disintegrative disorder, and Pervasive developmental disorder not otherwise specified. (American Psychiatric Association, 2003)

The median estimate of Autism syndrom disorder and other Pervasive developmental disorder(PDD) prevalance in high income countries is known to be 17/10000 and 62/10000 respectively (Elsabbagh et al., 2012). However, in Ethiopia and most low income countries prevalence studies are not undertaken, hence statistical evidence on the problem is hardly available (Freedman, 2011; Pottie et al., 2008). Hence, most low income countries including Ethiopia often adopt the above mentioned global prevalance rate. However, chronic problems related to reproductive health, prevelance of disesses like malaria, poverty and food security are assumed to contribute for increased prevalance of ASD and PDD in Ethiopia and other low income countries (Elizabeth et al., 2003).

While undertaking a literature search for this study, statistics or published/peer reviewed study document related to ASD in Ethiopia is hardly available. Such lack of statistics studies and initiatives could imply that there is critical lack of attention regarding ASD or other PDD in Ethiopia. Needless to say, traditionally they are often considered as humiliations and big burdens for parents who lack the means, ideas, and external support on how to deal with the situation. As a result, children are left/ neglected as pioneers in an unknown world of disability.

Many parents of autistic children also report a feeling of lack of support. A 2008 study, following the experiences of 14 parents of children with autism, found that parents commonly experience extreme social isolation and a lack of understanding from others. "Group support can offer parents knowledge, understanding and acceptance they seek," notes Mary Banach. Parents can find comfort, friendship and support in networks like the Autism Support Network http://everydaylife.globalpost.com/challenges-being-parent-child-autism-3878.html

1.2. Statement of the problem

According to Elsabbagh et al. (2012), the median estimate of ASD and pervasive developmental disorders (PDD) in developed countries is 17/10,000 and 62/10,000 respectively. Autism spectrum disorders impose a huge emotional and economic burden on families. Caring for children with these disorders is demanding, especially in contexts where access to services and support are inadequate. Worldwide, most individuals with such a disorder and their families do not receive any care from health or social care systems.

Initial data from studies in the United Kingdom of Great Britain and Northern Ireland and the United States of America indicate that estimated lifetime costs of caring for individuals with autism spectrum disorders lie between US$ 1.4 million and US$ 2.4

million per case according to the level of intellectual impairment. The reduction in family earnings due to the need to provide care for family members with autism spectrum disorders compounds the problem (WHO, 2013).

There is critical lack of awarness among the community and parents about ASD. Once the parents found out that their child experienced developmental challenge, even with out being diagonised, they consider their child as usless and un worthy of spending resources on him/her. Children with ASD are often denied any rights whatsoever, even the right to see daylight, enjoy sunshine, or the right to participate in society. Such disorders are sometimes even seen as punishment for some spiritual wrongdoing or a tragic incidence. Most parents had no knowledge about ASD and felt that they were not fully empowered with information about autism by professionals before or after diagnosis. Many parents of autistic children also report feeling a lack of support.

Commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves. Burdened with the full responsibility of care, and likely having very little income, their child’s disability directly constrains their ability to work and make a living to take care of their children and themselves. Often, the exceptional demands of the child’s disability also create emotional and financial problems for the parent.

Greater levels of daily positive mood were associated with more emotional and instrumental support, and less parenting stress and unsupportive interactions. Greater daily negative mood was associated with less emotional support and more parenting stress, unsupportive interactions, and disruptive child behaviors. Emotional support, unsupportive interactions, and disruptive child behaviors moderated the stress-mood relationship.

1.3. Objectives

1.3.1. General Objective

The study is aimed at understanding the pscycological, social and economic experiences of parents/caregivers from having or parenting a child who has ASD.

1.3.2. Specific objectives

- To describe parental perceived psychcological experiences in having/parenting a child with ASD;
- To elucidate parents’ awareness and perception of ASD ;
- To elucidate the socoeconomic impacts of having a child with ASD

1.4. Research Question

What are the experiences and care practices of Ethiopian parents/caregivers in having and raising a child with ASD?

1.5. Significance of the Study

This study generated evidence based information that highlight the situation of parents or caregivers experience in relation to autism. The finding emerged is helpful to develop policies and programs for stakeholeders; improve awarness on ASD and limit social misconception, stigma and initiate low cost social support packages. In addition to this, this research result could trigger further studies using strong study designs related to the issue.

1.6. Scope of the Study

The study was conducted on participants selected from a hospital and two centers in Addis Ababa: Yekatit 12 Hospital, Nehmiya Autism centre and Humanity for change autism centre in Ethiopia. As families could use centers around them and their experience could be the reflection of their living environment, the finding in this study, to the maximum, is delimited to the parents or caregivers of children with autism in these centers and the hospital. The study findings are also delimited to all the methods the study followed to answer the research questions.

Chapter Two

2. Literature Review

2.1 Definition of ASD

Symptoms of autistic disorder fall under three domains: social relatedness, communication, and behaviors and interests, with delays or abnonnal functioning in at least one of these areas prior to age 3 years. To meet criteria for autistic disorder, an individual must demonstrate at least 6 of 12 symptoms, with at least 2 coming from the social domain and 1 each from the communication and restricted behaviors/interests categories (Ozonoff, et al., 2005).

2.2 Parents' awareness

Although knowledge about autism has improved in recent years, Autism in Ethiopia is still surrounded by lack of awareness and stigma. There is a severe lack of diagnostic and educational services for individuals with autism and their families; facilities are non-existent in rural areas.(Marquis, et.al 2014)

Most parents had no knowledge about ASD and felt that they were not fully empowered with information about autism by professionals before or after diagnosis. Commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves. Burdened with the full responsibility of care, and likely having very little income, their child’s disability directly constrains their ability to work and make a living; to take care of their children and themselves. Often, the exceptional demands of the child’s disability also create emotional and financial problems for the parent. (http://everydaylife.globalpost.com/challenges-being-parent-child-autism-3878.html)

2.3 Importance of Early Diagnoses

Some parents are completely devastated upon learning that their child has been diagnosed with autism. The early diagnosis in turn, leads to early treatment that can offer a child that is autistic a better chance of what society considers a semi normal life. (Sonya , Jessica , 2012).

Children as young as 2 to 3 years, who exhibit behavior associated with a diagnosis can qualify for early intervention services. This alarming rise in the number of children, clearly calls for additional services to meet the needs of these children and their families. (Ashum & Nidhi , 2005)

The diagnosis of autism begins a journey that places profound demands on family human and financial resources for the remaining lifetime of the child. (Aadil. et al., 2014).

More than half of school-aged kids were age 5 or older when they were first diagnosed with autism spectrum disorder, the study showed. Less than 20% were diagnosed by age 2. The American Academy of Pediatrics recommends that pediatricians screen children for autism at 18 months of age. (Denise, . 2012)

From birth to at least 36 months of age, every child should be screened for developmental milestones during routine well visits. When such a screening or a parent raises concerns about a child's development, the doctor should refer the child to a specialist in developmental evaluation and early intervention.(https://www.autismspeaks.org/what-autism/diagnosis)

There are no diagnostic or educational services in the rural areas, where 85% of the population lives. In these areas autism usually remains undetected because of limited health care, low levels of awareness and stigma. Autism type symptoms are often seen as a punishment for wrongdoing from supernatural forces. (Marquis D, 2014)

Getting children early intervention that increases IQ’s, social interactions and communication skills will increase the ability for individuals with ASD to gain employment and be able to live independently. This will increase the individual’s well-being and decrease overall costs. . (Sonya & Jessica, 2012)

2.4 The causes of Autism

Scientists aren't certain about what causes ASD, but it's likely that both genetics and environment play a role. Studies of people with ASD have found irregularities in several regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. While these findings are intriguing, they are preliminary and require further study. **http://www.ninds.nih.gov/disorders/autism/detail_autism.htm**

2.5 Prevalence of ASD

Recent reviews estimate a global median prevalence of 62/10 000, that is one child in 160 has an autism spectrum disorder and subsequent disability. In Europe, the median rate is 61.9/10,000 (range 30.0–116.1/10,000) and in America, the median rate is 65.5/10 000 (range 34–90/10 000). Autism spectrum disorders account for 0.3% of all disability-adjusted life years. Autism spectrum disorders impose a huge emotional and economic burden on families (WHO, 2013).

Although most studies on ASD prevalance reflect the estimates for developed countries, little is known about the ASD /PDD prevelance in low income countries. However, the estimates suggest that it is less that or as high as in developed countries (Nyoni and Serpell, 2014).

Although prevelance studies reflect the prevalance of developed countries and the global rate is adopted for developing countries, chronic problems related to reproductive health, prevelance of disesses like malaria, poverty and food security are assumed to contribute for increased prevalance of ASD and PDD in Ethiopia and other low income countries (Elizabeth et al., 2003).

A study conducted between 2000-2011 by different resesrchers at different regions revealed that the prevelance of all forms of autism combined is estimated to be 1 in 162 individuals (Elsabbagh et al., 2012). Taking the global median estimate, Autism Spectrum Disorder ASD=17/10000 and Pervasive Developmwntal Disorders (PDD) 62/10000 (Elsabbagh et al., 2012). 5000 and 18500 children and parents/care givers are estimated to suffer from having children with ASD and PDD.

If one in every 115 children is diagnosed with autism in the United States, we should fairly be able to say that with Ethiopia's population of more than 80 million, we can estimate that there are at least 530,000 children suffering from autism and related developmental disorders in the country**. https://niafoundation.wordpress.com/autism/**

Despite the above estimated number of children suffering from ASD and other PDD syndroms, the prevailing lack of prevalance study and diagonistic capacity/setup implies the pervasive lack of attention and awarness. There is lack of awarness among the community and parents about ASD. Usually when parents found out that their child has some kind of mental development problem, even with out being diagonised, they consider him/her as usless. Children with ASD are often denied any rights whatsoever, even the right to see daylight, enjoy sunshine, or the right to in some way participate in society. Such disorders are sometimes even seen as "punishment for some spiritual wrongdoing or a tragic incidence" (Autism in Ethiopia, 2014).

2.6 Burden of Mental Health

The Global Burden of Disease study measures burden in "disability adjusted life years" (DALYs), which is a way of quantifying the health gap between current and ideal health status. One DALY is equivalent to one lost year of healthy life. In 2010, mental and behavioral disorders accounted for 183,912,000 DALYs globally, or 2,669 out of every 100,000 DALYs. Neurological disorders made up 73,814,100 DALYs globally, or 1,071 out of every 100,000 DALYs. http://www.brainfacts.org/policymakers/global-burden-of-neurological-and-mental-disorders/.

In less than 1/3 of all counties, is it possible to identify an institution or a governmental entity with clearly identifiable overall responsibility for child mental health programmer in the country. It is typical that child and adolescent mental health services, not necessarily identified as such, are supported to varying degrees by ministries of education, social services and health with little or no coordination. Europe 24%, North America 28%, Oceania 33%, Asia 39%, Latin America 42% and Africa 54% (WHO, Atlas, 2005).

Currently, mental health and long term physical illnesses are becoming the main concerns of the World Health Organization. Globally, over 12.5% of disease burden is caused by mental and neurological disorders (Sambo, 2010). Though there is limited evidence on mental health problems in the African Region, studies from a few countries indicate that one in six patients visiting the health service has at least one mental, neurological or behavioural disorder (Report of the Round table on mental health, global action plan, for African countries, 2009).

2.7 Importance of Care and support

The Autism Specific Early Learning and Care Centers provide early learning programs and specific support to children aged zero to six years with autism spectrum disorders (ASDs) in a long day care setting. They also provide parents with support in the care of their children and give them the opportunity to participate more fully in the community. https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services

Regarding Special Needs program, there are no specifically designed curriculum, syllabus, and/or modules that intend to meet the educational needs of children with autism spectrum disorder in segregated or inclusive classrooms. Although it is based on the country's capacity, this fact is far from the national and international convention of human rights and education for all. http://www.ethioautism.org/Joy/Autism_in_Ethiopia.htm

Greater levels of daily positive mood were associated with more emotional and instrumental support, and less parenting stress and unsupportive interactions. Greater daily negative mood was associated with less emotional support and more parenting stress, unsupportive interactions, and disruptive child behaviors. Emotional support, unsupportive interactions, and disruptive child behaviors moderated the stress-mood relationship. (Pottie, et al., 2008)

Environmental risk factors such as lack of services and negative attitudes can also have an adverse influence on the prognosis of the child with autism, the family concerns are difficulty in accessing services, limited involvement in interventions, services that are not effective in meeting the needs of the child or family, and a lack of interagency collaboration. (Ashum G* Nidhi S, 2005)

2.8 Economic Effects

According to a study in 2005 the expenses for a child with autism was more than triple that of a child without, and for those children that also had a co-occurring condition the costs were even higher. The larger portion of the expense is incurred during adulthood. (Sonya & Jessica, 2012)

Costs associated with having a child with autism are not, only, limited to the cost of interventions. Like any other forms of childhood disability, parents of a child with autism often face greater outlays of time and money than they would for a neurologically typical child. (Aadil ,et al., 2014).

In a few cases, fathers acknowledged that their child’s autism might have encouraged a great commitment to work. In addition, many mothers who worked were often forced to miss work. They performed below average and some eventually worked part-time or ultimately left the workplace altogether. (Sonya & Jessica, 2012)

2.9 Psychosocial Effects

Research into families under stress has demonstrated a link between relationship breakdown and poor physical and mental health. The evidence points ultimately therefore to a significant cost to the state in the stress placed on individual carers, and the consequent breakdown in health and family relationships. (Fiona, 2001)

Other important factors associated with parental stress in families of children with autism, include, feelings of loss of personal control, absence of spousal support, informal and professional support. (Aadil, .et al., 2014).

Parents of children with disabilities experience more marital stress and discord than parents with normal children. Families with autistic children face many stressors and challenges, today's partnership in marriage is more challenging and more difficult than in the past years; especially couples with special needs children(AlHorany et al 2013)

Mothers of autistic children have higher parenting-related stress and psychological distress as compared to controls. Outwardly, it might appear as if the psychological stressors exerted specific effects resulting in mental ill-health attributable these stressors. (Abdullahi & Samira, 2013)

Positive attitude, social support and faith in God, helped mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving and Interventions focused on parents' coping skills have reported positive results (Ashum & Nidhi, 2005)

Siblings of children with autism are significantly more likely to experience depression than the general population. Along with psychological problems, exhaustion may affect siblings who may be responsible for domestic tasks and physical care. (Ashum & Nidhi, 2005)

Fear of discrimination and the stigmas surrounding disabilities lead many families to refuse to go to professionals and receive a diagnosis for their children. (Aadil.et al., 2014)

2.10 Associations with Seizures

Seizures are another common problem for children and teens that are autistic. According to researchers, “one in four children with an Autism Spectrum Disorder will develop seizures. (Sonya & Jessica, 2012)

Chapter Three

3. Method and Materials

3.1. Study Center

The study was conducted in Addis Ababa, the capital of Ethiopia with population of 3,384,569 according to the 2007 population census and an area of 530.14 square kilometer.

3.2. Study Design

Phenomenological qualitative study based on semi structured in-depth interview was used. This qualitative phenomenological study methodology is chosen to understand and discribe subjective experience, gaining insights into parents/care takers motivations and actions (Lester (1999) explained phenomenological study as a powerful method for understanding and discribing the meaning of events and subjective experiences of the human sphere. It sets aside the researchers hypothesis and emphasizes on describing rather than explaining participants personal experiences as much as possible to take a fresh perception towards the phenomenon under study (Husserl, 1970 cited in Lester, 1999).

3.3. Study Population

The study populations are those parents or care givers who have/are parenting a child with ASD in Addis Ababa sub city, Autistic children in A.A Selected Facilities.

3.4. Study Participants

A total of 17 individuals were involved in this study, while additional study participants will be added till the idea is saturated.

3.5. Participant Selection Procedure

A purposive sampling method was used to select study participants in order to obtain wide representation of views across the study populations. It is assumed that by using this method, it is possible to include both parents or/and care givers who have/are parenting a child with ASD. Thus the researcher was selected 17 parents and care givers as study participants.

However, the final participant size was determined while working in field, conducting constant comparative analysis and the point of sensing saturation. Hence, the final sample size may be higher or lower than the initial size stated above.

Hence, the following selection criteria were considered:

- The child with ASD symptom is up to 10 years and lived with family caretaker; who are found in A.A selected facilities.

- Finally, willingness of the family particularly the family caregiver for in-depth interview.

3.6. Data Collection

The data needed to answer the research questions were collected using semi-structured in-depth interview. , In semi-structured interview, questions that could guide the interview are needed to develop before any of the interview sessions. These guiding questions incorporated multiple-questions that could open wider and flexible answering space. In this study, the guiding questions were designed in line with –the research questions of the study. It mainly considered or incorporated questions about participants' views to ASD, its challenges, availability and acceptability of care services and their overall experiences. This guide was first prepared in English and then translated into a local language. The final version was cross matched with the original version and will be pretested once in field. If any incompatibilities occur, correction measure was taken to keep its consistency as the in-depth interview was conducted by the principal investigator assisted by other data collectors. It was mainly tape recorded which was supplemented by written notes.

Three days before data collection date, the principal researcher was contact participants who agreed to take part in the study by telephone and arrange a convenient time and place for the interview to take place, probably on weekdays. The interview may last from one hour to one hour and 30 min. It was informal and open-ended, and carried out in a conversational style. Interview was held primarily in Autism centers and Yekatit 12 Hospital phsycatiriy department to participate participants who come for autistic child follow up. In this case, refreshment (tea, coffee, soft drink) was provided and travel expenses will be reimbursed at flat rate at the end of the session (to be determined on the spot).

Principal investigator with one note taker was leading each session. After a brief explanation of the study purpose, a written consent will be obtained from the participant before commencing interviewing, using forms designed for the study. The whole session will be tape-recorded and one note taker will take field notes on non verbal cues.

3.8. Data Management and Analysis

At the end of each data collection session, the tape recordings was transcribed verbatim and translated. Transcription and translation were done by two individuals working independently and comparison was made. This was help to reduce biases in transcription and translation. The transcripts and translations were compared with the field notes to confirm the topics of discussion.

Analysis was done using themes emerged from the data. 'Constant comparative analyses', a process whereby data collection and data analysis occur on an ongoing basis, was done during data collection, certainly before the next interview takes place, and any interesting findings was incorporated into the next session. After careful line by line reading and understanding, the data was divided into meaningful analytical units. After analyzing the data, rating the frequency of occurrence of each code was done and similar codes were grouped together to form minor and major categories. After defining the core categories, issues around them and their relation and interconnection were explored. The frequency of each issue was presented to give an indication of the relative importance and result was summarized.

3.9. Ethical Considerations

This studies which explore subjective experiences which is often seen as stigmatizing, and often private, ethical consideration would be critically considered. Each participant were received a form entitled ”Informed Consent” which explaned the nature and purpose of the study and participants’ role in the study. Confidentiality of the information; their right to decline selected questions and withdraw from the interview at any time of the interview; willingness to audio recording; and freedom of the respondents to speak or reserve on selected topics they feel dangerous to their life were incorporated in the consent form. Both the researcher and respective particpants signed on two copies of the consent form and each have their own copies of the signed form. Such ethical consideration is important to build participants confidence and get approprate ressponse.

3.10. Limitation of the study

During the study time some Autism centers were not willing even to contact and link parents with researcher and to ask parents their willingness for interview; due to this the study is not supported by other data collection techniques like FGD.

Chapter Four

4. Finding

4.1 Introduction

This chapter deals about findings of the study that could answer the research questions of the study based on the data collected from the in-depth interviews with participants (parents/caregiver) who have been providing care for a child who has ASD. Data analysis was concurrent with data collection. All interviews and field notes were transcribed. The transcripts were reviewed repeatedly for significant statement in an attempt to find meaning and understanding through themes. All phrases, sentence clusters, notes, and textual data were then reduced until essential themes emerged. Essential themes were made by considering unique to the phenomenon of parents who have a child with autism and are fundamental to the overall shared description of their experience.

The major thematic categories identified were:

- Profile of the participants
- Knowledge, awareness, perception of autism and causes of the Autism disorders
- Care practice and any help/supports related to the autistic child and the from and source of support
- General socioeconomic and psychological impacts of having ASD child

4.2 Demography of the Study participants and their children

Table 4.1 Participants' and their autistic Childs' profile

The parents profile						**The autistic child profile**			
Code of family	**Gender of the participant**	**Religion**	**Marital status**	**Educational status**	**Total no of children**	**Autistic children no**	**Gender of autistic children**	**Age of autistic children**	
001	Female	Orthodox	Married	Illiterate	9	1	M	9	
002	Female	Orthodox	Divorced	Diploma	1	1	M	4	
003	Female	Orthodox	Divorced	Illiterate	1	1	M	7	
004	F & M	Muslim	Married	Illiterate	6	1	M	9	
005	Female	Muslim	Divorced	Diploma	2	1	M	6	
006	Female	Muslim	Divorced	8 grade	1	1	M	4	
007	Female	Muslim	Divorced	Diploma	1	1	F	7	
008	Female	Protestant	Single	Diploma	1	1	M	8	
009	Female	Orthodox	Widowed	12 complete	2	1	M	4	
010	Female	Orthodox	Married	Diploma	4	1	M	9	
011	M & F	Muslim	Married	Diploma	2	2	M (both)	9,5	
012	Female	Muslim	Divorced	12 complete	2	1	M	7	
013	Female	Muslim	Divorced	12 complete	1	1	M	5	
014	Female	Muslim	Divorced	Diploma	1	1	M	6	
015	Female	Orthodox	Married	Degree	3	1	F	10	1F is dead at the age of 14

As it can be seen from the above table, the participants' selected to participate in the study have the required parenting/caring experience to provide reliable information that could help answer the research questions of this study.

Among a total of 15 interviewees participated during the study, 11(73.3%) parents were interviewed at Yekatiet 12 Hospital psychiatric department for autistic child follow up. Only two (13.3%) of them attended as caregivers in Nehmiya Autism centre in addition to parenting their child and another two (13.3%) parents were from Humanity for Change Autism centre. Two of them are having two autistic children, but one family (code 015) is one child is dead recently at the age of 14 due to autism and its related problems.

Among the study participants 17 parents of children with autism participated. 15 (88%) were mothers and two were fathers with a total of two couples participating in the study. The parents' age ranged from 30 to 50 yrs. About eight (53.3%) were divorced, while five (33%) married, one parent were single and widowed respectively.

Fourteen of the 15 caregivers in the study have only one child with autism during the interviewing time. The only family with two autistic children was the family with code number 11 where they have two boys with autism. But one of the fourteen families had two female autistic children but one of the autistic passed at the age of 14. At the time of the interviewing all participants have autistic children whose age ranged from 4-10 years.

4.3. Awareness and perceptions about Autism

Initially all study participants' does not have any awareness about problems of their child with autism except some signs and symptoms. Three family members give similar explanation about their child problems. The participant with code number four said that "the *problems of my child include does not communicate at all, not give attention for things, not walk on time, need loneliness and not socialize*".

Other families have also reflected their perception about the problem. The participant labeled by number eleven said that *"I have two children both have communication problem. They were also restless, do not give attention for things, do not listen, and don't respond properly. They lack the skill of socialization."*

According to the in-depth interview result, participants have noticed that their kid is abnormal from as compared to other kids of their age. Four (25%) participants noticed their child problem at the age of three and below, eleven (68.8%) of the participants of their children above three years of age among these one mother noticed at the age of 6 years.

All the respondents do not know about ASD. 13 (86.6%) parents respond that they went to health facility when they noticed their children have problems in his/her communication, socialization or seems abnormality, and then all parents known the child have autism from medical professionals.

Participants code no seven said that

> *When we observe our child, he can't talk at all, he doesn't hear words like no and he is so restless, then we went to health center, the nurse told us he needs examination in hospital, and then we went to hospital and a doctor told us our baby have a problem which is autism.*

Two participants (number ten and four) have no any idea and didn’t notice any abnormality in their children before they heard from other people. The parent participant of family ten said that

> *One of my husband’s friends is a doctor in his profession, and one day he came to our home to visit us. Noticing the abnormal doings of our child he said “do you know your child have autism did you went to a hospital before for this child?” we said no then he told us to went to a hospital to check for his problem after that we went to Yekatit 12 Hospital and he was diagnosed as autism case and started his follow-up. At that time his age was four year.*

A caregiver who participated in the study under code number four also said

> *Before one year my child was sick, he have got cough and fever then I went to a health center for examination and treatment. At that time the nurse told me that my child have developmental delay, he is not on expected developmental with age, he needs further examination and she referred us to Yekatit 12 hospital. The diagnosis in the hospital indicated that my child had autism. Before that I didn’t know he had the problem.*

According to the finding from the in-depth interview, five family members have similar answers regarding the causes of autism. They Said “*I don’t know the causes of Autism”*, four family members related the child case with “*my baby was got fallen down from bed and I think the cause of the problem is related with it”.* One mother with code no three said that “*when I was pregnant the health professional told me that I had uterine cyst, I think the cause is the cyst*” and three family members mentioned that the cause is related with instrumental delivery such as vacuum and forceps.

One mother with code fifteen said that

> *I think the cause is with late Caesarian section, because when I was in labor for my first child, my child was in distress but the health professionals didn't take decision on time for caesarian section. And I did not get appropriate help from the health professionals; I think the cause is that.*

One father with code no eleven said that

> *I think the cause of my children is pre term lobar because both children were born before nine month, the first one at seventh month and fifteen days and the second one at eighth month; we think that must be the cause.*

4.4. Care Practice and any type of supports

From the in-depth interview finding, 13(81.25%) of the 16 children with autism spend the day and night at home with their families. Only three (18.75%) autistic children spend their day time in autism centers. which claim the scarcity, distance and un-affordable transportations for autism centers or placements.

4.4 .1 Care practice

Results from the in-depth interview had also indicated that all parents of children with autism required intensive care and always need somebody to follow up the child with autism. They respondents explain that they are not able to deal with the child about danger things through discussion and the children can't guard themselves from danger.

Twelve (80%) of the respondents give similar responses about the type of care their child needed. For instance, the participant labeled by number eleven, while reflecting the care practice said that:

> *My children needs an intensive care, need to play and they want someone to watch over them all the time since they are very restless and they want to do whatever they want at all time, they don't listen to 'no and don't.*

The remaining three (20%) parents cannot indicate about the type of care their child needed. One among these, reflecting her confusion on the care she should give to the autistic member of the family, the participant labeled by number 005 said that

> *I am always confused and stressed when I think of him. Because I do not know what kind of care or help he needs and how to manage him. Since he is usually restless, hard to communicate and he doesn't listen to me at all.*

Among 16 children the majority 13(81.25%) spent their day and night at home and always parents are expected to feed, dress, give intensive care and follow them. Only three children spent their day time in autism centre, two of them at Nehmiya and one of them is at Joy Autism center.

Except one mother (number 15) who has a half day job, all didn't have job and spent their time with their child. But two respondents from Nehmiya autism centers were caregiver at the center for autistic children and spend their day time with their autistic child in the center along with other children with similar problem. All respondents answered that most of the time the mother is the most responsible and burdened in caring children with autism. But sometimes father, sisters, brothers and a housemaid also give the care. Parent code no thirteen said that "*Usually I am responsible and give the care to the child, since I am home all the time. But sometimes my mother, brother and sister are helping me.*"

One participant's with code no one said that:

> *Most of the time I give the care because I have a fear that the family members are not understanding the child's problems like me and also sometimes I observed that when other family members get bored to give the care, I also think that am responsible for the problems.*

And also Code no three said that:

> *I am the only one to give the care for this child, as I told you my husband had left me and this is the hardest part of my life. Sometimes my brother help me, but most of the time I spent days and nights with this child.*

4.4.2 Any support related autistic child

All participants indicated that they didn't get any financial support. One parent identified by number 07 said that "*before a year an organization called Compassion used to gave me 150.00 Birr (7.5 $) per month but now they stop it and I don't get any help"*. Twelve of the 15 respondents didn't get any help/support from any source including autism centers, they are given similar explanations. Parents with Code no eight said that*:*

> *We Didn't get any type of help until now, I know that there is Joy center which is autism Center , but it is so far from our village , I can't afford the transportation cost and also I didn't know how to accept the child or the criteria's also.*

But only three family members have got free training for their autistic child from Autism centers. Two of them from Nehmiya Autism centre and one child from Joy autism centre.

Parent with code no ten said that: "*I don't get any financial support but my child gets free education service from Nehmiya Autism center.* "

4.5. Eeconomical, Social and psychological impacts

4.5.1. Economic Effect

The results of in-depth interview have indicated that; all parents said that having autism child have extra expense in different aspects, one parent with code number 15 comprehensively indicated that

> *Having child with autism has extra expenses. For example sometimes they do not chew food so we have to prepare soft foods. They can't order their interest so the prepared food may be discarded and I should have prepared another food at same time. There is Long term diaper usage as they do not control urine timely and do not train using bowl for urine. They have extra cost for washing/launders. In addition to this there is extra transport cost and cost for medication when we went to Hospitals for follow ups.*

Three parents respond that their children have epileptic case in addition to autism so they have extra cost for medication and transport for their child follow-ups. In addition to this some of them explained that they have transport costs even to take their children to Holy-water in different churches, prayer centers repeatedly. And also they claimed extra cost for house servant needed and high turnover of house servant due to the hardships of giving care to autism case child.

In addition to extra expense having autistic child most of the parents especially mothers can't do any type of jobs to generate income to support their family. Sometimes the father and other family members also not fully functional due to stress related with the child case.

Parent labeled by number thirteen said

> *All the time the child needs to follow up. In addition to this I am expected to feed, to bath to dress and to do all the care for the child. So it is difficult to be away from home or to involve in income generation for family. We live by my brother and sister financial support.*

As the parent number eight said

> *Government talks a lot about HIV and peoples affected by HIV but what is HIV now? They can take medication and live healthy life and they can participate in any type of work. But we can't participate in any type of jobs so why doesn't the government talks about us and try to help us.*

4.5.2 Social Effects

According to the result of the in-depth interview, all parents explain that they have problems in their social life, for instance: attending any social affairs like work environment, wedding, funeral and birthday ceremonies. Parents code no. two said that "*Yes there are social problems. For example I can't find any jobs, not attend funeral and weeding ceremony or can't rich on time as others"* According to the respondent, the community perceives that autism and other mental problems as taboo that you can notice that your neighbors won't let their kids play or go to a family where there is a kid with ASD or other developmental disorder.

One parent with code no. ten said that

> *Other parents don't let their children to play with my child I feel bad. Our community does not understand the diseases. Although there is a little change in awareness now a days, government should give attention especially to change the community perception, at least the community should understand it is not a disease that transmitted from one to another and not to stigmatize the child as well as the family.*

One parent code no fourteen is said that

> *I felt sorry while looking my neighbor closing the door on my child; I think they perceive it as communicable disease. Our society not understands about autism case. Not only this; but also the owner forced me to leave the rented house because of my child problem.*

It's difficult for parents to bring their children out in public for fear of reaction of the children with ASD and the way others react. And also parent labeled by number eleven said that

> *Yes there are lots of social problems for example we can't attend on social affair programs. We can't visit relatives like other people do; and we have fears to go to play centers with our children for refreshment; I can't enjoy by my child like others people because people does not understand my children problems or my children also not understand people.*

When we see the marital status of parents, beyond 50% of the respondents are divorced and got family crises, from in-depth interview for instance a parent with code No. seven also said that *"I made divorce before three years, I don't know the reasons we can't understand each other especially after we knew our child have diagnosed as autistic child."*

And also code no three said

> My *husband left us. He said 'you are the cause for my child to have this problem, because you didn't give enough care for my child'. His families also blame me for the case of our child problem and now he married another woman and gives birth and lives his life.*

4.5.3 Psychological Effects

From in-depth interview finding all parents experienced feeling of sadness, stress, and fear about their child problems. There are also guilty feelings claimed by parents especially mothers. Parent code no 10 side that

> *Some parents living around me did not allow their children to play with my child, for this reason I feel so bad and get disturbed. And this shows me that the problem is not well understood by the community.*

Parent code no fifteen said that

> I *have fear about my child because who can understand my child if I am dead one day. Now she is 10 years, she is going to be adolescent and I have fear how I can teach her sexuality and keep prevent her from sexual abuse or harassment.*

Parent code no seven said that

> *Me and my husband had stress and emotionally disturbed by our child problem. We can't understand each other, and one day my husband blame me as the cause he said "you took medication when you were pregnant, that is why my child have such kind of problem" I felt so sorry.*

One parents code no fourteen said that

> *It is difficult to explain the situation I am always in stresses: thinking about the solution but there is no solution, thinking about community understanding that is also so painful because they think it like devil, as rewards for bad personality, thinking about my child problem and his futurity also.*

According to the result of the in-depth interview, all parents have positive expectations on their child future and have hope in”God” and “Allah” about their child development and improvement based on their religion. In addition to this

parents code no 10 said that” *Yes one day I hope God will make my child healthy and by giving continues training to the child there will be improvement*.”

Chapter five

Discussion

The study finding shows that all the respondents do not know about the without mentioned the sign and symptoms of autism, prior to the child diagnosed in health facilities. Besides other study participants' respond that they are not aware about their child have problem at all, they just heard after they went to health facility for other cases of the child. This indicated that the parents /community lack awareness about the autism case. This supported by previous study, most parents had no knowledge about ASD and felt that they were not fully empowered with information about autismn by professionals before or after diagnosis. (http://everydaylife.globalpost.com/challenges-being-parent-child-autism-3878.html)

According to the study more than half of the participants noticed their children problem lately. Most of them noticed when their child was around three and above, few of participants' noticed their child problem below three ages. This indicated that being noticed lately the child problems denied early diagnosed and management. According to Denise (2012), More than half of school-aged kids were age 5 or older when they were first diagnosed with autism spectrum disorder, the study showed. Less than 20% were diagnosed by age 2. The American Academy of Pediatrics recommends that pediatricians screen children for autism at 18 months of age. But previous study results indicated that, the early diagnosis in turn, leads to early treatment that can offer a child that is autistic a better chance of what society considers a semi normal life and early intervention has been proven to stimulate the brain receptors in autistic children under the age of 3 and taught to respond in a similar manner to a child without an ASD (Sonya and Jessica (2012)).

When it comes to the reason behind the children being autistic, according to the data collected from the parents of the children, differs from one another. Even though they cannot be sure or medically proven three parents for instance blame the medical centers during delivery. According to these parents it is instrumental delivery such as vacuum and forceps that brings autism to their child. In the same token one parent mentions that it is late decision for C/S, because of the negligence of the health professional, which contributes for the Childs being autistic. The other four respondents of the interview describe that it is childhood external problems like felling from bed which brings the trauma. One respondent who have two children that are autistic mention that it is their preterm delivery that creates the problem. One mother also related the cause with uterine cyst during pregnancy. The rest respondents of the interview could not identify any reason for their children's being autistic. But from pervious stud finding Scientists aren't certain about what causes ASD, but it's likely that both genetics and environment play a role. Studies of people with ASD have found irregularities in several regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. **http://www.ninds.nih.gov/disorders/autism/detail_autism.htm**

From the study finding, Most of the children spend their day and night at home. Which claim the scarcity, distance and un-affordable transportations for autism centers or care center. To conclude the respondents of the autistic children understand care to mean only feeding, washing, and other external activities. They rarely work on the development of skills towards the children. It can be said that almost all the respondents of this interview did not work on the development of their mental and other extra training activities. But three of the respondents mention that the fact that their children went to autistic center allows them to the development of this skills. From these three respondents two parents of the autistic children work in autistic a center which allows them to work on their children mental development and continues training. From pervious study The Autism Specific Early Learning and Care Centers provide early learning programs and specific support to children aged zero to six years with autism spectrum disorders (ASDs) in a long day care setting. They also provide parents with support in the care of their children and give them the opportunity to participate more fully in the community. https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services

Regarding about help for the child with autism, parent's responds that they need support from government and other organization. Moreover parents have also concern about existence of autism training centers. This helps family productivity of family members related with their economy. Absence of enough autism centers and lack of funding and resources are among the challenges in the study findings. Similarly From previous study, regarding special needs program; there are no specifically designed curriculum, syllabus, and/or modules that intend to meet the educational needs of children with autism spectrum disorder in segregated or inclusive classrooms. http://www.ethioautism.org/Joy/Autism_in_Ethiopia.html In addition according to (Ashum & Nidhi , (2005)) the family concerns are difficulty in accessing services, limited involvement in interventions, services that are not effective in meeting the needs of the child or family, and a lack of interagency collaboration.

All respondents answered that most of the time the mother is the most responsible and burdened in caring children with autism. As mentioned in the social effects of this study having an autistic child is leading for the beak up of families according to the data collected from the in depth interview. Because of this being a single mother will push the burden of taking care of the child to the mothers. In some cases however the mothers choose to be the sole care givers because they think that other people might not understand their children. Most of the time husbands participate in income generating activities for the family and it will overburden the mothers in taking care of their children. Similarly previous study finding supported this as commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves. Burdened with the full responsibility of care, and likely having very little income, their child's disability directly constrains their ability to work and make a living; to take care of their children and themselves. Often, the exceptional demands of the child's disability also create emotional and financial problems for the parent. (http://everydaylife.globalpost.com/challenges-being-parent-child-autism-3878.html

The finding of this study states that having a child with autism has extra costs and expense, for medication, transport and for others. Moreover, parents of a child with autism specifically mother can't do jobs to generate income to support their family. Sometimes the father and other family members also not fully functional due to stress related with the child case. This indicates that having a child with autism have impacts on family income to sustain their life. This is in line with a previous study that states, the expenses for a child with autism was more than triple that of a child without, and for those children that also had a co-occurring condition the costs were even higher. The larger portion of the expense is incurred during adulthood. (Sonya & Jessica , (2012))

This study also revealed that, parents having child with autism expressed their feeling of being isolated from social life due to different aspects like their child is need follow-up throughout the cant attend social affairs in addition to this they perceive a lack of understanding what autism is and what was involved in caring by the community . This leads to social stigma and discrimination both for the autistic child and the family. And according to Aadil B.,et al., (2014), there is a lot of discrimination not only of the autistic child but also of the family as a whole because the family is seen to be a part of the illness, fear of discrimination and the stigmas surrounding disabilities lead many families to refuse even to go to professionals and receive a diagnosis for their children.

The present study found that parents having autistic child have stress and emotional disturbance which leads to conflict and divorce. Most fathers choose to be far from the child than taking care of their autistic child who brings for the dissolution of marriage.

This is supported by a study done on families under stress has demonstrated a link between relationship breakdown and poor physical and mental health. (Fiona. (2001))

According to the study finding participants mentioned that they have fears, stresses related to their child case. The mothers are more affected by stresses and lack happiness thinking about their child case and also have concerns about their future. From previous study also there is similar finding; Mothers of autistic children have higher parenting-related stress and psychological distress as compared to controls. Outwardly, it might appear as if the psychological stressors exerted specific effects resulting in mental ill-health attributable these stressors. (Abdullahi & Samira (2013))

Chapter six

6. Conclusion and recommendations

6.1 Conclusion

This study aims that understanding the pscycological, social and economic experiances of parents/caregivers from having or parenting a child who has ASD.

The study finding shows that the community has lack of awareness about the autism case child developmental age and lately noticed about their children problems, so this indicated that being noticed lately the child problems denied early diagnosed and intervention.

Most of the children spend their day and night at home. Which claim the scarcity, distance and un-affordable transportations for went to autism centers. To conclude the respondents of the autistic children understand care to mean only feeding, washing, and other external activities. They rarely work on the development of skills towards the children. Mothers are more affected by stress and take big part for the burden of the problem. Parent's responds that they need support from government and other organization. Moreover parents have also concern about existence of autism training centers.

Parents are suffering with economical challenges in bidirectional having the child extra costs as well as impacts' on income generation within the families. Having a child with autism indicates lots of psychosocial problems for families' life which leads to stigma and discrimination. The present study found that parents having autistic child more stress and emotional disturbance which leads to conflict, divorce and family crises.

The participants have concern about existence of autism training centers. Absence of enough autism centers and lack of funding and resources are among the challenges in the study findings. This all is due to lack of awareness, lack of support and attention from government, community as well as other organization.

6.2 Recommendation

The following recommendations that are expected to limit the parent's frustration and facilitate improved attention and recognition of the problem and further action are provide from government and other stakeholders.

- I strongly recommend for government to give the problem due attention as one of a public health issues and include it in ministry of health top priority seeking public health problem.
- The media also need to give coverage to create awareness on ASD for the public as it is one of the untouched public problems.
- FMOH should work on HEWs and other health professionals who are working in health institution to identify the case with in the community and to facilitate early diagnosis.

- The Government and partner organizations should work on expansion of autism centers since it is the only preferable mechanism to support family burden and to facilitate the child support and care practice.
- The autism centers and other stakeholders should design counseling programs and other support mechanisms for families and care takers who serve children with ASDs to minimize family experience associated with psychosocial and economic challenges.
- The government should expand its policy and structures that are intended to promote and support women's empowerment and child welfare particularly those children with disabilities in all sectors
- Further broader study is recommended to know the country situation regarding ASD, prevalence, causes and associated factors

References

Aadil, . B. , Unjum B., Afifa L., Zahoor A. () Challenges Faced by families of Autistic Children. International *Journal of Interdisciplinary Research and Innovation.(*2)1*,* pp: 64-68 .Retrieved from **www.researchpublish.com**

Abdullahi Fido*, Samira Al Saad (2013) Psychological effects of parenting children with autism prospective study in Kuwait PDF retrieved from http://www.scirp.org/journal/ojpsych/

AlHorany, A.K., Hassan, S.A. and Bataineh, M.Z. (2013). A review on factors affected Marital Adjustment among parents of autistic children and gender effects. *Life Science Journal*, 10(1).Retrieved from http://www.lsj-marsland.com/uploadfiles pdf

American Psychiatric Association, 2003

Ashum G. and Nidhi S. (2005) Psychosocial support for families of Children with autism. *Asia Pacific Disability Rehabilitation Journal.* J.C. *No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd*

Autism in Ethiopia | Nia Foundation: Autism in Ethiopia [WWW Document], n.d. URL retrieved from http://niafoundation.wordpress.com/autism/

Autism in Ethiopia. Nia Foundation: Autism in Ethiopia Retrieved from http://www.ethioautism.org/Joy/ Autism_in_Ethiopia.html

Autism Fact Sheet. Retrieved from http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

Autism Specific Early Learning and Care Centers. Retrieved from https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services

Denise M. (2012). Most Children with Autism Diagnosed at 5 or Older Retrieved from http://www.webmd.com/brain/autism/news/20120523/most-children-with-autism-diagnosed-at-5-or-older

Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y.S., Kauchali, S., Marcín, C., et al, (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders: Global epidemiology of autism. Autism Research .5, 160–179.

Elizabeth, A. (2014). The quality of health care delivered to adults in the United States. Retrieved from http://www.enatal.com/pdfs/NEJM-RANDStudy.pdf

Fiona, L. (2001). The Impact of Autism. A report compiled for the All Party Parliamentary Group on Autism. pdf on June 2001

Freedman, S. (2011). Top 10 strategies for success: emotional parenting of the child with Autism/Asperger's or PDD | Autism Support Network [WWW Document]. Autism Support Netw. Retrieved from URL http://www.autismsupportnetwork.com/news/top-10-strategies-successemotional

Global Burden of Neurological and Mental Disorders, retrieved from http://www.brainfacts.org/policymakers/global-burden-of-neurological-and-mental-disorders/

How Is Autism Diagnosed https://www.autismspeaks.org/what-autism/diagnosis

Jaime, B. (n.d). The Challenge of Being a Parent of a Child with Autism. Retrieved from http://everydaylife.globalpost.com/challenges-being-parent-child-autism-3878.html

Lester, S. (1999). An introduction to phenomenological research. Retrieved from the www.sld.demon.co.uk/resmethy

Marquis, D., TekolaGebru, B., Baheretibeb,Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C., & Hoekstra, A. (2014). Services for Childeren with Autism AND Their Families in Ethiopia: Service Providers perspectives. Retrieved from https://imfar.confex.com/imfar/2014/webprogram/Paper17321.html

Mike, D. **(**2013). Autism in Ethiopia: a good start**,** 01 June 2013) Retrieved from http://www.thereporterethiopia.com

NEJM-RAND Study.pdf, (n.d.)

NNaquviprevalenceoutsideUS.pdf, (n.d.)

Nyoni, J., Serpell, R., n.d. The impact on parents of raising a young child with autism: APhenomenological study of parents in Lusaka, Zambia. Int. J. Disablity Community Rehabil.

Ozonoff, S., L.Goodlin-Jones, B., Solomon, M., 2005. Evidence-Based Assessment of Autism Spectrum Disorders in Children and Adolescents. *Journal of Clinical Child and Adolescent Psychology*, 34 (3): 523–540

Pottie, C. G., Cohen, J., Ingram, K. M., (2008). Parenting a Child with Autism: Contextual Factors Associated with Enhanced Daily Parental Mood. *Journal of Pediatric Psychology*. *34*, 419–429.

Prevalence on Autism and Other Pervasive Developmental Disorders: Global epidemiology of autism. *Autism Research*, 5 (3): 160–79.

Regional strategy for Mental Health, 2000-2010, pp 4

Report of the Round table on mental health, global action plan (mhGAP), for African countries. (2009). Abuja: Unpublished Report.

Sonya M, Jessica V. (2012). the dynamics of autism: meeting the social & economic challenge. pdf on November

Understanding Autism Specterm Disorders the Basics .Retrieved from, http://www.webmd.com/brain/autism/understanding-autism-basics

WHO (2013). Comprehensive and coordinated efforts for the Management of autism spectrum disorders, executive board eb: 133/4

WHO (2005). Child and adolescent mental health resource: Global concern implications for the future.

Annex

Interview questions:

The following 14 interview guide questions which are expected to get data needed to answer the research questions will be considered to be central to disclose /describe the experiences of the parents/care taker. Those semi-structured interview, questions are

Demography and socioeconomic of the households: Household size, number of kids, sex and age, Livelihood type, Age and physical condition of the kid

1. What is the problem of your child?

2. When did you notice that your child has the problem?

3. How / when did you know the problem of your child is ASD/ autism?

4. What do you think is the cause for autism?

5. What kind of care do you think your child needs?

6. What kind of care do you give your child currently?

7. Who in the family is responsible for providing care for the child?

8. Do you receive any help related to your child? What kind and from whom?

9. Do you think that caring of your child made burden on your financial consumption. How?

10. What would make caring for your child easier for you and your family?

11. How does having a child with autism influence in any way the functioning of your family?

12. What is the attitude of your neighbour and other siblings towards your child problem?

13. Have you ever thought that Children with ASD can be taught to the right behaviours? HOW?

14. Do you have additional thing to tell me regarding the child?