A study on the contribution of autism centers to mothers of children with autism; the case of joy autism center

BY:

Helina Meshesha Amare

Advisor: Mesele Mengsteab (PHD)

JUNE 2020

ADDIS ABABA, ETHIOPIA

ADDIS ABABA UNIVERSITY
COLLEGE OF SOCIAL SCIENCES
SCHOOL OF SOCIAL WORK
SCHOOL OF GRADUATE STUDIES

A study on the contribution of autism centers to mothers of children with autism; The case of joy autism center

BY:
Helina Meshesha Amare
Advisor: Mesele Mengsteab (PHD)

A thesis submitted to school of graduate studies of Addis Ababa University for partial fulfillment of master's degree in social work

JUNE 2020
ADDIS ABABA, ETHIOPIA

DECLARATION

I declare that this study entitled *A STUDY ON THE CONTRIBUTION OF AUTISM CENTERS TO MOTHERS OF CHILDREN WITH AUTISM; THE CASE OF JOY AUTISM CENTER* is my own work. All the sources that I have used or quoted have been indicated. I have acknowledged by means of reference and that this work has not been submitted before any others degree at any other institution.

Name of the Student: Helina Meshesha Amare

Signature: ___________________________

Date: _______________________________

Name of the Advisor: Mesele Mengsteab (Phd)

Signature: ___________________________

Date: _______________________________

CERTIFICATION

This is to certify that the thesis prepared by Helina Meshesha Amare, entitled *A STUDY ON THE CONTRIBUTION OF AUTISM CENTERS TO MOTHERS OF CHILDREN WITH AUTISM; THE CASE OF JOY AUTISM CENTER* submitted in partial fulfillment of the requirements for the Degree of Master of Arts in Social Work complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

APPROVED BY THE EXAMINING BOARD

Advisor ____________________________ Signature _____________ Date ____________

Internal examiner___________________ Signature _____________ Date _____________

External examiner ___________________Signature _____________ Date ____________

Department Chair ____________________ Signature _____________ Date ___________

ACKNOWLEDGEMENT

Firstly, I would like to thank my advisor Mesele Mengsteab (PHD) for his unreserved critical and professional comments throughout this study. Without his insightful comments and kind advice this study would never been completed.

All the staff members of joy autism center, its founder W/ro Zemi Yenus and mothers of children with autism who participate in the data collection process of this study deserve to be acknowledged, since this work is the result of their tireless assistance, humble support and frank cooperation.

I would also like to thank my husband for all his encouragements and support through the course of conducting this study.

Of course “oh the almighty you are all my strength.”

DEDICATION

I want to dedicate this work for all mothers of children with autism around the world!

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ACRONYMS

ASD	Autism Spectrum Disorders
NGO	Nongovernmental Organizations
PDDs	Pervasive Developmental Disorder
PDDNOS	Pervasive Development Disorder Not Otherwise Specified
CDD	Childhood Disintegrative Disorder

ABSTRACT

The most difficult burden in relation to the diagnosis and treatment of autism rests on parents in general and mothers in particular. Due to the nature of the disorder taking care of an autistic child alone is an insurmountable task for mothers. The objective of this study is assessing the contribution of autism centers for mothers of autistic children by particularly addressing the difficulties mothers face and the services rendered in autism centers. The framework of the study is that there is a direct relationship between the contributions or the services of autism centers to mothers of autistic children and the resultant improvements in the life of the autistic child, mothers and the whole family. Qualitative research method is used in the whole process of conducting this research. Focus group discussion and an in depth interview are utilized as instruments of data collection from the participants of the study. The study was conducted in joy autism center. According to the data gathered from the center there are 80 autistic children receiving education, training and treatment from the center. The populations of the study are mothers of these autistic children at joy autism center. Among them 12 are purposively selected to participate in the in depth interview and focus group discussion according to the duration of admission and their background. The findings of the study revealed that mothers of children with autism face different social, economic, psychological and other problems. Particularly lack of awareness, shortage of time, financial scarcity, stigma and stress are some of the problems mothers encounter. The study also found out that autism centers are ideal in solving these problems faced by mothers by providing different services for their autistic children and the mothers themselves. In order to albeit all the problems associated with autism the government, the media, health institutions and civil society organizations shall give due concern for autism and its overall impact. Future researches shall be conducted on the impact of autism at individual, family and societal level. Particularly the impact of autism of family and the society in Ethiopia is unaddressed area.

Key Words; Mothers, Autism, Mothers’ of Children with Autism, Contribution, Autism Centers

CHAPTER ONE

1. Introduction

1.1. Background of the Study

Autism is a developmental disorder characterized by difficulties with social interaction and communication, and by restricted and repetitive behavior (S. K. Thomas, 2016). According to Findling, (2015) and Ornoy et al., (2015) parents often notice signs during the first three years of their child's life. These signs often develop gradually, though some children with autism experience worsening in their communication and social skills after reaching developmental milestones at a normal pace (Vohr et al., 2017). It is also called autism spectrum disorder (ASD) (Reichow et al., 2018). The developmental problems associated with autism sustains through the whole life span of the affected persons (Bird & Cook, 2013) and if you are autistic you are autistic for life (Gerdts, 2010).

Autism spectrum disorder (ASD) is not only a complex but also a pervasive neurodevelopmental condition with lifelong impacts (Lyall et al., 2017). Genetic and environmental factors contribute to ASD etiology, which remains incompletely understood (Zerbo et al., 2015). Autism is prevalent in almost whole countries and continents (Franz et al., 2017). Even though it is not in flat rate (Thurm et al., 2019), autism exists all over the globe (WHO, 2019). According to WHO (2019), one out of 160 children has an autism spectrum disorder in the world. While there is no official count of the number of people who have been diagnosed with autism (Maenner et al., 2020), CDC's most recent estimate is that 1 out of every 59 children, or 16.8 per 1,000, have some form of ASD as of 2014 (Xu et al., 2018).

Persons with autism face inability to conduct effective communication and social interaction and show repetitive behavior (Frye, 2018). Due to its nature the diagnosis and treatment of autism requires the involvement of multiple professionals (Srinath et al., 2019) such as caregivers, pediatricians, psychologists, psychiatrists, social workers and the like. As a result autistic children need an institutional support from where they can get all these professionals and their services (Camm-Crosbie et al., 2019). According to Stroth et al. (2019) autism affects not only the child but also his family. It is heterogeneous in many ways, including developmental trajectory. For example, while most children with an ASD diagnosis continue to experience substantial social difficulties, the family gets primarily hurt along their way adulthood.

Any health problem on family member in normal course of things always affects the life of the whole family (Golics et al., 2013). The situation will be worst and difficult if the disease is related to some mental health problem like autism (Fuld, 2018). Like the nature of the disorder, the impact of autism on the mother is pervasive and multifaceted (Karst & Van Hecke, 2012). The mothers of autistic children face a multitude of challenges because of the behavioral problems associated with the disorder (Weiss et al., 2014). Having a child with autism in the family may have adverse effects on the mother's life including marital relationships, sibling relationships and adjustment (Begum & Mamin, 2019). According to a study by (Zhou et al., 2019) mothers of autistic children generally exhibited high levels of anxiety and depressive symptoms. The core symptoms of the autistic children were observed to be strongly associated with both maternal anxiety and depressive symptoms (Zhou et al., 2019). Improvements in the core symptoms of children with ASD may help reduce maternal anxiety and depressive symptoms to some extent (Theses & Villar, 2018).

Different studies showed that autism centers are very helpful for the prevention of the anxiety and depression felt by the mothers of the autistic children. A study by Bölte et al. (2019), showed that mothers whose autistic children were admitted to the autistic centers were found to be less stressed than they were before their children were admitted to those centers. Mothers of autistic children often report decreased levels of stress, depression, and anxiety after their children with ASD got admitted to the autism centers (Catalano et al., 2018). Supporting this idea (Grant et al. 2015) found that mothers after admitting their child got less stressed and got a very convenient environment to work and got advanced in their economic and psychological life.

Autism centers are ideal places in solving the problems of autism for the autistic individual and their families especially for the mothers since most of the burden lies on the mothers (Birhanu, 2016). According to her study (Birhanu, 2016) found out that there are only few autism centers in Ethiopia which are located in the capital city. This study also labeled autism as unstudied disorder in Ethiopia and recommended its every aspect to be researched in local context. The other study by (Abera, 2013) showed that lack of awareness is the main reason for the absence of adequate number of autism centers in the country. She stressed that non-governmental and societal organizations always consider their contribution before participating in any sector. This study also showed that the absence of studies which clearly reveals the possible contributions of any organization in the sector is the main reason for lack of sufficient service provision (Abera, 2013).

Demissie (2015) and Berhane (2016) in their respective study recognized the increased burden of mothers of autistic children in the diagnosis and treatment of autism and the lack of adequate family, social and institutional support. Both concluded that studies shall be made to show the impact of autism on the individual and the mothers and the possible contribution to be made in order to draw the attention of the government and other responsible organs.

1.2. Statement of the Problem

Practically speaking though there are different non-governmental and civil society organizations, almost most are not interested in autism. According to the researcher this is due to lack of studies which clearly shows the demand of the sector and the contribution to be made. Hence studying the possible contribution of autism centers to mothers of autistic children will fill this gap partly.

It is natural that all families want to lead a happy and peaceful life free from any social, economic and health problems (Abatemarco, 2020). Any kind of problem happened to one family member usually affects the life of the whole family especially the life of the mother (Thomas et al., 2017). The condition of the mother would be more difficult if the problem is associated with health (Ji et al., 2007).

Among all health problems autism is unique and challenging in many ways both for the autistic children and their mothers (Begum & Mamin, 2019). The mother suffers a lot from the autistic condition of their children than any member of the family (Mann, 2013). Researchers found that mothers of children with autism had higher levels of parenting-related stress (Oprea & Stan, 2012), and their wellbeing is on the frontline (Ilias et al., 2017).

If autism has such magnitude problems on the mothers of autistic children, then it is important that a socially involved institution like Joy Autism Center takes a good care of these autistic children. Some studies studied the importance of professional help that the mothers of autistic children needed to cop up with the challenges they face (Oprea & Stan, 2012). Autism centers give different services to the mothers of the autistic children such as providing reliance on family to give courage (Oprea & Stan, 2012), school involvement (Khudhair & Jassim, 2018), support mothers to act so as to improve the condition of their child (Bölte et al., 2019).

The other contributions of the autistic centers to the mothers of autistic children is that interventions by the autistic centers to the autistic children can promote development and produce significant and lasting improvements (Paul, 2008). This gives the mothers pleasure and relief. According to Rogers & Vismara (2008), interventionist autistic centers positively modify the course of development of children with ASD, and hence impact the life of the mothers positively.

Begum & Mamin (2019) from Savar, Dhaka, Bangladesh studied the impact of autism on the family as a whole, in which it didn't see the effect of autism centers to the mothers of autistic children. A study conducted in Pakistan (Furrukh & Anjum, 2020) explored lived experiences of the mothers who have children with autism spectrum disorder (ASD) including but not limited to the mothers, in which it didn't study the contributions from the autistic centers.

Even though it is a pressing issue, researches and studies conducted in relation to autism are hardly available in Ethiopia. Due to the government's lack of attention and the society's lack of awareness to the disorder it is not easy to found data, statistics and information about autism. There is a study, which tried to address the challenges and the help need of autistic children's parents in Addis Ababa, Ethiopia taking Nehemiah autism center as a case study (Abera, 2013). But this study didn't see the contribution of the autism center to the mothers of the autistic children and this study is conducted before seven years. Another study by (Kebed, 2015) assessed the autistic children's families' practices with their children in Addis Ababa, not the contribution of autism centers. A study by Tadesse (2014) tried to assess the challenges and coping mechanisms of the families living with an autistic child.

All the above studies and others didn't study the contribution of autism centers to the mothers of the autistic children. Most of the studies so far are focused only to the autistic children and persons around them are neglected. Some of the studies tried to address the challenges faced by the families of the autistic children in which the mothers are included. The challenges faced before their children got admitted to the centers, the contributions by the centers and the lives of the mothers in relation to the status of their children was not studied yet and comes the importance of this study.

1.3. Basic Research Questions

As per the problems stated above and the gaps from previous theories, articles, journals, and researches, the following basic research questions were raised.

1) What were the difficulties the mothers of autistic children face before their children's admission to Joy Autism Center?
2) What did mothers expect from joy autism center just before their children got admitted?
3) What differences were made in the life of mothers after the admission of their children to Joy Autism Center?

1.4. Objectives of the Study

1.4.1. General Objective

The overall objective of this study is assessing the contribution of autism centers to mothers of autistic children in the case of Joy Autism Center.

1.4.2. Specific Objectives

This research has the following specific objectives as numbered and presented below.

1) To assess the difficulties mothers of children with autism face before their children's admission to Joy Autism Center.
2) To identify the expectations of mothers of children with autism from Joy Autism Center during their child's admission.
3) To assess the difference in the life of mothers after the admission of their children to Joy Autism Center.

1.5. Significance of the Study

Effective diagnosis and treatment of autism require the comprehensive participation of professionals and families. But due to different social, economic, legal, political and psychological problems the burden of undertaking household activities relies on women. Unlike the ordinary and obvious responsibilities, taking care of autistic children for life is not something to be overlooked. Mothers in such situation highly need someone to share their burdens. But husbands and other family members, the community and the government had seen giving little attention for the issue. Even only few NGO'S and civil society organizations, among multiple are engaged in autism and related issues. Autism is just neglected. The contribution of autism centers is not studied well in Ethiopia.

For the researcher the failure of these organs to give attention for the issue emanates from two reasons. For One thing these organs are ignorant about how much taking care of an autistic children increase the already crowded household burden of mothers. In addition these organs are not aware about how much contribution they will have for the autistic children, the mother, the family and the community in general if they engaged in the issue. Accordingly this study will contribute a lot in narrowing down the knowledge gap described by closely researching autism centers contributions to mothers of autistic children there by attracting the attention of different stake holders to the issue.

1.6. Scope of the Study

The study is limited in topic to the contribution of autism centers to mothers of autistic children taking one autistic center in Addis Ababa, Ethiopia. The center selected for the study was Joy autism Center which the researcher visited during her course study.

Hence mothers whose children had been diagnosed with autism spectrum disorder and admitted to joy autism center are the population of the study from whom samples for data collection are selected from. The employees of the center were also involved in the study.

The research was conducted in 2019/20 and the data was collected in April 2019. The responses of mothers of autistic children in Joy Autism Center were collected. The annual report of 2018 and the annual activity plan for 2019 were also consulted in the course of this study.

1.7. Operational Definition

Autism center - is an institution which gives a comprehensive treatment services for persons diagnosed with autism and for the case of this study it refers joy autism center.

Autism is a developmental disorder characterized by difficulties with social interaction and communication, and by restricted and repetitive behavior often noticed during the first three years of a child's life.

Autism Spectrum Disorder (ASD) – a range of complex developmental problems manifested by either atypical behaviors in social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior.

Autistic child- an individual who is diagnosed with autism officially and admitted to joy autism center.

Mother - is a woman whose child or someone in her custody is diagnosed with autism.

1.8. Organization of the Research

This project is organized in five chapters. Chapter 1 is going to present the general introduction about the whole report. Chapter 2 describes both theoretical and empirical literature review related to the issue under study; Chapter 3 provides research design and methodology employed for conducting the study. Chapter 4 is going to contain data presentation, analysis and interpretation. Finally, the last chapter concludes the total work of the project and gives relevant recommendations based on the findings. A list of related literatures that was referred while writing the paper and annex were included after chapter five.

CHAPTER TWO

2. Literature Review

2.1. Introduction

This section reviews existing literature in relation to the main concept and the assessment questions. First, a brief review of literature regarding the nature of autism is presented in order to provide an overall understanding of the condition. Afterwards, literatures in relation to the experiences of parents raising a child with autism are presented. There are numerous studies that have been conducted regarding autism including its diagnosis, symptoms, treatments and its effect on an individual, family and societal level. However, limited studies are available in the context of Ethiopian societies and they mainly focus on the prevalence of autism. Other dimensions of autism such as parents' perspectives on coping mechanisms have not been the emphasis of studies in an Ethiopian context. Particularly the contribution of autism centers for mothers of autistic children is not addressed well.

2.2. What is Autism

Autism is the most common pervasive, neurological based developmental disability which causes different range of disorder in the way individuals learn, communicate and act which usually begins before the age of three (Johnson & Myers, 2007). According to APA (2013) it is characterized by qualitative impairments which results in difficulties in verbal and non-verbal communication, social and emotional functioning which in turn hampers autistic person's ability to understand the world around them.

According to Bolton et al. (2011) autism is one of the developmental disorders called pervasive developmental disorders (PDD). Pervasive developmental disorder is a general term which includes the following five disorders: Rett's disorder; Childhood Disintegrative Disorder (CDD); Asperger's Disorder; Pervasive Developmental Disorder Not Otherwise Specified (PDO-NOS) and finally Autism (Steven & Rubenstein, 2006). Despite the fact that each disorder possess its own unique features in relation to cause, diagnosis, progress, treatment and the like there is still some kind of overlap.

Due to the absence of a clear and definite scientific neurological and biological marker, autism spectrum disorders are necessarily identified and characterized by their respective behavior (Reichow et al., 2018), which results in a greater degree of uncertainty and frustration. However the last twenty years have been marked by major advances in the ability to meaningfully define and quantify the behavioral patterns that differentiate autism and other ASDs from other disorders and from typical development problems (Steven & Rubenstein, 2006).

Autism is a heterogeneous disorder (Masi et al., 2017). No two autistic persons have same level of problems in all ranges of activities. Some autistic people possess an average intelligence, but significantly impaired in social skills. Again some autistic individuals are capable to taking care of themselves, function well, live independently, maintain relationships and work at high level jobs (Schriber et al., 2014). While others face difficulty even in basic need activities like eating, drinking, dressing, waking and the like. This vast difference of ability between autistic people is due to different reasons like the severity of the disorder, the age of the autistic individual, the accessibility of due care and intervention or the nature of the disorder itself. Thus, effective treatment and intervention mechanisms and procedures need to be made in accordance with these personal circumstances (Veague, 2010).

Autism which begins during childhood persists to exist through the whole lifespan of the person as an incurable disorder. Due to the similarities that exists between autism symptoms and childhood activities, it is usually difficult to identify autism early in childhood (Martínez-Pedraza & Carter, 2009). Parents may not be able to identify their child as autistic before the age of three, because the symptoms of autism are more apparent after the age of three.

Autism spectrum disorder is basically different from the common health problems labeled as diseases like tuberculosis, epilepsy or blood pressure(Mughal et al., 2020). A disease is an illness or a condition which resulted from the impairment or dysfunction of one of the body organs, where as an ASD is a condition in which there is abnormality in the mental and physical development of a person often retardation(Exkorn, 2008).

Generally speaking autism spectrum disorder is a neurobiological developmental disorder which affects the regular development process and functioning of the brain. Even if autism exists and grows up even in adulthood, it starts during the early period of childhood. Even though it differs from person to person, the effects of autism ranges from causing simple communication problems to complex abnormalities. Impairment in social interaction is the basic characterizing feature of autism (Gerdts, 2010).

Unlike other kinds of health problems the treatment of autism is more social, behavioral and psychological and less medical in line with its cause, diagnosis and effect. It is not possible to treat and cure autism by administering some kind of tablets. There is no specific treatment and medication for it. The basic treatments for it still remain an educational and behavioral approach which probably continues for the whole life span of the individual depending on his/her progress (Abera, 2013).

2.3. Diagnosis of autism

Unlike other health problems and diseases diagnosis of autism is a very difficult task for professionals since there is no a simple blood or laboratory test to determine who is autistic. As already noted above, the exact causes of autism are still unknown. This in turn pushes the diagnosis to rely on physical observation and history. The already identified effects of autism (social interaction, communication and repetitive behavior) are also ideal in the diagnosis of autism. The diagnosis of autism by its very nature requires a multi-disciplinary team of psychologists, neurologists, psychiatrists, speech therapists, social workers and other related professional (Abera, 2013).

Like its others aspects, the diagnosis of autism has witnessed improvements from time to time. In the last 20 years standard measured for assignment of diagnostic status was adopted internationally (During, 2005). Now a days the diagnosis and statistical manual, fourth edition, text revision (DSM Iv-TR) is the official manual used by physicians and mental health professionals for diagnosing children on the autism spectrum. According to this manual, a child with autism display a qualitative impairments in their reciprocal social interaction and communication and a restricted, repetitive and stereotyped patterns of behavior, interest and activities to some degree before the age three. However there also exists other features that some professionals use as the above ones (Abera, 2013).

2.4. Autism in Ethiopia

According to (Hoekstra et al. 2018) the knowledge and understanding of autism in developing countries was sourced from studies and researches conducted by developed countries particularly in America and Europe. It leads that the disorders' status and prevalence is understudied in least developed countries including Ethiopia. This in turn means the peculiar features and characters of the disorder in each local context are not known.

Unlike other disorders autism demands an extensive treatment which usually requires the involvement of different professionals, family members and the society as a whole if possible in an institutional setup (Thurm et al., 2019). But in most developing countries finding the service of these stake holders is a nightmare including Ethiopia, which in turn affects the life of not only the autistic person but also his family too. Lack of appropriate services and adequate special education provision are among the challenges mothers of children with autism in Ethiopia face (Berhane, 2016; Guler et al., 2018; Kebed, 2015). Due to insufficient number of institutions and service providers, finding places which suites the interests of autistic children in Ethiopia is hardly possible (Berhane, 2016).

There is a severe service provision problem in relation to autism in low income countries including Ethiopia (Dejene Tilahun & Hoekstra, 2019; Tekola et al., 2016). This similar study described that the services being provided are not capable to address the personal circumstances of each autistic individual and his/her family. In order to fully appreciate autism conducting continuous and detail studies in all parts of the world is mandatory (Faras et al., 2010). But according to Elsabbagh (2014) almost all of the studies in relation to autism are conducted in the developed western world and there exists a serious shortage of studies in low income countries including Africa. Tekola et al. (2016) found out the absence of practical studies on autism in Ethiopia and the existence of lack of awareness and knowledge on the issue among the public and other stake holders.

The role of professionals like pediatricians, psychologists, psychiatrists, social workers and volunteers is indispensable to help children with autism in the diagnosis and treatment process (Jacobs et al., 2019). It is the synergy of the service of these professional which results in betterment of autistic children (Subramanyam et al., 2019). Hence the service shall be provided in an institutional set up. However, in Ethiopia there is inadequacy of mental healthcare facilities and a severe shortage of trained personnel (Tekola et al., 2016).

Even though there is no accurate statistics about autism prevalence in Ethiopia (Kebed, 2015), around one million individuals are estimated to be living with it (Berhane, 2016). Making special autism centers accessible to all these individuals is challenging due to different reasons. Though mainstream schooling appears to be an ideal substitute to autism centers, schools in Ethiopia are not equipped with the necessary facilities and didn't recognize children with autism (Tekola et al., 2016). This lack of adequate service provision for children with autism results in stress and depression among mothers of children with autism (Abera, 2013).

According to Berhane (2016) one of the main obstacles that hinder the establishment of efficient support programs for parents of children with autistic disorder in Ethiopia is the lack of studies that can inform about the impacts of raising children with autism on parents and lack of adequate number of centers and trained staff. This prevents the mothers of the autistic children and the autistic children not to benefit from the fruits of those autistic centers. Besides to lack of studies there is another factor that challenges mothers, lack of adequate information and knowledge about autism which leads them to face extreme difficulties in dealing with the challenging behaviors (Weiss et al., 2014). This problem could not be different in Ethiopia. Most mothers of autistic children in Ethiopia doesn't have the necessary knowledge and information about the nature of autism and its symptoms (Berhane, 2016; Tekola et al., 2016).

Generally most studies reviewed (Cloete & Obaigwa, 2019; Furrukh & Anjum, 2020; Hubert & Aujoulat, 2018; Piercy et al., 2017) provided rich and descriptive information on firsthand accounts of the lived experiences of actual families particularly mothers affected by autism which allows us to better understand, using lived experiences, what it is like to be a parent of an autistic child, and what that experience means. Since autism is an issue that still needs much exploration in our country (Abera, 2013; Berhane, 2016; Kebed, 2015; Tekola et al., 2016) the various reviewed studies across the globe (Andersson et al., 2017; Chung et al., 2012; Gona et al., 2015; Jacobs et al., 2019; Picardi et al., 2018; Sumiya et al., 2018; Taderera & Hall, 2017) will add more information regarding autism to the body of the current study and will give the audience a better ability to gain knowledge of the feelings, motivations, challenging experiences and coping mechanisms of raising a child with autism across cultures.

Additionally, the researcher hopes that by synthesizing the literatures conducted looking at the experiences of mothers of children on the spectrum, a more holistic view of the kinds of interview questions to the current study and identifying gaps in the current literatures has been provided.

2.5. The Impacts of Autism

2.5.1. The Impact of Autism on Family Members in General

2.5.1.1. The Social Impact

In most societies of the underdeveloped world autism is still linked to some kinds of wrong beliefs and attitudes. Pursuant to this autism is believed to be an evil spirit phenomenon and a result of super natural anger on the autistic individual and his family. Even it is considered as a penalty for the sins and misdeeds of ancestors. As a result of this it is a source of stigma and discrimination on the autistic individual and his family (Gona et al., 2015). Following this Autism diagnosis and treatment may result in the stigmatization of the autistic person, family members, school mates, friends, medical providers and caregivers by the community

(Papadopoulos et al., 2019). Studies have also revealed that families of children with autism experience practical and psychosocial challenges, including severe stigma (Tekola et al., 2016). According to (Evans, 2013) families with autistic children have been perceived by their societies in different ways causing the families to be shaped by the beliefs systems of autism specific to their society (Evans, 2013). Because of social stigma, 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 (Aadil Bashir, 2014). A study by Rössler (2016) found that parents having child with autism feel being isolated from social life due to a perceived lack of understanding about what autism is and what was involved in caring by the community.

The activities and behavioral patterns of an autistic person are different from the normal move of a child and it could be strange for family members. Family members of an autistic person may face multiple difficulties in managing and dealing with these behavioral problems related to the disorder (Weiss et al., 2014). Dealing with the case of autism usually impacts the other segments of life since it demands a considerable part of attention, money, time and energy. As a result this process adversely affects various domains of family life including marital relationships (Hartley et al., 2018), sibling relationships and adjustment (Picardi et al., 2018), family socialization practices (Hartley et al., 2018) as well as normal family routines (Aadil Bashir, 2014).

As per (Bambaeeroo & Shokrpour 2017) most social interactions are dependent upon either verbal speeches or nonverbal gesture. However one of the major symptom and impact of autism is lack of adequate reciprocal social interaction and verbal and nonverbal communication (Steven & Rubenstein, 2006). In parallel to Bambaeeroo & Shokrpour (2017) and Steven & Rubenstein (2006), LaGasse (2017) found that it is hardly possible for an autistic individual to manage social relationship even though, according to Sauter (2017), social interaction, joy, and verbal and nonverbal communications are presumed to be the best rewards of family hood. Aadil Bashir (2014), also confirmed that autism negatively impacts those social interaction, joy, and verbal and nonverbal communications, which are the best rewards of family.

Autism only does not have family impact, but also it has impact on a person with autism him/herself (Sauter, 2017). S/he may not have friends, may face difficulties while playing with others (Sumiya et al., 2018), may not secure a job (Lorenz et al., 2016), and may be unable to express his emotions (Rump et al., 2009). So that mothers of children with autism need to provide a great deal of social support for her child in order to enable him/her make friends, interact successfully in social situations and eventually become adults who can hold jobs, relationships and other activities of life (Robledo & Donnellan, 2016).

2.5.1.2. Psychological Impact

There is no medical test for ASDs and a diagnosis is made after a thorough evaluation of the conditions of the concerned individual (Huerta & Lord, 2012). The evaluation might include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments, and possibly the use of one or more autism diagnostic tests (Randall et al., 2018). The unusual mechanism of diagnosis of autism usually results in fear and psychological stress among family members (ESHG, 2019).

The mere existence of some symptoms in their child's childhood would obviously leave the family in fear and frustration that, the individual might be diagnosed autism (Pierce et al., 2009). This might possibly create tension and stress among family members long before the individual formally diagnosed autism (Bravo-Benítez et al., 2019). Due to lack of adequate support and treatment family members of autistic persons Families with an autistic child frequently undergo through anxiety and depression (Nadeau et al., 2011). Other important phenomenon which arises from parental stress in families of children with autism, include, feelings of loss of personal control, absence of spousal support, informal and professional support (Bluth et al., 2013). Studies also showed that brothers and sisters of children with autism are at risk of bearing the psychological and emotional burden of growing up alongside a child with behavioral difficulties (Orsmond et al., 2009). Many siblings have felt that their parents perceived their needs as being secondary, with more time and attention given to the child with autism (Ooi et al., 2016).

As a childhood disorder autism usually, diagnosed on children under the age of three. However, for many families locating a diagnosis before the age of three is very difficult. Some families even have not been able to obtain a diagnosis until their child was much older. Such families may feel isolated, confused, unsupported and very anxious due to inability to secure early diagnosis (Lawson, 2004).

In addition to this, the type and effectiveness of the treatment mechanism, the attitude of others towards the autistic individual and them, the cost of treatment and other related issues will also be sources of stress and disappointment for individuals around him.

2.5.1.3. Economic impact

The burden of family members increases after their child diagnosed with autism since it is a beginning of a journey which demands the families human and financial resources for the remaining lifetime of the child (Hodgetts et al., 2015). Intervention strategies are expensive and require long hours of one on-one interaction with a trained therapist or use of costly foods or drug supplements (Ventola, 2010). Costs associated with having a child with autism is not only limited to the cost of interventions (Horlin et al., 2014). 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. Additional cost is also associated with extracurricular activities for children with disabilities (Memari et al., 2015). In general According to a study in 2005 the expense for a child with autism is three times more than that of a child without autism (Payakachat et al., 2012).

When an individual shows some kinds of abnormal activities, his families or friends would obviously bring him to hospital. The process of examination and treatment will in turn cost them some amount of money. Likewise an autistic individual and his family members would incur an abundant amount of money for the diagnoses and treatment of the individual (Weiss et al., 2014). This cost includes examination cost, medication costs, drug costs and payments for the professionals. The lifelong existence of the disorder and the treatment as well adds an insult to injury. According to Elder et al. (2017) autism highly affects the social interaction and communication of the individual towards others and leaves him in a lonely environment.

As a result of this it is difficult for such persons to get involved in different jobs and earn a living.

2.5.1.4. Other impacts

Autism is considered to be a severe disability because of the intense lifelong impacts it has on the individual and his or her family (Faras et al., 2010). Parents raising a child with autism face extreme difficulties in dealing with challenging behaviors (Khudhair & Jassim, 2018; Miranda et al., 2019), teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life. There are high-risk factors that might induce acute or chronic stress and trauma to the parents of autistic children and, in turn, lead to dysfunctional parenting (Emberti Gialloreti et al., 2019; Padden & James, 2017). As mentioned above there is serious shortage of service providers and professionals working in relation to autism (Tekola et al., 2016). As result securing formal diagnosis and treatment is challenging for families of children with autism. The failure to incorporate children to mainstream schooling is also struggling for family members (Chandrasekhar & Sikich, 2015).

2.5.2. The Impact of Autism on Mothers

As already mentioned, effective diagnosis and treatment of autism require the comprehensive participation of professionals and family members (Thabtah & Peebles, 2019). Due to different social, economic, legal, political and psychological problems the burden of undertaking household activities relies on women (Jenkins et al., 2011; Kaur & Garg, 2008). In such patriarchal family women hold difficult responsibilities inside and outside of home especially when they have children with autism (Weiss et al., 2014). Unlike the ordinary and obvious responsibilities, taking care of autistic children for life is not something to be overlooked. As studies on the family strain revealed, raising an autistic child is the most challenging and demanding task that has a serious impact on family life (Hoefman et al., 2014). Mothers in such situation highly need someone to share their burdens. But husbands and other family members, the community in general and even the government seem giving no attention at all for the issue. Even only few NGO'S and civil societies, among multiple organization are engaged in autism and related issues in Ethiopia (Tadesse, 2014).

Mothers sacrifice their education, jobs, social status, opportunities, money, and other advantages in favor of their family. This fact worsens when there is health problem in the family (Cidav et al., 2012). If the problem is a life time like autism it is not even possible to explain how women will suffer in handling the situation. In general mothers of autistic children lead the most difficult life like no one did (Oprea & Stan, 2012; Weiss et al., 2014). Mothers always experience the most difficult situations in relation to their autistic children (Navot et al., 2017; Zhou et al., 2019).

Different reasons can be mentioned for the difficulties mothers of autistic children face. Stigma and discrimination, lack of support from other members of the family and the society (Khanlou et al., 2017), financial constraints (Taderera & Hall, 2017), and lack of awareness are among them (Kinnear et al., 2015). In her work Helen Berhane mentioned lack of awareness as the basic reasons for the challenges mothers encounter in the handling of autism cases (Berhane, 2016). In short family members in general and mothers in particular experience the heavy burden related with autism.

In additions to the obvious difficulties they share with other family members, mothers particularly experience great problems in relation to autism. In many developing and African countries still autism is presumed to be the result of poor parenting by mothers (Ilias et al., 2019). This is always a source of anxiety and stress in mothers of autistic children. Studies have showed that the level of distress is higher in mothers than other family members including fathers (Aadil Bashir, 2014). Mothers of children with ASD appear to suffer from increased levels of parenting stress compared with fathers (Allen et al., 2013). Mothers of autistic children have higher parenting-related stress and psychological distress as compared to others (Kebed, 2015). Berhane (2016) also asserted that mothers make the most intense adjustment to a child's developmental disability and they are at a higher risk of long term stress than fathers.

Autism, a lifelong disorder, demands a considerable time of family members in general and mothers in particular. Mothers are also expected to undertake the lion share responsibility in her marriage (Hartley et al., 2010). Peace in marriage and autism are not usually go together. Hence mothers of autistic children experience more marital stress in their marriage which is more likely to end up in divorce (Taderera & Hall, 2017).

Zuckerman et al. (2014) stated that handling a child with autism requires a joint effort of all members of the family. An isolated act cannot result in the expected outcome than exhausting the person. In a study on the issue, Tekola et al. (2016) concluded that mothers of children with autism are the main cares with little or no support at all. Lack of support from anybody let some mothers to chain their child when they go out as per this similar study (Piercy et al., 2017). Many mothers of autistic children also report a feeling of lack of support (Kebed, 2015). This again hinders mothers from participating in economic activities. Many mothers who worked before were often forced to miss work. They performed below average and some eventually worked part-time or ultimately left the workplace altogether (Chung et al., 2012).

Commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves due to the burdened of full responsibility of care and likely having very little income (Kebed, 2015). Mothers of children with disabilities had insufficient time for other household chores and other social interactions as a result of being engaged in caring for their children fulltime (Berhane, 2016).

As discussed above the nature of autism by itself demands the involvement of different individuals for the sake of both the autistic children and his family. The challenges of raising an autistic child forces parents to demand professional's advice and information and social support (Burrell et al., 2017). If we love mothers, if we want to share their burdens, professional support is mandatory. Studies showing ways of support and intervention for mothers of autistic children are very important. But most of the studies about autism focus on causes of autism, characteristics of autism, and dimensions of autism. The challenge of this disorder on parents is investigated only by few researchers with limited scope (Abera, 2013). Whether autism centers are ideal in relieving the burden of mothers of autistic children or not is something necessary to be studied and never investigated before. This study is significant since it will contribute a lot by identifying the contribution of autism centers to mothers of autistic children (Thurm et al., 2019).

2.6. The Support Needs of Families of Autistic Children

Some of the challenges of autism are beyond the reach of the hands of the autistic individual and his family. Families with autistic children need social support for coping with stress and attunement due to having a child with developmental disability (Aadil Bashir, 2014). Parents of children with autism need support to assist them emotionally and physically by being provided resources (Berhane, 2016). In addition to this, in a study conducted by Tekola et al. (2016) culturally and contextually appropriate autism instruments are very important for the autistic individual and his family. This enables family members of autistic children to approach the disorder in their cultural way and the disabilities particular feature.

Due to our level of development and other factors it might be impossible to establish multiple special autism centers in Ethiopia (Tekola et al., 2016). The best possible alternative and solution for this is admitting children with autism to mainstream school by furnishing at least the basic infrastructure and supplements. After directly interviewing mothers of children with autism Tekola et al. (2016) identified that mainstream schools with autism facilities are more in the burning needs of autistic children and their families than special autism centers.

Family members of children with autism always want to undertake their day to day activities despite the demand of attention from the child (Kebed, 2015). As a result they require service providers to take care of their children and support them so that they can perform other tasks and engage in other socio economic activities.

2.7. Contributions of the Centers in the Treatments of Autism

Even though conflicting and overlapping, there are so many effective treatments for autism by both the interventionist centers or the families (Weitlauf et al., 2014). Applied behavioral analysis, floor time approach, medications, occupational therapy, pivotal response training, physical therapy, sensory integration therapy, social skills training, speech and language therapy and dietary intervention and alternative and complimentary treatment are among the most popular treatments for children With ASD (Exkorn, 2008) by the centers of Autism or institutions supporting people with autism.

Since autism is a heterogeneous disorder (Masi et al., 2017) no two children with autism are identical which in turn demands different treatment approaches depending on individual circumstances (Andersson et al., 2017). The main effects of autism are related to social interaction and communication. As a result of this treatment mechanisms are usually focused on social and communication skills. The treatment always begins with more foundational skill and move towards more complex skills (Gerdts, 2010).

The multi-dimensional nature and effect of autism demands the involvements of different categories of professionals and other individuals (usually parents) for an effective treatment (Payakachat et al., 2012). Like the case of diagnosis, parents, physicians, pediatricians, psychologists, social workers and the like have an indispensible role in the treatment of children with autism (Jacobs et al., 2018). The treatment also includes home setting treatment, school setting treatment and institutionalized treatment (Gerdts, 2010).

The other most important point related to treatment of autism by the autistic centers and other institutions helping the autistic children is early intervention (Elder et al., 2017). A child diagnosed with autism shall be given treatment as soon as possible (CDC, 2020). For that matter diagnosis should also be as early as possible. This is due to the fact that children’s brain is receptive and easy to shape at young age (Exkorn, 2008).

2.8. Contributions of Autism Centers to Mothers of Children with Autism

Children with autism require a continuous and professional support in order to coup up with the disorder. Different studies have revealed that it is not possible for family members alone to bear the challenges of the disorder (Khanlou et al., 2017). If children with autism need to bring improvements in the way they communicate and do things, they shall get an institutionalized training and support from different concerned professionals and care givers (Abera, 2013).

Autism centers and multi professional care givers are ideal in dealing with autism disorder unlike health institutions which focuses only on the medical aspect of the disorder (Cloete & Obaigwa, 2019). It is not possible to give the self-help trainings and other person specific guidance for these children at home or other place without adequate training and equipment (Weiss et al., 2014). A study by Evans (2013) mentioned that nowadays the world have understand the indispensable need of autism centers to children with autism.

According to Masi et al. (2017) the challenges of autism however are not limited to the autistic individual. Another report by McHale et al. (2012) parents, family members including siblings, friends and other members of the society also face different social, economic psychological and other challenges in relation to autism. Parents in general and mothers in particular hold the most unbearable suffering in relation to the disorder of their child (Hubert & Aujoulat, 2018). In relation to this different studies have been conducted in order to show the challenges parents face due to the disorder (Neece et al., 2012). According to Weiss et al. (2014) autism affects the life of not only the autistic individual but also his parents in different ways. Berhane (2016) also discussed that mothers are exposed to the most difficult problems of autism and it impacted their life negatively. According to Mahapatra et al. (2019) parents need direct and indirect external assistance in order to coup up with the challenges of autism. However, none of the above authors (Hubert & Aujoulat, 2018; Khanlou et al., 2017; Mahapatra et al., 2019; Masi et al., 2017; McHale et al., 2012; Neece et al., 2012) identified the necessary types of external interventions and the benefits that are going to be derived for parents.

Logically speaking any service or help provided to children with autism indirectly has a positive impact on the life of the whole family (Bluth et al., 2013). However, Tekola et al. (2016) found out in their study that the blessings of autism centers and other care providers for the family and the society must be studied separately in order to attract eyes not only for the autistic individual (Plaisted Grant & Davis, 2009), but also for persons around him or her (Ooi et al., 2016). The studies by Gillespie-Lynch et al. (2017) and others conducted previously limit the contributions and the need of autism centers to the autistic individual only.

CHAPTER THREE

3. Research Methodology

3.1. Introduction

In this chapter of the study the research methods, technics, data collection methods and procedures, sampling technics and sample sizes and ethical issues of the research were raised and presented.

3.2. Research Approach

Research approaches are plans and procedures for research that span the steps from broad assumptions to detailed methods of data collection, analysis, and interpretation (Creswell, 2014). It informs the philosophical assumptions the researcher brings to the study; procedures of inquiry; and specific research methods of data collection, analysis, and interpretation. In researches, quantitative, qualitative, or mixed methods approach can be applied to study a topic. Quantitative research design is used to examine the relationship between variables and test theory.

The main emphasis of quantitative research is on deductive reasoning, which tends to move from the general to the specific. It is proved to be suitable for the researches that will use structured questioners to collect data, depend on small sample size and results will be presented and analyzed using statistical methods. It places greater emphasis on the numerical data and statistical test to achieve conclusion that can be generalized (Saunders, 2012).

Qualitative research approach is applied for exploring and understanding the meaning individuals or groups ascribe to a social or human problem. Follower of this approach support honors an inductive style, a focus on individual meaning and the importance of rendering the complex (Creswell, 2014). The purpose of this study is to investigate the contribution of autism centers for mothers' of children with autism by making special reference to joy autism center. Qualitative research is one method of research which attempt to gain an understanding of the underlying reasons and motivations for actions and establish how people interpret the world around them (Austin & Sutton, 2014). The focus of qualitative research is to find explanations for questions of ‘what’, ‘how’ or ‘why’ of an occurrence (Goundar, 2012).

Qualitative research is in-depth research using a range of techniques, which aims to understand why people think, feel, react and behave in the way that they do. The aim of this approach of research is to generate concepts, strategies, for example, the contribution of the autism centers to the mothers of the autistic children. And hence, the researcher employed qualitative approach of research to conduct this study.

3.3. Research Design

According to (Kothari, 2004), research design is the conceptual structure within which Research is conducted. They specifically indicate the arrangement of condition for collecting and analysis of data in a manner that aims to combine relevance to the research purpose with economy in procedure. There are three types of research design based on the study purpose: exploratory, descriptive and explanatory (Babbie, 2007). Exploratory research studies aim at formulation of a problem from more precise investigation or of developing the working hypothesis from an operational point of view.

According to (Polit, 2001), exploratory studies are undertaken when a new area is being investigated or when little is known about an area of interest. Its major emphasis is on the discovery of ideas and insights (Kothari, 2004). Descriptive research design can be related to statistical research, which means that it describes data and different characteristics about a specific population and/ or phenomenon. The primary concern of descriptive research is finding out "what is”. It stems from prior knowledge and is concerned with describing a specific phenomenon (Saunders, 2012). It usually is the best methods for collecting information that will demonstrate relationships and describe the world, as it exists.

Descriptive research involves gathering data that describe events and then organizes, tabulates, depicts, and describes the data collection (Tadayon Nabavi, 2010). On the other hand, the main aim of explanatory research is to identify any causal links between the variables that pertain to the research problem. Explanatory studies look for explanations of the nature of certain relationships. It focuses on why questions. Descriptive research design is used in conducting the study because is used to demonstrate the current reality.

3.4. Population and Sample

Population is “the total number of units from which data can be collected”, such as individuals, artifacts, events or organizations. Polit (2001) define a sample as “a proportion of a population”. A carefully selected sample can provide data representative of the population from which it is drawn.

3.4.1. Study Center

This study is conducted at Nia foundation, joy autism center. Nia Foundation is a non-profit and non-governmental organization that provides treatment and education for children with autism. In a milestone laying ceremony for the construction of a new excellence center W/ro Zemi Yenus, founder of the center stated that the center is actively working since 2002, reaching out for children with autism in Addis Ababa and it is the first autism center in the country.

In addition to the treatment it provides for children, the Foundation also offers counseling and support to parents. The Foundation encourages parents to be active participants in the development of their children. It works closely with parents, extended family networks and children with the goal of integrating children with autism into the society. As the head of the center told me by now more than 80 children with autism are receiving treatment in the center.

According to the annual activity plan for 2019 of the center Nia Foundation is an indigenous, nonpolitical, non-religious and nonprofit making organization established in May 2002 in Ethiopia. In January 2006 the Nia Foundation received its legal recognition by the Ministry of Justice as a local humanitarian NGO and after wards the Foundation was re-registered as per the new Charities and Societies proclamation number 621/2009 as Ethiopian Residents Charity Organization on November, 2009 bearing registration # 0854. The center has been enthusiastically engaged in community awareness creation activities side by side with the center based holistic rehabilitation services, and the center attracted different organizations and individuals interested to visit its work and be part of it. The awareness creation engagements also encouraged parents to send their confined children with autism to the center so that the number of children we serve increased through time to 13 in 2005 and now more than 80.

Moreover, based upon the need for advocacy, services, support, training and education, the Nia Foundation has established to play a key role in educating and training and serving children and adults with autism, families affected by autism, the autism community as well as vulnerable youths and women.

3.4.2. Study Population

Target population is defined as identifiable total set of elements of interest being investigated by a researcher. Therefore, the target populations for the study were the mothers of the autistic children admitted to Joy Autistic Center. Since the center have more than 80 children with autism it is possible to access more mothers of children with autism than other centers. The mothers of these children enrolled in the center are from different background. Some of them are educated and financially rich, while others are illiterate and poor. Again some of them have other family members, but some have no or only one or two.

According to the annual report of 2018 of the center most of the mothers of children with autism whom their children enrolled in Joy center are single and destitute. This in turn enables the researcher to gather sufficient information and data on the research question. Joy autism center is the first autism center with more than 15 years of service. This also allows the researcher to access detail and examined data on the issues of the study. Finally the varieties of the services being given at the center are important to clearly sort out its contribution to mothers of children with autism.

3.4.3. Sampling Technique

According to Kothari (2004), two general approaches to sampling are used in social science research i.e. Probability sampling or non-probability sampling. Probability samples are those based on simple random sampling, systematic sampling, stratified sampling, cluster/area sampling whereas non-probability samples are those based on convenience sampling, judgment sampling and quota sampling techniques.

Sampling in qualitative study tends to be small number of people nested in their context and studies in-depth unlike quantitative studies, which aim for large number of context of stripped cases and seek statistical significance. In this study purposive sampling is employed to select the research participants. Purposive sampling is a non-probability sampling in which the investigator selects a sample which will yield results favorable to his point of view.

If the researcher selects the samples impartially, work without bias and have the necessary experience so as to take sound judgment, the results obtained from an analysis of deliberately selected sample may be tolerably reliable (Kothari, 2004). Accordingly the researcher selected six mothers for in depth interview and six mothers as one focused group discussants by using the duration of their child’s admission to the center, the connection with the center. According to the data available in the center the children of these mothers selected for the study are enrolled at least before five years. Due to the personal observation of the researcher and information from the centers these selected mothers have a relatively close connection with the center and low socio economic condition. Close connection is traced from the frequency of bringing their children to the center personally, attending regular meetings and events and information they provide to the center.

3.5. Data Collection Tools

Data collection tools in a study are sources of data from which you directly obtain data (Kabir, 2016). In this study both primary and secondary sources of data were collected.

3.5.1. Primary Data Collection Tools

A primary data source is an original data source, that is, one in which the data are collected firsthand by the researcher for a specific research purpose or project. Primary data can be collected in a number of ways. However, the most common techniques are self-administered surveys, interviews, field observation, and experiments. Primary data collection is quite expensive and time consuming compared to secondary data collection (Salkind, 2010). As parts of primary sources of data are in-depth interviews, focus group discussion and observations were utilized to gather reliable and sufficient data to answer the research questions.

3.5.1.1. In-depth Interview

According to Showkat & Parveen (2017) an interview is an important qualitative research method in which the researcher collects data directly from the participants in-depth interview. In-depth interviews (IdIs) are mostly long-duration, face-to-face, interviews conducted to achieve desired goals. In-depth interview also known as one-on-one is a method of extracting more detailed information or deep understanding of a subject or concept (Showkat & Parveen, 2017). The researcher also develop an open ended interview guide line to conduct an in depth interview. Interviews provide in-depth information pertaining to participant's experiences and viewpoints of a particular topic. The researcher chooses open-ended interviews as it allows participants to discuss their opinions, views and experiences fully in detail. Perhaps a set interview with closed ended questions may prohibit them to express their full opinions and feelings. Six mothers of children with autism were interviewed open ended questions.

3.5.1.2. Focused Group Discussion

Focus groups have advantages for researchers in the field of health and medicine: they do not discriminate against people who cannot read or write and they can encourage participation from people reluctant to be interviewed on their own (Al-Majdhoub et al., 2015; Kitzinger, 1995). Focus group discussion was also conducted with a view of obtaining some information as to how mothers see the activities and services of the center. FGD allows participants to openly express their ideas. In addition, the group communication creates a condition for participants to trigger memories and feelings over certain forgotten issues about the matter being discussed. There was one group of focused group discussants in this study which comprises six mothers who participated after expressing their willingness by the checklist.

3.5.1.3. Observation

The use of observational research methods in the field of care is vital to building the evidence base, identifying best practices, and understanding disparities in access to and delivery of health care services (Carlson & Morrison, 2009). Observation was one tools of data collection for this research. The researcher tried to observe the feeling, gesture, facial expression and the match between their internal feeling and external expression of mothers of children with autism.

3.5.2. Secondary Data

Secondary data refers to data that is collected by someone other than the user (Horn, 2018). Common sources of secondary data for social science include censuses, information collected by government departments, organizational records and data that was originally collected for other research purposes. Among those organizational records of the center and comment book were also used as secondary sources of data in line with the regulation of the center.

3.6. Procedure of Data Collection

There were four data collected through in-depth interview, focus group discussion, observation and Joy Autistic Center records content analysis. The researcher scheduled the in-depth interviews and interviewed twelve mothers of the autistic children. Throughout the researchers first visit there had been a number of opportunities to engage with participants and build relationships with them prior to interviewing. It was felt that this report building prior to collecting data led to greater openness and willingness to engage with the researcher during the whole process. After wards depending on their preferences, the mothers were interviewed at a time and location convenient to them which is their home, at the center and an event in a recreation center.

An interview was begun with briefing of the situation under which interviews came about to participants, purpose of the interview, and the use of a sound recorder. The length of each interview ranged from 45 minutes to an hour in some cases and the focus group discussion took 2 hours and data were collected in 45 days. They were audio-taped to get all the detailed information that the researcher intended to investigate for a detailed analysis and to ensure that the participants' answers are captured in their own terms. The participants were informed that they could request the tape recorder to be shut off at any point during the interview.

Then the data using the FDG after meeting all the mothers in person and made sure that they are willing and can give rich information regarding contribution of Joy Autistic Center in raising a child with autism and relation with the center was collected. Different questions were raised and responded by the mothers' focus groups and the notes were taken from the members of the focus group discussants.

3.7. Method of Data Analysis and Processing

According to Kabir (2016) data analysis is a mechanism for reducing and organizing data to produce findings that require interpretation by the researcher. Data analysis consists of preparing and organizing the data for analysis, reducing the data into themes through a process of coding and condensing the codes, and finally representing the data in figures, tables, or a discussion (Kothari, 2004). First the data gathered was manually transcribed by the researcher. Since the researcher conducts the interview in Amharic, transcription included two steps. The first step was transcribing directly from the native language and the second step was also be translating it to English. After finishing the pre-coding process, the researcher coded the data in to meaningful segments and terms. Following the coding the data categorized in searching for patterns or grouping exactly alike, very much alike data or data which have something in common within coded data. Then both data from interview and FGD were analyzed thematically.

3.8. Ethical Consideration

Ethics is the core to human relations and dignity. Ethical codes are written to cover the specific problems and issues that researchers frequently encounter during research work. In this study, the researcher informed the participants about the objectives of the study. The respondents were assured of confidentiality of the information they were going to provide and protection of their name. Also it was made clear that the information gathered would solely be used for the purpose of this study. Any deceptions in data collection were avoided.

CHAPTER FOUR

4. Findings and Discussion

The major objective of this research is studying the contribution of autism centers to mothers of children with autism specifically in Joy Autism Center. Accordingly, this chapter presents the main research findings obtained from the data gathering process combined with the researcher's analysis.

First the demographic information of participants will be presented in a table format. (See table 1). Then the results of the raw data will be presented in different major and minor themes in accordance with necessary categorizations. The situation of mothers before their child's admission to the center, their expectation while enrolling their child to the center and the actual changes brought to their life after enrollment will serve as major themes.

4.1. Findings

4.1.1. Demography of Participants

All mothers of children with autism in the center are not in the same situation and background. The reason to present the demography of the mothers is that their demographic variables highly affect their perception and opinion about the contribution of Joy Autism Center towards their life and their children with autism. Hence it is very much good to know their demographic background.

The needs and demands of the mothers of children with autism are different according to the situation they are in and according to their demography. For instance few of them didn't want any financial support from the center since they have adequate source of money. Again some of them don't want any family counseling service from the center since there is no such a problem with their husband and other family members. The same works for awareness, marital problems, economic issues and other factors. Hence in order to signify the relation between the contribution of the center and the background of mothers, demography of the participants is provided below.

Table 4.1: Demography of Interviewees and Focused Group Discussants

Sr. No.	Mothers	Marital status	Education background	Job/work
1	Mother one	Married	7th	House wife
2	Mother two	Widow	7th	Daily worker
3	Mother three	Married	Illiterate	Employed
4	Mother four	Unmarried	Diploma	Small business
5	Mother five	Unmarried	4th	Shop owner
6	Mother six	Married	4th	House wife
7	Mother seven	Widow	6th	House wife
8	Mother eight	Married	Illiterate	Unknown
9	Mother nine	Married	Illiterate	Small business
10	Mother ten	Unmarried	8th	Daily worker
11	Mother eleven	Widow	10th	No job
12	Mother twelve	Married	Degree	House wife

Source: Own Interviewed Data Presentation, 2019

4.1.2. Difficulties Mothers of Children with autism face before Their Children's Admission to Joy Autism Center

One of the basic research questions explored by this study is the life experience of mothers of children with autism before their child's admission to Joy Autism Center. Thus, the changes after enrollment will be revealed critically. During the course of gathering the data participants come up with different shortcomings and explain how these factors impact their life.

4.1.2.1. Lack of Awareness

Before their children's admission to the center almost all participants of the study were not aware about autism. Only one of them knows the term 'autism' and some of its symptoms before. But her understanding was very much limited.

The participant labeled as mother two said that;

"Being ignorant of the disorder I considered my child as a late talker and walker while he can't talk and walk at the age of four."

Some of the participants expressed that they considered the problem of their children as an evil spirit phenomenon which is totally unknown to the other people. They considered what happened to their child happened only to their child and to them. Supporting this fact mother seven stated that she believes her child's problem as supernatural and an evil spirit in which she took her child with autism to holy water.

Another mother labeled as mother one replied that she had never thought of another person with similar disability with her child, and she was not aware where to take him. What all the interviewees and the focus group discussant knew was that their children's behavior and action is different from what they know before from others. None of them even know the term autism before approaches to diagnosis and treatment to different health institutions, except one.

According to the findings of the in-depth interview and the focus group discussion, all participants of the study have similar understanding about the causes of autism, its effects and how it could be treated. Ten out of twelve respondents believed that autism is an evil spirit phenomenon and it couldn't be treated and cured. Only two of them described it as a biological problem like other disease but unaware of its diagnosis and treatment.

4.1.2.2. Stress

All participants of the study unanimously experienced high level of stress before their children's admission to the center. They have similar reasons for being in such kind of stress. For instance, mother twelve stated that

'My ignorance about the disorder/the problem forced me to experience heavy stress and headache which sometimes let me in a severe sickness. Had I known that it is this kind of disorder, I wouldn't be in such terrible situation.'

Another respondent, mother ten also expressed that considering their child as the only person with the disorder let them to experience a high level of stress and confusion. Others also describe lack of support, economic problems, social stigmas, and considering the disorder as untreated as factors leading them to stress. As per the principal investigator's visit and observation of the mothers during interviewing most of the mothers were very stressed. It was heartedly felt by the principal investigator that the situation of the mothers of children with autism were very stressed by reading their facial expression when talking about their past.

4.1.2.3. Lack of Social Support and Stigma

All of the participants of the study believe that taking care of an autistic child is cumbersome. Added to the already over loaded household task of mothers, treating children with autism demands cooperation between family members and society, as mothers said.

However, most of the respondents experienced severe social stigma and fail to get support from family members. All mothers mentioned that siblings are more cooperative in providing support for mothers and taking care of their autistic brother or sister. For example, one respondent (mother three) told the principal investigator that after disturbing her the whole day, her child (a boy) gets calm when his elder sister comes home after school.

The participants have different experience with regard to support from husbands and other family members. Only three of the respondents genuinely mentioned the support they received from their husband and other family members. Three of them had never received any support from their husband regarding taking care of their autistic children. To the worst mother seven responded that her husband left her and their children and got married to other women after their son was diagnosed autism.

As the respondents explain another difficult problem before their child's enrollment to Joy Autism center was social stigma. All the participants said that members of the community and relatives don't want to look children with such disorder. As a result, all of them stigmatize the mother and the child from all social events like birthdays, idir, and weddings. According to them it is not possible to use public transportation, gathered in public places and bring them to play grounds.

The participant labeled as mother six said that; *'One day when I and my daughter enter in to a train to come to the center, she runs to the corner, immediately every one shouted at her saying crazy. That was very irritating for me.'*

Mother three also stated that *'Autistic children expressed their felling in different ways. They may kiss you in the street. But the community is not even ready to accept their love.'*

As they reported this social stigma exclude them from their social life and let them to be pessimist. In addition, they considered it as the main source of stress and sorrow equal to the disorder itself among mothers of children with autism.

4.1.2.4. Time Constraints

All participants of this study underlined that the nature of the disorder by itself demands an intensive care from family members. It is only family members that can be able to manage the behavior and action of children with autism. Even it is not possible to take away your eyes from the child day and night. One of the respondents, mother ten explained this fact as follows: *'Due to the nature of the disorder, my son usually engages in self-destructive activities like biting himself or attacks others. So, if I left him unattended even for a moment, he may inflict injury on himself or on others including his siblings.*

Mother nine also stated that; *'My daughter has an aggressive behavior which can arise at any time in day or night. Letting her alone at any time means accepting the consequences of her aggressive behaviors which could sometimes be terrible.'*

Most of the mothers mentioned that from their experience it is only mothers themselves that are able to provide such demanding care for their child. Some of them said that the children themselves don't want to be attended by other persons, including family members except mothers. One respondent labeled as mother two said that; *'His actions and behaviors are manageable for me than other family members. When he is hyper active, it is only me that can calm down him.'*

Others responded that it is difficult to trust others and let them attend your child while you are not around. On this regard mother five said: *'Even though possible, for me letting him attended by others and leaving him amounts to betraying him. My emotion can never be collected in such situation.'*

Only one participant is willing and able to let her son stay with his sister while she left home, but with some insecurity. Stressing on the intensive care and follow up demanded by the child, all mothers similarly argue that they fall short of time to undertake other activities of any type. They all are marginalized from different socio-economic activities due to lack of time. It is hardly possible either to bring the child with them everywhere or leave him at home. Most of them believed that an attempt to do this may cause an irreversible consequence on the child himself or others. Mother one mentioned that for about six years before her child joined the center she had never participated/attended any social event since she had been busy of attending him.

Another respondent, designated as mother eight also expressed that before having a daughter with autism, she had a job with a good salary. But everything has gone after her daughter diagnosed with autism. A third respondent, mother eleven, after a long breath said that; *"when you have autistic children, social events and job are luxurious for you. It is not even possible to take care of yourself and others in a similar home.*"

4.1.2.5. Financial Constraints

All mothers who participated in this study similarly identify money as one of the challenges of having an autistic child. According to them the problem of finance is twofold. For one thing bringing the children to different health institutions before diagnosis consumes them a considerable sum of money. One respondent in this regard (mother one) stated that she spent all the money she had been saving before for her boy's medication. Had his problem been identified early and joined the center, I would not have fallen in such kind of life.

Another respondent, mother three, said that health institutions took her a lot of money for medication and medicines, which I thought aggravated my child's problem. For the participants another factor which aggravated the scarcity of finance is their inability to work and earn something. Mother seven this regard discussed that

"As I have told you earlier, I have to attend my child day and night. So, it is absolutely impossible to go out for work and earn money. Let alone work every day it is not even easy to search other sources of finance like loan."

Another participant, mother five, expressed her experience as follows; before the condition of her child get worse, she used to work and earn an average income. Later on, though she struggled to the last, leaving the job becomes evident. However, all of the participants did not experience financial problems despite expending a huge sum of money for pre diagnosis treatments. Few of them have had adequate wealth and financial source to cover all the expenses. In relation to this one of the respondents, mother twelve told me that;

"Even though I am not able to work, finance had never been a concern for me and the family. My husband earns a sufficient amount of money for our autistic children treatment and other household expenses thanks to God."

4.1.2.6. Impact on Marital Relation

In the course of gathering data for the study, all mothers who participated in in-depth interview and focused group discussion agreed that Autism has an adverse impact on their marital relationship in different ways. One of the respondents, mother two said that "*sometimes it is better to be a single mom; at least you can give your full attention to your child. Otherwise, if your husband is not understanding and tolerant, it is like trying to treat two competing interests for mothers".* According to her if her child was not admitted to the center, she was on the verge of divorce.

Another participant mother eight described her situation in relation to her marriage saying that taking care of their autistic children had totally changed her behaviors. Usually she was depressed, upset and in tears. Her husband, though polite and concerned, faced difficulty in accepting her situation. As a result, they were always in disagreement and quarrel not due to their child's situation but her new behavior.

A third mother (mother seven) who suffers from the worst situation in relation to her marital relation stated that; "*Being ignorant of what is going on me and my husband always quarrel and can't agree on every issue. Me after attending our child the whole day get depressed and impatience at night. He while coming back to home is not willing to accept this let alone helping me. Gradually he insisted divorce, leave the home and married to another woman. I am not in the situation of saving my marriage. Later on, what I have realized is that marriage by itself needs treatment."*

Only few participants responded that they were able to manage and protect their marriage, though there were some difficulties. Mother number ten on this regard expressed that; *"her husband was as concerned as she was for their child. He understood the situation and took every necessary care. Though different issues had been risen different times, they fall short of threatening our marriage due to our cooperation."*

Mother twelve on her part added that; *'My husband is so strong. He always takes responsibilities in our life. He tries to look every incident from positive point of view. This helps us to develop a strong bond. As a result, I had never been in a situation to worry about my marriage.*

4.1.3. Expectations of Mothers of Children with Autism from the Autism Center during Their Children's Admission

More or less all participants of the study have some positive expectations while enrolling their children to Joy Autism center. Speaking of what she has expected from the center, mother three stated that; *"after spending more than 6 years at home, with such stress and frustration, for me finding a place out of home to spend his time with children who are in a similar situation by itself was enough."* She felt that her son was the only person with this disorder. Knowing that there are other children with similar problem where he can spend his days with was satisfactory. Another respondent with similar idea (mother four) told me that she didn't expect anything in relation to his disorder. However she expected her child would experience some new place with children of similar problems so that she could have some free time and space.

Mother six said that; *"I had no information about the disorder. I was totally unaware about the overall issues of autism. As a result, when I am directed to the center and my son enrolled there, I thought he will be cured. I personally expect to be relieved from all the problems associated with the situation of my child believing that he will be cured and be normal. My understanding about the incurability of the disorder comes gradually after his admission to the center."*

Some of the participants of the in-depth interview and the focused group discussion had a great expectation for their children and themselves while being admitted to the autism center. Speaking on this regard mother two stated that she was very much eager to place her child in the center. While he was in the waiting list, she felt that all the challenges that happened to her life will no more exist after his admission. She believed that they would improve his overall personality and bring the happiness back to her home. From the first day of his admission, all her worries were gone and she got all the physical and mental freedom immediately she had dreamt before.

Another mother labeled as mother nine with similar experience mentioned that she felt she can regain all the things she lost if he joined the center when he was registered in the waiting list. She believed she can have all the confidence, life, happiness and job back to my home. Another mother with a different idea expects nothing from the center and feels that they will reject him after some time. In her own words, this mother four stated that; "*Before joining the center, I had enrolled him in to two different schools, both of which expel him after some time. After that I have decided to keep him at home. It is only the pressure of others which forced me to bring him to the center. Having no idea about the center and its difference with the schools, what I was thinking off is that they will expel him like the schools did after some time.*"

The expectation of two participants was more or less similar. They expect something for their autistic children but nothing for them. Mother number eight stated that when she decided to let him join the center resisting different socio-economic and family problems, she thought they will do something to manage his behavior and educate him how to do things. But nothing was in her mind regarding her situation. She didn't dream of that she would be relieved from her worries. That was an extra thing for her.

The other mother, mother one expressed her expectation as follows: "*My expectation and the actual thing in the center are very much different. From the very beginning I was not willing to let him go out of home. I had never thought of a place suitable for his situation. My decision to bring him to center is from a 'let's try' sense. Hence, I had never thought any improvement in his and my life rather than finding an alternative place for him to spend his days.*"

4.1.4. Contributions of the Center to Mothers of Children with Autism

The feedback of the in-depth interview and focused group discussion indicates that the contributions of the center are not limited to the autistic children only. According to them the services in the center have a far-reaching consequence for families in general and mothers in particulars. While responding on this point mother six emphasized that for a mother of a child with autism, finding someone with institution and professional knowledge to take care of her child by itself is a great support. But the center is more than that for them.

4.1.4.1. Freedom of Time

As already noted above, all respondents of the study agree that taking care of a child with autism is a full-time job for mothers. It is not possible to participate in socio-economic activities if you are the one to take care of the child due to the nature of the disorder, as per them. All participants of the study admitted that the center, while taking care of their child, solves their problem of shortage of time.

Mother eleven on this regard stated that; *'Before his admission to the center, I have no time to take care of myself and the family let alone going out for socio-economic activities. But after his admission to the center I have free time of the whole day. What I am required to do is to bring him to the center at 9:00 pm in the morning and take him back in 3:00 am in the afternoon. In between I am free to take a rest or enjoy socio-economic activities.'*

Mother nine added that before the admission of her child he was always on her back and she couldn't do anything. Now he is on the center's services, which gave her ample time to move on. Mother ten had a relative freedom time even before her son's admission to the center and expressed the difference as follows; *"The help of my husband and siblings gives me a relative freedom of time even before my son's enrollment to the center. However, the freedom of time after admission is absolute, it is with no worries."*

Some of the participants have also reflected a different perspective on the freedom of time even when their child is at home. Mother one and mother five have said the following. Mother one said, "*The care givers give training for the children how to do things by themselves. After some time my daughter begun to eat, play, dress and sit independently which enables me to do all household activities while she is at home with little supervision."*

According to mother five after her son's admission, he gradually began to help him-self without my assistance back in home. This gave the mother additional time and space to do other activities while he is at home.

4.1.4.2. Awareness Creation and Empowerment

Almost all of the participants have no or little information and knowledge about their children disorder. They told the researcher that they have suffered from lack of awareness and sufficient knowledge about the disorder which is now tackled by the center's service. According to them the services from the center enables them to better understand the nature of autism as a general awareness and how to treat their children at home in particular.

4.1.4.2.1. About the Disorder

Talking about awareness mother nine expressed that before her sons' admission to the center she knew nothing about autism. She thought it is only her son with such a disorder. But the center changed everything for her. On the first day of her appearance, the employees of the center told her everything about the disorder which changes her understanding about her son and the disorder. All other respondents of the study also stressed their lack of knowledge and information about autism and recognized that the center's awareness creation program equipped them with the necessary knowledge about it.

Mother twelve, the only mother with prior information about the disorder said that she had some information about the disorder which she got from reading a book. But that sort of knowledge was not enough to understand her son's problems and stay collected. It is only after she received consultation from the center that she get settled and fully understand the disorder.

In addition to lack of awareness some of the study participants told the research that they have wrong perception and understanding about the disorder. Among them two mothers stated their wrong appreciation about the disorder as follows; Mother one said that; "*The awareness creation and development activity of the center not only give me new insights about it but also corrects my wrong beliefs. While taking my daughter to the center, I believe autism is a curable disorder and they will cure my daughter. But, the center through different programs thought me about its incurability and how to adapt myself with it.*

Mother eight said that; '*before enrollment to the center I believe that the disorder of my child is an evil spirit phenomenon which happens to him due to my sins. Hence, I use to blame myself by considering my faults as reasons for the disorder. This was my long held believe until my son joins the center. But the professionals in the center told me that there is no connection between autism and mother's sins and its occurrence is due to biological factors. This is not simple for me. I feel a heavy weight lifted from me.'*

4.1.4.2.2. About Home Treatment

All of the mothers unanimously accepted that the biggest problem in relation to autism is the difficulty to manage the behavior, emotion and activities of the autistic child. Speaking on this issue mother twelve mentioned that the behavior and actions of her son is not normal, regular and with patterns. He accidentally becomes aggressive, silent, naughty and sad. She didn't know what to do in every change of his behavior and action.

According to the participants the center had administered training for mothers in order to acquaint them with skills to handle and manage their child's behavior and action out of the center and they have something to say about it. Mother four said that the center gave her continuous trainings and advices on how to treat her child at home by considering his specific condition. After the training she can easily treat him at home in accordance with his emotions. She realized that his every activity and feeling have their own interpretations.

According to mother nine before her child's admission to the center she was very sad because she didn't know what to do in his every action and emotion, more than pitying him. As per her being unaware of what to do while your son is in a problem is hurting for a mother. But after receiving training from the center she is able to manage all his emotions and activities.

4.1.4.3. Economic Assistance

Whether it happens to them or not all the participants of the study in their responses agreed that the diagnosis and treatment of autism requires a substantial amount of money. They also stressed that the economic challenges of autism are multi-dimensional. For mothers, for one thing the disorder demands a relatively huge sum of money for overall medical treatment. In addition, the nature of the disorder by itself demands mothers to spend their whole time with their children which forced them out from all economic activities to earn a living.

According to the respondents the center provides different direct and indirect economic assistances for mothers. Telling the research about this point, mother ten stated that; '*The center is generous enough to provide direct and indirect economic benefits to mothers of the autistic children depending on their demand and living conditions.' I informally heard that due to the help of the center many dependent mothers are now able to finance the living of their families.'*

4.1.4.3.1. Direct Economic Assistance

Among the participants of the study, two mothers are beneficiaries of this scheme by the center. Mother two and mother five expressed the economic assistance provided to them and how it impacts their life as follows as. Mother two had a permanent job which earns her living money before she gave birth to her son. But after she gave birth, she was not able to proceed with the job. She has to spend the whole time with her child. Her employer fired her after waiting her long to recommence her job. Gradually she began to experience shortage of money. Finally, she fall in to a severe financial problem and sacrificed a lot. After her child's admission to the center, the persons in the center discussed with her about her economic condition and gave her three thousand birr in order to start a small business. Giving her child to them, she started preparing French fraise and other fast foods for sale. By saving every little money she got from the business, she expanded her business to a medium scale. Now she has a sufficient income to finance all expenses of her family, and she is able to extend some support for the needy.

Mother five says; '*Before my child was admitted to the center I have no source for income and no one to support me. I use to beg publicly in order to cover some expenses. It was absolutely the worst history of my life. When we called to the center after spending a long time on the waiting list, I start thinking about our future and try to seek some source of money. In the meantime, the center asked me to begin a small business and encouraged me to* *do that. They gave me three-thousand-birr cash and advise me to begin a small business. Using the money and advice from the center I started to operate a small shop. Gradually I scaled up it and now I have a reliable source of income. Currently I have no worries regarding money and I am able to finance the expenses of my child and mine'*

4.1.4.3.2. Indirect Economic Assistance

According to the respondents, the center provides different kinds of indirect economic help for different mothers whose children enrolled to the center. Some of the indirect economic assistances provided by the center to participants of the study are expressed below.

According to mother one when the autism center called her to be enrolled in the center, she had no money to pay for entrance and tuition. After recognizing her condition, they accepted her without any registration and monthly payment. And according to mother six, before her admission to the center, even though she had different job opportunities, she was not able to work since she was expected to take care of her daughter the whole day and night. But after they take over her child, she secured a part time job. Accordingly, she begun to work while her child is in the center and subsidize her life. She doesn't have any problems in working at times when she is in the center.

According to mother seven; '*Even after she admitted to the center, I faced shortage of money for different expenses. Sometimes I kept her at home due to lack of money for transportation to the center. Later on, I started baking injera at restaurants and hotels due to a connection created by the center for me. From that time onwards I am able to at least cover basic household expenses'.*

Pursuant to Mother eleven before the admission of her child to the center there were a lot of expenses she had to cover like for food and sanitation. But after he enters in to the center they begun to feed him and he stopped using diapers. This saved the mother an incredible amount of money. The remaining mothers who participated in the study also mentioned the economic contribution of the center as an immense. They short listed that it helped them to concentrate on their work, the positive developments in their children saved them from incurring additional costs, the center gave them an ample time for economic activities, and the trainings given to their children make their behaviors manageable by any one. Hence to the maximum they can engage in a time taking economic activity letting their child cared by the center.

4.1.4.4. Psychological Rehabilitation

All participants of the study acknowledged that the psychological challenges of autism are the most suffering for mothers and other members of the family. Some of them strongly asserted that other problems like finance and time are easily forgettable once they are solved. But the psychological influence of autism is far reaching and difficult to forget.

The results of the in-depth interview and the Focused group discussion signified that the center administers different schemes for solving the psychological problems of mothers of children with autism. All of these participants have something to express in relation to the psychological support extended by the center to them. Mother nine as a beneficiary of a monthly family communication program indicated that she always attends the monthly family communication program. In the program mothers and professionals discussed about the psychological influence of autism and how to be relieved from it. It helped the mother a lot to avoid the stress and depression associated with the problem.

Mother eleven was a participant of a one to one/ a face to face consultation program by the center. She expressed what she got from the program as follows: '*Even after my child was admitted to the center, I use to experience a severe stress, depression and headache which all results from the psychological influence of the problem. In the face to face consultation the professional told me different mechanisms of getting rid of these problems. After seriously attending the program and implementing the advice I gradually feel relaxed and become normal. That program is the one which brings happiness and joy back to my life at least to that extent.'*

Mother three have a different view on the psychological contributions of the center. The center helped her a lot in rectifying the stress and depression she experienced before and after her son's enrollment to the center. Let alone the face to face and family communication programs, the improvements in her son's behavior significantly avoided the sorrow and stress and make her strong psychologically. Mother six also have a different perspective on the psychological contribution of the center said that; *'I was totally ignorant about the disorder of my daughter. I don't know what happen to her, how it will be solved and what our fate will be. Even I was not able to express her situation to others. I had felt all the stress and depression of ignorance. Crying was my day and night activity. But the awareness creation and training given to me changed everything. They told me everything about the disorder and how it will be treated, persuade me to accept the problem and undertake my responsibility. This wiped out all my tears and backs me to a relatively stable and better life.'*

In addition to the mothers whose views are expressed above, all the participants in similar way mentioned that admission to the center by itself is a great relief for mothers. According to them a child may be expected to stay in the waiting list for long before joining the center. Getting the turn and joining the center by itself is something great for mothers. Mother twelve on this point said that immediately after her child joins the center, she was free from any sort of problem. Thinking that her child is going to spent his days with professional who can give better care than her and with persons of similar disorders took all the sadness and stress from her.

4.1.4.5. Social Attributes

Almost all of the participants of the study expressed that they faced different social problems due to their child's disorder in one or another way. Particularly the stigma and discrimination from the community and even from family members is challenging as per them. Mother seven who participant in an FDG stated that due to her son's disorder all her relatives gets away from her. Even my husband left the home and marries another woman. Neighbors and the society were not willing to let her son play with their children. This was more painful for her than the disorder itself. As per most of the respondents the services given to the children and mothers have also the power of stabilizing the family and social life of mothers. Responding about this mother three told the researcher that; '*The center thought us a lot about how to handle our family and social life. The mother's discussion forum and the face to face consultation enabled me to get my family happiness and social life back. Sometimes, I even use to advice some community members and aware them about the disorder.*

Mother eleven who have similar ideas with mother three stated that she is free to attend any social phenomenon after admitting her child with autism to the center. This allowed her to get her former social life back. Even at home, though there was not that much problem, after his admission all family fun, enjoyment and happiness are at their former place.

Mother six also mentioned not only improvement in her family and social life but also the reasons for that. Before her daughter admitted to the center all family members were worried and depressed. There were no laugh and other family companion. But after her admission, her behavioral changes by itself change the family mood. Regarding the society due to lack of awareness no one wants to approach her and her child. she cannot also attend social events. But after admission since she have ample time, she attends social events and try to aware individuals about the disorder. Now she has a happy family and social life.

4.2. Discussion

The purpose of this research is to study the contribution of Joy Autism center to mothers of children with autism. Accordingly, the aim of this chapter is to discuss and present the key findings from the analysis of the qualitative data. The finding will then be presented in light of the basic research questions and objectives of the study in different themes.

4.2.1. The Burden of Mothers of Children with Autism

The findings of this study revealed that almost all the burdens of having an autistic child are on the backs of mothers, with no or little support from family members and husbands. Among the participants of the study only two of them received supports from their husbands except financial contributions. Again, only two of the respondents are able to secure support from siblings though they have other children. Another similar study has already concluded that most of the time, the mother is the most responsible and burdened in caring children with autism (Kebed, 2015).

All mothers who participated in the study admitted that having an autistic child and taking care of them resulted in different problem on their life. This study accordingly discovered that mothers of autistic children face time constraints for socio-economic activities, mental strain and depression, social stigma, economic problems, family instability and pessimism due to the nature of the disorder, lack of awareness and family and institutional support. Similar previous study 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; and to have social interactions. Usually the exceptional demands of the child’s disability also create emotional, social and financial problems for mothers (Kebed, 2015).

4.2.2. The Role of the Center to Mothers

This study found that the center has a far-reaching contribution not only to autistic children but also to their mothers too. All participants of the study unanimously agreed that all the activities of the center whether to their children or to them personally brought some positive improvements in their overall life. Even though the type and magnitude differ, all mothers witnessed positive changes in different aspects of their life after their child’s enrollment to the center. The contribution provided to mothers is provided in different categories below.

4.2.2.1. Freedom of Time

This study found out that one of the most prevalent difficulties in treating an autistic child for mothers is shortage of time. Since the disorder demands an intensive and whole-time care, all participant mothers of the study face lack of adequate time for other socio-economic activities. In a previous study (Abera, 2013) concluded that parents of an autistic children in addition to other problems suffers from lack of adequate time for their own life by quoting the answer of a mother to an interview as ‘I spent most of my time with him, I don’t have my own time. If there was some institution that I can trust, I could have at least some time.’ In another similar study (Berhane, 2016) stipulated that parents of an autistic children particularly mothers are vulnerable to time scarcity for other activities due to the nature of the disorder and lack of support.

According to this study the center has a pivotal role in solving the scarcity of time faced by mothers for other activities. Regarding this issue some mothers expressed that they are open to do anything in time when their child is at the center. They mentioned household activities, rest, personal caring, social life involvement and economic engagements as some of the activities they performed due to the space of time created by the center. As a common idea one respondent mother stated that 'the center is a relief for mothers. As the burden is on mothers, the contribution is also for us. All of us are free from 9:00 PM up until 3:00 PM since our children are in the center.'

Abera (2013) stipulated that institutional support is mandatory in order to relieve mothers from the time intensive care of autism. In line with that this study revealed that the center is providing an immense contribution in at least minimizing the time problem faced by mothers while spending the whole day taking care of their autistic children by sharing the caring responsibility and training them to be self-sufficient.

4.2.2.2. Awareness Creation and Empowerment

Almost all mothers who participated in this study are not aware of the disorder and were not cognizant about how to treat their children. Only one of them has some information about it which was not complete and sufficient.

In her study Berhane (2016) find out that lack of awareness is a source of different problems in families raising autistic children which includes stress, divorce and decrease in family happiness. Birhanu (2016) added that due to the nature of the disorder most parents are neither aware about it nor able to treat it, which increase the problems associated with it.

According to this study the center employed different mechanism in order to solve the awareness problem which proved to be fruitful as per the participants of the study. The face to face consultation program and the regular family (parents) gathering and other informal programs have the power of changing the awareness of mothers and equipping them with the techniques of treating an autistic child. One mother among the respondents stated that *'what they did before anything was explaining to me about the disorder then they gradually trained* *me how to treat him at home and other places out of school. This releases me all my stress and let me to enjoy the home time by treating him in accordance with his activities.'*

In support of this finding Birhanu (2016) already noted out that autism institutions have an indispensable role in counseling and training not only autistic children but also their parents too. Hence in realization of this the center planned intervention programs extends consultations and trainings for mother in order to raise their awareness and enable them treat their children out of school which is successful as revealed by this study.

4.2.2.3. Economic Support

Different studies conducted on the effect of autism showed that it has a huge impact on the economic condition of the family (Rastelli, 2006). Expensiveness of the diagnosis and treatment of autism added to the inability of parents to earn a living due to time scarcity worsen the situation of parents in relation to finance.

Similarly, participants of this study admitted that the disorder affects their economic life negatively. According to this study the economic challenge of the disorder is in two ways. For the first the diagnosis and treatment of the disorder is much expensive which consumes all the remains of parents. In addition, it leaves parents particularly mothers unable to work since they are required to provide the necessarily care for the child day and night. All participants of the study agreed that it is not possible for mother of autistic children to engage in any financial activity since it requires time. Accordingly, all of them were without earnings before the admission of their respective children to the center.

Pursuant to this study the economic contribution of the center to mothers is not only important but also multi-dimensional. The center by taking autistic children and keep them with it enable women to have free time to engage in economic activities. Some of the participants mentioned that they started doing business and earn a living after the enrollment of their children to the center.

Three of the respondents were also beneficiaries of a direct funding for mothers from the center. According to them the center extended some free money for them to start a business by using which all of them start doing small scale business and become self-subsistence and economically independent.

Thus, the center contributes directly and indirectly for the economic life of mothers. It enables them to work and earn money by employing different mechanisms. Kebed (2015) Already noted that parents of autistic children need support from different organs in order to have a job and earn money to cover family expenses.

4.2.2.4. Psychological Support

Most mothers of an autistic children experience stress and other psychological traumas due to the disorder (Kebed, 2015). Participants of this study also expressed that all of them were in a difficult psychological situation before their children admission to the center. According to them this was mostly for two reasons. For one thing they have no awareness about the disorder. For another thing, they are neither able to treat their child nor able to find someone to treat him/her. This exposes them from headache and stress to severe psychological problems.

This study figures out that the center is successful in solving the psychological problems of mothers of autistic children. As all mothers accepted, the mere admission of their children to the center wiped away their stress believing it is the appropriate place for their children. Most of the participant mothers stated that due to the trainings and therapies administered to them, children are becoming self-sufficient from time to time. This gives mothers hope about their children future. On this regard one mother mentioned that

'I was always in confusion about my daughter's future. Will she lasts in this way or will there be any change was my always frustration. But after she joined the center, she tried and starts successfully doing things by her. I am speechless, all my worries left away.

The center then contributed for the psychological well-being of mothers by the services it delivered to children and to mothers themselves. The progress of the children, their admission, the awareness raising and training programs enabled mothers to be psychologically stable and relayed as to the results of this study.

4.2.2.5. Social Support

The impacts of autism on the social life of parents and family members are difficult to hold. In her study Birhanu (2016) expressed that mothers in addition to the shortage of time to attend social gathering, face severe stigma in their approach to the society. Most of participant mothers of the study were also victims of different societal problems due to the disorder. One mother stated that

‘I don’t know why I was suffering that much. The scarcity of time for social life is at least out of any one’s control. But why should I suffer from the improper attitude of the society.’

According to this study the center has something to do in order to solve the social problems faced by mothers. The most important thing provided by the center for mother is freedom of time. Mothers were not free to go out for social events before their children admission to the center. But after enrollment they use to go and attend social events there by maintaining and strengthening their social life.

In addition to that mothers stated that the center in the face to face and family gathering programs advice and train mothers how to uphold their social life and enjoy it to the fullest. This enables them to reintegrate with the society and be part of it. Kebed (2015) in her previous study figure out that for mothers in order to have their social life back, they shall have someone trustworthy to take care of their children and consult them how to rejoin the societal life afresh. In line with that the results of this study showed that the center helped mothers to have free time for social life and train them how to use it.

CHAPTER FIVE

5. Conclusion, Recommendation and Implications

5.1. Conclusion

This study provided a preliminary look on the experience of mother's raising a child with autism before and after the child's admission to joy autism center. Accordingly it grasped the difference in the life of mothers due to their child enrollment to the center.

In conclusion to the first research question, mothers of children with autism face different psychological, economic, social and other related difficulties before the admission of their children to the center. Psychologically due to lack of adequate awareness about the disorder and its treatment mechanisms they experienced high level of stress and depression. Economically the disorder poses short of time for mothers to engage in financial activities and by itself consumes a considerable amount of money for medical and home treatment. It hampers the mother's readiness and actual participation in economic activities. Equally mothers of children with autism face serious challenges in their social life from marriage and family to neighborhood and the community.

Lack of adequate finance in addition to the societies and family members' attitude towards the disorder and its causes almost exclude mothers from enjoying their social life. Other problems associated with autism for mothers include divorce, lack of solidarity from family members and the society, lack of economic support, inadequate professional support, stigma and discrimination and the nature of the disorder itself.

These problems faced by mothers are not mere challenges. They impacted the life of mothers in different ways. The synergic effect of the problems let mothers to experience a health problem which includes high level stress, depression and loneliness. These psychological problems in addition disturbed their family relation which in turn leads to divorce in one case. The shortage in time totally bars mothers from taking part in self-caring, social and economic activities. This also let mothers to live in extreme poverty and destitute segregated from other members of the society and dependent on the help of others, if any. Lack of awareness and professional as well as family and social support also impacted mothers to feel pessimist about their children and their own future.

In general among family members the impacts of raising a child with autism first hampers mothers in multi dimensions. Except differences in magnitude all mothers covered by this study face different socio economic and psychological problems due to having a child with autism. The other research question addressed by this study is the necessity of external intervention to bring improvements on the life of mothers which is deteriorated due to the problems discussed above. This study found out that the challenges of autism are not bearable for a single mother or the family as a whole. It requires the concern and actual participation of community members, government organs and other organizations. These mothers who participated in the study unanimously stated that the challenges of autism are out of the reach of mothers and family members. Different studies have already noted out that the diagnosis and treatment of autism requires a combined effort of family members, the society, the government, civil societies and health related professionals in personal and institutional setup for the betterment of the child as well as the family and the community in general.

The types of the external interventions necessary for mothers of children with autism include educational, psychological, social and economic which can bring changes and reverse the challenges mothers' experience. The main theme of this study is identifying the contribution of autism centers for mothers of children with autism. Accordingly the study explored the difference in the overall life of mothers after the admission of their children to joy autism center. All mothers covered by this study admitted that their child enrollment to the center bring positive changes both in the life of their children and themselves. The benefits mothers received are multiple. For one thing they indirectly benefited from the services the center administered for their children and the improvements there in. in addition they are also benefited from the direct accommodations accorded for mothers by the center in different aspects.

As per this study the center provided different services for children with autism and their mothers which equally contributed for the progress of the child and the life of mothers. Keeping the children by itself gave mothers freedom of time to engage in other socio economic activities. Believing that their children are in the hand of a professional institution also help mothers to get rid of their psychological distress. The trainings, coping and self-help activities for the children and the results that follow also enable women to develop confidence and feel relaxed unlike the case of their child’s admission to the center. The center also administers different awareness raising programs and home treatment trainings for mothers. This allows mothers to avoid awareness related challenges stated above and treat their child at home in a learned manner. It also helps them to reconnect with the society and strengthen it.

Mothers in the center are also beneficiaries of direct economic assistance provided by the center. The center gave cash money and business idea for some mothers. Using that mothers run and own different business which enables them to fully engage in economic activity and liberate themselves from dependency. In general this study discovered that autism centers have contributions not only for children with autism but also for mothers in different aspects. Autism centers are indispensable in eradicating and meaningfully reducing the psychological, social, and economic and awareness problems of mothers and the impacts on their life that follows.

5.2. Recommendations

The findings of this study clearly figured out that mothers of children with autism face the most difficult burden related to autism in different socio economic and psychological aspects. At the same time the study revealed that autism centers have a lot to contribute in solving these challenges faced by mothers. However, due to different reasons so many mothers are still facing the darkness of autism. Hence I strongly recommend the following;

- The government to give due attention for the disorder as one public health issue and act accordingly

- The media also need to give wide coverage to create awareness about autism and attract stake holders to the issue
- Health institutions shall also establish special unit for the diagnosis and treatment of autism
- Civil society organizations and non-governmental organizations shall also participate in the establishment and progress of autism centers
- Academicians and researchers are also recommended to conduct further studies on the impact of autism.

5.3. Implications

The findings of this study revealed that mothers of children with autism face different psychological, social, economic and other problems in relation to autism and its adverse effects. Despite the diversity and gravity of problems autism centers are found to be the most important institutions in mitigating and avoiding the problems mothers of children with autism face in different spheres of their life.

Accordingly this study implies that social work practices and intervention in relation to autism should not be limited to the autistic individual only. Mothers of children with autism should also be the subject matters of social work practice. Since there are only few autism service centers in Ethiopia social workers need to advocate for an increased number of autism centers and special emphasis by different concerned bodies.

The results of this study have already showed that the challenges of mothers of children with autism are not recognized well. Most of previous studies and intervention focused on front line victims, children with autism, though mothers face huge problems as their autistic children face. As a result this study signified that social work practice must be directed towards making the issue of mothers as a mainstream problem in relation to autism.

The autism service centers in the country are organized by private individuals and charitable organizations. The government’s role in the treatment of autism is very much limited. Due to this the researcher has already recommended the government to establish special units for the diagnosis and treatment of autism in mainstream health institutions. The policy implication of this study is that autism as a disorder and its adverse impacts on mothers of children with autism shall be parts of the health policy of the government. In its policies the government shall propose to create conducive environment for the engagement of charitable organizations and non-governmental organizations in the sector since the government by itself cannot do everything.

This research is limited to studying the challenges mothers of children with autism face and the contribution of autism centers in reducing and alleviating these problems. It also recommends researchers to investigate the impacts of autism on individual, family and societal level at local context and the possible mechanisms of solving these problems. Hence further researches can take the findings of this study in order to investigate the challenges mothers of children with autism face and the possible coping mechanisms.

REFERENCES

Aadil Bashir, U. B. (2014). Challenges Faced by families of Autistic Children. , 2(1),. *International Journal of Interdisciplinary Research and Innovations*, *2*(1), 24–28.

Abatemarco, D. (2020). *Social, economic, health, and health care factors related to the use of zidovudine in HIV-infected women who delivered births /.*

Abera, M. (2013). Assessment of challenges and support needs of parents of children with autism at nehemiah autism center in addis abeba. *Unpublished Master's Thesis, Addis Ababa University*.

Al-Majdhoub, F. M., Hamzah, A. B., & Ariffin, M. Y. (2015). Focus group discussions on the coverage of the southern separatist movement crisis in Yemeni newspapers. *SpringerPlus*, *4*, 229. https://doi.org/10.1186/s40064-015-1000-0

Allen, K.-A., Bowles, T., & Weber, L. (2013). Mothers' and Fathers' Stress Associated with Parenting a Child with Autism Spectrum Disorder. *Journal of Autism Insights*, *5*, 1–11. https://doi.org/10.4137/AUI.S11094

Andersson, G. W., Miniscalco, C., & Gillberg, N. (2017). A 6-year follow-up of children assessed for suspected autism spectrum disorder: parents' experiences of society's support. *Neuropsychiatric Disease and Treatment*, *13,* 1783–1796. https://doi.org/10.2147/NDT.S134165

APA, A. P. A. (2013). *Autism Spectrum Disorder. 299.00 (F84.0); Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). American Psychiatric Publishing.

Austin, Z., & Sutton, J. (2014). Qualitative research: getting started. *The Canadian Journal of Hospital Pharmacy*, *67*(6), 436–440. https://doi.org/10.4212/cjhp.v67i6.1406

Babbie, E. (2007). *The Practice of Social Research* (11th ed.). Thompson - Wadsworth.

Bambaeeroo, F., & Shokrpour, N. (2017). The impact of the teachers' non-verbal communication on success in teaching. *Journal of Advances in Medical Education & Professionalism*, *5*(2), 51–59. https://pubmed.ncbi.nlm.nih.gov/28367460

Begum, R., & Mamin, F. A. (2019). Impact of Autism Spectrum Disorder on Family. *Autism-Open Access, 09*(04). https://doi.org/10.35248/2165-7890.19.9.244

Berhane, H. (2016). Reactions, Challenges and Coping Mechanisms of Mothers Raising Children With Autism Spectrum Disorder (ASD): The case of Addis Ababa City. addis ababa. *Addis Ababa University Press*.

Bird, G., & Cook, R. (2013). *Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism: Translational Psychiatry*.

Birhanu, M. (2016). *Resources in raising a child with autism in Ethiopia: parents' perspectives. burgen.*

Bluth, K., Roberson, P. N. E., Billen, R. M., & Sams, J. M. (2013). A Stress Model for Couples Parenting Children With Autism Spectrum Disorders and the Introduction of a Mindfulness Intervention. *Journal of Family Theory & Review*, *5*(3), 194–213. https://doi.org/10.1111/jftr.12015

Bölte, S., Girdler, S., & Marschik, P. B. (2019). The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cellular and Molecular Life Sciences*, *76*(7), 1275–1297. https://doi.org/10.1007/s00018-018-2988-4

Bolton, P. F., Carcani-Rathwell, I., Hutton, J., Goode, S., Howlin, P., & Rutter, M. (2011). Epilepsy in autism: features and correlates. *The British Journal of Psychiatry : The Journal of Mental Science*, *198*(4), 289–294. https://doi.org/10.1192/bjp.bp.109.076877

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief Experiences in Family Caregivers of Children with Autism Spectrum Disorder (ASD). *International Journal of Environmental Research and Public Health*, *16*(23), 4821. https://doi.org/10.3390/ijerph16234821

Brooks, X. (2017). *Darren Aronofsky on Mother! - 'Jennifer Lawrence was hyperventilating because of the emotion*.

Burrell, A., Ives, J., & Unwin, G. (2017). The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *47*(4), 1135–1147. https://doi.org/10.1007/s10803-017-3035-2

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, *23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

Carlson, M. D. A., & Morrison, R. S. (2009). Study design, precision, and validity in observational studies. *Journal of Palliative Medicine*, *12*(1), 77–82. https://doi.org/10.1089/jpm.2008.9690

Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review. *International Journal of Environmental Research and Public Health*, *15*(2), 341. https://doi.org/10.3390/ijerph15020341

CDC. (2020). *Treatment and Intervention Services for Autism Spectrum Disorder*.

Chandrasekhar, T., & Sikich, L. (2015). Challenges in the diagnosis and treatment of depression in autism spectrum disorders across the lifespan. *Dialogues in Clinical Neuroscience*, *17*(2), 219–227. https://pubmed.ncbi.nlm.nih.gov/26246795

Chung, P. J., Lui, C. K., Cowgill, B. O., Hoffman, G., Elijah, J., & Schuster, M. A. (2012). Employment, family leave, and parents of newborns or seriously ill children. *Academic Pediatrics*, *12*(3), 181–188. https://doi.org/10.1016/j.acap.2012.02.001

Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, *129*(4), 617–623.

https://doi.org/10.1542/peds.2011-2700

Cloete, L. G., & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with autism spectrum disorder in Kenya. *African Journal of Disability*, *8*, 435. https://doi.org/10.4102/ajod.v8i0.435

Creswell, J. W. (2014). *Research Design Qualtitative, Quantitive and Misxed Methods Approache* (4th ed.). SAGE Publication inc.

Dejene Tilahun, A. F., & Hoekstra, C. H. (2019). Ethiopian community health workers' beliefs and attitudes towards children with autism, impact of a brief training intervention. *Open Research Online*, *23*(1), 39–49.

Demissie, M. (2015). *Autism: Parents' Experience And Care Practice; Addis Ababa.*

Elder, J. H., Kreider, C. M., Brasher, S. N., & Ansell, M. (2017). Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology Research and Behavior Management*, *10,* 283–292. https://doi.org/10.2147/PRBM.S117499

Elsabbagh, E. m. (2014). Autism; a global perspective. switzerland: springer. *International Publisher*.

Emberti Gialloreti, L., Mazzone, L., Benvenuto, A., Fasano, A., Alcon, A. G., Kraneveld, A., Moavero, R., Raz, R., Riccio, M. P., Siracusano, M., Zachor, D. A., Marini, M., & Curatolo, P. (2019). Risk and Protective Environmental Factors Associated with Autism Spectrum Disorder: Evidence-Based Principles and Recommendations. *Journal of Clinical Medicine*, *8*(2), 217. https://doi.org/10.3390/jcm8020217

ESHG. (2019). Abstracts from the 51(st) European Society of Human Genetics Conference: Posters. *European Journal of Human Genetics*, *27*(Suppl 1), 1–688. https://doi.org/10.1038/s41431-019-0404-7

Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. *History of the Human Sciences*, *26*(3), 3–31. https://doi.org/10.1177/0952695113484320

Exkorn, K. S. (2008). The autism source book. newyork. *Perfect Bond Publisher*.

Faras, H., Al Ateeqi, N., & Tidmarsh, L. (2010). Autism spectrum disorders. *Annals of Saudi Medicine*, *30*(4), 295–300. https://doi.org/10.4103/0256-4947.65261

Findling, R. (2015). An update on pharmacotherapy for autism spectrum disorder in children and adolescents. *Current Opinion in Psychiatry*, *28*(2), 91–101.

Franz, L., Carolina, N., & Chambers, N. (2017). Autism Spectrum Disorder in Sub-Saharan Africa: A Comprehensive Scoping Review. *Autism Research*, *10*(5), 723–749. https://doi.org/10.1002/aur.1766.Autism

Frye, R. E. (2018). Social Skills Deficits in Autism Spectrum Disorder: Potential Biological Origins and Progress in Developing Therapeutic Agents. *CNS Drugs*, *32*(8), 713–734. https://doi.org/10.1007/s40263-018-0556-y

Fuld, S. (2018). Autism Spectrum Disorder: The Impact of Stressful and Traumatic Life Events and Implications for Clinical Practice. *Clinical Social Work Journal*, *46*(3), 210–219. https://doi.org/10.1007/s10615-018-0649-6

Furrukh, J., & Anjum, G. (2020). Coping with autism spectrum disorder (ASD) in Pakistan: A phenomenology of mothers who have children with ASD. *Cogent Psychology*, *7*(1), 1728108. https://doi.org/10.1080/23311908.2020.1728108

Gerdts, R. b. (2010). *Autism spectrum disorders a reference handbook*. greenwood publishing group.

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology*, *8*, 438. https://doi.org/10.3389/fpsyg.2017.00438

Golics, C. J., Basra, M. K. A., Finlay, A. Y., & Salek, S. (2013). The impact of disease on family members: A critical aspect of medical care. *Journal of the Royal Society of Medicine*, *106*(10), 399–407. https://doi.org/10.1177/0141076812472616

Gona, J. K., Newton, C. R., Rimba, K., Mapenzi, R., Kihara, M., Van de Vijver, F. J. R., & Abubakar, A. (2015). Parents' and professionals' perceptions on causes and treatment options for Autism Spectrum Disorders (ASD) in a multicultural context on the Kenyan Coast. *PloS One*, *10*(8), e0132729–e0132729. https://doi.org/10.1371/journal.pone.0132729

Goundar, S. (2012). *Chapter 3 - Research Methodology and Research Method*.

Grant, N., Rodger, S., & Hoffmann, T. (2015). Evaluation of autism-related health information on the web. *Journal of Applied Research in Intellectual Disabilities*, *28*(4), 276 – 282.

Guler, J., De Vries, P., Seris, N., Shabalala, N., & Franz, L. (2018). The importance of context in early autism intervention: A qualitative South African study. *Autism*, *22*, 1005–1017. https://doi.org/10.1177/1362361317716604

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology : JFP : Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, *24*(4), 449–457. https://doi.org/10.1037/a0019847

Hartley, S. L., Papp, L. M., & Bolt, D. (2018). Spillover of Marital Interactions and Parenting Stress in Families of Children With Autism Spectrum Disorder. *Journal of Clinical Child and Adolescent Psychology : The Official Journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53*, *47*(sup1), S88–S99. https://doi.org/10.1080/15374416.2016.1152552

Hodgetts, S., Zwaigenbaum, L., & Nicholas, D. (2015). Profile and predictors of service needs for families of children with autism spectrum disorders. *Autism : The International Journal of Research and Practice*, *19*(6), 673–683. https://doi.org/10.1177/1362361314543531

Hoefman, R., Payakachat, N., van Exel, J., Kuhlthau, K., Kovacs, E., Pyne, J., & Tilford, J. M. (2014). Caring for a child with autism spectrum disorder and parents' quality of life: application of the CarerQol. *Journal of Autism and Developmental Disorders*, *44*(8), 1933–1945. https://doi.org/10.1007/s10803-014-2066-1

Hoekstra, R. A., Girma, F., Tekola, B., & Yenus, Z. (2018). Nothing about us without us: the importance of local collaboration and engagement in the global study of autism. *BJPsych International*, *15*(2), 40–43. https://doi.org/10.1192/bji.2017.26

Horlin, C., Falkmer, M., Parsons, R., Albrecht, M. A., & Falkmer, T. (2014). The cost of autism spectrum disorders. *PloS One*, *9*(9), e106552–e106552. https://doi.org/10.1371/journal.pone.0106552

Horn, N. (2018). *The Immense Value Behind Data Enrichment with Secondary Data*.

Hubert, S., & Aujoulat, I. (2018). Parental Burnout: When Exhausted Mothers Open Up. *Frontiers in Psychology*, *9*, 1021. https://doi.org/10.3389/fpsyg.2018.01021

Huerta, M., & Lord, C. (2012). Diagnostic evaluation of autism spectrum disorders. *Pediatric Clinics of North America*, *59*(1), 103–xi. https://doi.org/10.1016/j.pcl.2011.10.018

Ilias, K., Cornish, K., Park, M. S.-A., Toran, H., & Golden, K. J. (2019). Risk and Resilience Among Mothers and Fathers of Primary School Age Children With ASD in Malaysia: A Qualitative Constructive Grounded Theory Approach. *Frontiers in Psychology*, *9*, 2275. https://doi.org/10.3389/fpsyg.2018.02275

Ilias, K., Liaw, J. H. J., Cornish, K., Park, M. S.-A., & Golden, K. J. (2017). Wellbeing of mothers of children with "A-U-T-I-S-M" in Malaysia: An interpretative phenomenological analysis study. *Journal of Intellectual & Developmental Disability*, *42*(1), 74–89. https://doi.org/10.3109/13668250.2016.1196657

Jacobs, D., Steyaert, J., Dierickx, K., & Hens, K. (2018). Implications of an Autism Spectrum Disorder Diagnosis: An Interview Study of How Physicians Experience the Diagnosis in a Young Child. *Journal of Clinical Medicine*, *7*(10), 348. https://doi.org/10.3390/jcm7100348

Jacobs, D., Steyaert, J., Dierickx, K., & Hens, K. (2019). Physician View and Experience of the Diagnosis of Autism Spectrum Disorder in Young Children. *Frontiers in Psychiatry*, *10*, 372. https://doi.org/10.3389/fpsyt.2019.00372

Jenkins, R., Baingana, F., Ahmad, R., McDaid, D., & Atun, R. (2011). Social, economic, human rights and political challenges to global mental health. *Mental Health in Family Medicine*, *8*(2), 87–96. https://pubmed.ncbi.nlm.nih.gov/22654971

Ji, G., Li, L., Lin, C., & Sun, S. (2007). The impact of HIV/AIDS on families and children--a study in China. *AIDS (London, England)*, *21 Suppl 8*(Suppl 8), S157–S161. https://doi.org/10.1097/01.aids.0000304712.87164.42

Johnson, C., & Myers, S. (2007). Council on Children with Disabilities “Identification and evaluation of children with autism spectrum disorders.” *Pediatrics*, *120*(5). https://doi.org/10.1542/peds.2007-2361

Kabir, S. M. (2016). *METHODS OF DATA COLLECTION* (pp. 201–275).

Karst, J., & Van Hecke, A. (2012). Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation. *Clinical Child and Family Psychology Review*, *15*, 247–277. https://doi.org/10.1007/s10567-012-0119-6

Kaur, R., & Garg, S. (2008). Addressing domestic violence against women: an unfinished agenda. *Indian Journal of Community Medicine : Official Publication of Indian Association of Preventive & Social Medicine*, *33*(2), 73–76. https://doi.org/10.4103/0970-0218.40871

Kebed, M. D. (2015). Autism: Parents’ Experience And Care Practice. *Indira Gandi National Open University School Of Social Work*.

Khanlou, N., Haque, N., Mustafa, N., Vazquez, L. M., Mantini, A., & Weiss, J. (2017). Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada. *International Journal of Mental Health and Addiction*, *15*(2), 239–259. https://doi.org/10.1007/s11469-017-9732-4

Khudhair, A. S., & Jassim, S. K. (2018). The Knowledge of Autistic Children’s Mothers Regarding Autism in Basra City. *American Journal of Nursing Research*, *6*(5), 296–298. https://doi.org/10.12691/ajnr-6-5-11

Kinnear, S., Link, B., Ballan, M., & Fischbach, R. (2015). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families’ Lives. *Journal of Autism and Developmental Disorders*, *46*. https://doi.org/10.1007/s10803-015-2637-9

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *BMJ (Clinical Research Ed.)*, *311*(7000), 299–302. https://doi.org/10.1136/bmj.311.7000.299

Kothari. (2004). *Research Methodology Methods and Techniques*. New Age International Publishers.

LaGasse, A. B. (2017). Social outcomes in children with autism spectrum disorder: a review of music therapy outcomes. *Patient Related Outcome Measures*, *8*, 23–32. https://doi.org/10.2147/PROM.S106267

Lorenz, T., Frischling, C., Cuadros, R., & Heinitz, K. (2016). Autism and Overcoming Job Barriers: Comparing Job-Related Barriers and Possible Solutions in and outside of Autism-Specific Employment. *PloS One*, *11*(1), e0147040–e0147040. https://doi.org/10.1371/journal.pone.0147040

Lyall, K., Croen, L., Daniels, J., Fallin, M. D., Ladd-Acosta, C., Lee, B. K., Park, B. Y., Snyder, N. W., Schendel, D., Volk, H., Windham, G. C., & Newschaffer, C. (2017). The Changing Epidemiology of Autism Spectrum Disorders. *Annual Review of Public Health*, *38*, 81–102. https://doi.org/10.1146/annurev-publhealth-031816-044318

Maenner, M., Shaw, K., & Baio, J. (2020). *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years: Autism and Developmental Disabilities Monitoring Network*.

Mahapatra, P., Pati, S., Sinha, R., Chauhan, A. S., Nanda, R. R., & Nallala, S. (2019). Parental care-seeking pathway and challenges for autistic spectrum disorders children: A mixed method study from Bhubaneswar, Odisha. *Indian Journal of Psychiatry*, *61*(1), 37–44. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_257_18

Mann, A. R. (2013). The Experiences of Mothers of Children with Autism in Jamaica: An Exploratory Study of Their Journey. *University of South Florida Scholar Commons*.

Martínez-Pedraza, F. de L., & Carter, A. S. (2009). Autism spectrum disorders in young children. *Child and Adolescent Psychiatric Clinics of North America*, *18*(3), 645–663. https://doi.org/10.1016/j.chc.2009.02.002

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An Overview of Autism Spectrum Disorder, Heterogeneity and Treatment Options. *Neuroscience Bulletin*, *33*(2), 183–193. https://doi.org/10.1007/s12264-017-0100-y

McHale, S. M., Updegraff, K. A., & Whiteman, S. D. (2012). Sibling Relationships and Influences in Childhood and Adolescence. *Journal of Marriage and the Family*, *74*(5), 913–930. https://doi.org/10.1111/j.1741-3737.2012.01011.x

Memari, A. H., Panahi, N., Ranjbar, E., Moshayedi, P., Shafiei, M., Kordi, R., & Ziaee, V. (2015). Children with Autism Spectrum Disorder and Patterns of Participation in Daily Physical and Play Activities. *Neurology Research International*, *2015*, 531906. https://doi.org/10.1155/2015/531906

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting Stress in Mothers of Children With Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies. *Frontiers in Psychology*, *10*, 464. https://doi.org/10.3389/fpsyg.2019.00464

Mughal, S., Faizy, R., & Saadabadi, A. (2020). *Autism Spectrum Disorder (Regressive*

Autism, Child Disintegrative Disorder).

Nadeau, J., Sulkowski, M. L., Ung, D., Wood, J. J., Lewin, A. B., Murphy, T. K., May, J. E., & Storch, E. A. (2011). Treatment of comorbid anxiety and autism spectrum disorders. *Neuropsychiatry*, *1*(6), 567–578. https://doi.org/10.2217/npy.11.62

Navot, N., Jorgenson, A. G., & Webb, S. J. (2017). Maternal experience raising girls with autism spectrum disorder: a qualitative study. *Child: Care, Health and Development*, *43*(4), 536–545. https://doi.org/10.1111/cch.12470

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities*, *117*(1), 48–66. https://doi.org/10.1352/1944-7558-117.1.48

Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, *12*, 745–762. https://doi.org/10.2147/NDT.S100634

Oprea, C., & Stan, A. (2012). Mothers of Autistic Children. How do They Feel? *Procedia - Social and Behavioral Sciences*, *46*, 4191–4194. https://doi.org/10.1016/j.sbspro.2012.06.224

Ornoy, A., Weinstein-Fudim, L., & Ergaz, Z. (2015). *Prenatal factors associated with autism spectrum disorder (ASD): Reproductive Toxicology*. *56*, 155–169.

Orsmond, G. I., Kuo, H.-Y., & Seltzer, M. M. (2009). Siblings of individuals with an autism spectrum disorder: sibling relationships and wellbeing in adolescence and adulthood. *Autism : The International Journal of Research and Practice*, *13*(1), 59–80. https://doi.org/10.1177/1362361308097119

Padden, C., & James, J. E. (2017). Stress among Parents of Children with and without Autism Spectrum Disorder: A Comparison Involving Physiological Indicators and Parent Self-Reports. *Journal of Developmental and Physical Disabilities*, *29*(4), 567–586. https://doi.org/10.1007/s10882-017-9547-z

Papadopoulos, C., Lodder, A., Constantinou, G., & Randhawa, G. (2019). Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health. *Journal of Autism and Developmental Disorders*, *49*(4), 1665–1685. https://doi.org/10.1007/s10803-018-3835-z

Paul, R. (2008). Interventions to Improve Communication in Autism. *Child and Adolescent Psychiatric Clinics of North America*, *17*(4), 835–856. https://doi.org/10.1016/j.chc.2008.06.011

Payakachat, N., Tilford, J. M., Kovacs, E., & Kuhlthau, K. (2012). Autism spectrum disorders: a review of measures for clinical, health services and cost-effectiveness applications. *Expert Review of Pharmacoeconomics & Outcomes Research*, *12*(4), 485–503. https://doi.org/10.1586/erp.12.29

Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I., & Nardocci, F. (2018). Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison Groups. *Clinical Practice and Epidemiology in Mental Health : CP & EMH*, *14*, 143–176. https://doi.org/10.2174/1745017901814010143

Pierce, K., Glatt, S. J., Liptak, G. S., & McIntyre, L. L. (2009). The power and promise of identifying autism early: insights from the search for clinical and biological markers. *Annals of Clinical Psychiatry : Official Journal of the American Academy of Clinical Psychiatrists*, *21*(3), 132–147. https://pubmed.ncbi.nlm.nih.gov/19758535

Piercy, H., Machaczek, K., Ali, P., & Yap, S. (2017). Parental Experiences of Raising a Child With Medium Chain Acyl-CoA Dehydrogenase Deficiency. *Global Qualitative Nursing Research*, *4*, 2333393617707080–2333393617707080. https://doi.org/10.1177/2333393617707080

Plaisted Grant, K., & Davis, G. (2009). Perception and apperception in autism: rejecting the inverse assumption. *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*, *364*(1522), 1393–1398. https://doi.org/10.1098/rstb.2009.0001

Polit. (2001). *Essentials of nursing research: methods, appraisals and utilization*.

Randall, M., Egberts, K. J., Samtani, A., Scholten, R. J., Hooft, L., Livingstone, N., Sterling-Levis, K., Woolfenden, S., & Williams, K. (2018). Diagnostic tests for autism spectrum disorder (ASD) in preschool children. *The Cochrane Database of Systematic Reviews*, *7*(7), CD009044–CD009044. https://doi.org/10.1002/14651858.CD009044.pub2

Rastelli, S. M. (2006). *Understanding autism for dummies*. Wiley Publishing, Inc.

Reichow, B., Hume, K., Barton, E., & Boyd, B. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *The Cochrane Database of Systematic Reviews*.

Robledo, J., & Donnellan, A. M. (2016). Supportive Relationships in Autism Spectrum Disorder: Perspectives of Individuals with ASD and Supporters. *Behavioral Sciences (Basel, Switzerland)*, *6*(4), 23. https://doi.org/10.3390/bs6040023

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology : The Official Journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53*, *37*(1), 8–38. https://doi.org/10.1080/15374410701817808

Rössler, W. (2016). The stigma of mental disorders: A millennia-long history of social exclusion and prejudices. *EMBO Reports*, *17*(9), 1250–1253. https://doi.org/10.15252/embr.201643041

Rump, K. M., Giovannelli, J. L., Minshew, N. J., & Strauss, M. S. (2009). The development of emotion recognition in individuals with autism. *Child Development*, *80*(5), 1434–1447. https://doi.org/10.1111/j.1467-8624.2009.01343.x

Salkind, N. J. (2010). *Encyclopedia of research design*. SAGE Publications, Inc. https://doi.org/10.4135/9781412961288

Saunders. (2012). . *(). Research Methods for Business Students* . Prentice Hall.

Sauter, D. A. (2017). The Nonverbal Communication of Positive Emotions: An Emotion Family Approach. *Emotion Review : Journal of the International Society for Research on Emotion*, *9*(3), 222–234. https://doi.org/10.1177/1754073916667236

Schriber, R. A., Robins, R. W., & Solomon, M. (2014). Personality and self-insight in individuals with autism spectrum disorder. *Journal of Personality and Social Psychology*, *106*(1), 112–130. https://doi.org/10.1037/a0034950

Showkat, N., & Parveen, H. (2017). *In-depth Interview*.

Srinath, S., Jacob, P., Sharma, E., & Gautam, A. (2019). Clinical Practice Guidelines for Assessment of Children and Adolescents. *Indian Journal of Psychiatry*, *61*, 158–175. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_580_18

Stefanatos, G. (2008). Regression in autistic spectrum disorders. *Neuropsychol Rev.*, *18*(4), 305–319.

Steven, O. M., & Rubenstein, J. L. R. (2006). *Understanding Autism From Basic Neuroscience to Treatment*. CRC Press.

Stroth, S., Paye, L., & Kamp-Becker, I. (2019). *Empathy in Females With Autism Spectrum Disorder. Front Psychiatry*. *10*(428).

Subramanyam, A. A., Mukherjee, A., Dave, M., & Chavda, K. (2019). Clinical Practice Guidelines for Autism Spectrum Disorders. *Indian Journal of Psychiatry*, *61*(Suppl 2), 254–269. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_542_18

Sumiya, M., Igarashi, K., & Miyahara, M. (2018). Emotions surrounding friendships of adolescents with autism spectrum disorder in Japan: A qualitative interview study. *PloS One*, *13*(2), e0191538–e0191538. https://doi.org/10.1371/journal.pone.0191538

Tadayon Nabavi, R. (2010). *Research Method Design*.

Taderera, C., & Hall, H. (2017). Challenges faced by parents of children with learning disabilities in Opuwo, Namibia. *African Journal of Disability*, *6*, 283. https://doi.org/10.4102/ajod.v6i0.283

Tadesse, A. (2014). Families Living With a Child Diagnosed With Autism: Challenges and coping mechanisms. *Addis Ababa University Press*.

Tekola, B., Baheretibeb, Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C., & Hoekstra, R. A. (2016). Challenges and opportunities to improve autism services in low-income countries: lessons from a situational analysis in Ethiopia. *Global Mental Health (Cambridge, England)*, *3*, e21–e21. https://doi.org/10.1017/gmh.2016.17

Thabtah, F., & Peebles, D. (2019). Early Autism Screening: A Comprehensive Review. *International Journal of Environmental Research and Public Health*, *16*(18), 3502. https://doi.org/10.3390/ijerph16183502

Theses, E., & Villar, A. Del. (2018). *Effects of Autism Spectrum Disorder on Mothers*.

Thomas, P., Liu, H., & Umberson, D. (2017). Family Relationships and Well-Being. *Innovation in Aging*, *1*(3), 1–11. https://doi.org/10.1093/geroni/igx025

Thomas, S. K. (2016). Autism Spectrum Disorder: Primary Care Principles. *American Family Physician*, *94*(12), 972–979.

Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the Field: Differentiating Intellectual Disability From Autism Spectrum Disorder. *Frontiers in Psychiatry*, *10*, 1–10. https://doi.org/10.3389/fpsyt.2019.00526

Veague, H. B. (2010). *psychological problems; autism*. Chelsea House Publishers.

Ventola, C. L. (2010). Current Issues Regarding Complementary and Alternative Medicine (CAM) in the United States: Part 1: The Widespread Use of CAM and the Need for Better-Informed Health Care Professionals to Provide Patient Counseling. *P & T : A Peer-Reviewed Journal for Formulary Management*, *35*(8), 461–468. https://pubmed.ncbi.nlm.nih.gov/20844696

Vohr, B., Poggi, D. E., Wanke, C., & Krebs, N. (2017). Neurodevelopment: The Impact of Nutrition and Inflammation During Preconception and Pregnancy in Low-Resource Settings. *Pediatrics (Review)*.

Weiss, J. A., Wingsiong, A., & Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism : The International Journal of Research and Practice*, *18*(8), 985–995. https://doi.org/10.1177/1362361313508024

Weitlauf, A., McPheeters, M., & Peter, B. (2014). *Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update Agency for Healthcare Research and Quality (US)*.

WHO. (2019). *Autism spectrum disorders*.

Xu, G., Strathearn, L., Liu, B., & Bao, W. (2018). Prevalence of Autism Spectrum Disorder Among US Children and Adolescents, 2014-2016. *JAMA*, *319*(1), 81–82. https://doi.org/10.1001/jama.2017.17812

Zerbo, O., Yoshida, C., Gunderson, E., Dorward, K., & Croen, L. (2015). *Interpregnancy Interval and Risk of Autism Spectrum Disorders. Pediatrics*. *136*(4), 651-657.

Zhou, W., Liu, D., Xiong, X., Xu, H., & Manchia, M. (2019). Emotional problems in mothers of autistic children and their correlation with socioeconomic status and the children's core symptoms. *Medicine (United States)*, *98*(32). https://doi.org/10.1097/MD.0000000000016794

Zuckerman, K. E., Lindly, O. J., Bethell, C. D., & Kuhlthau, K. (2014). Family impacts among children with autism spectrum disorder: the role of health care quality. *Academic Pediatrics*, *14*(4), 398–407. https://doi.org/10.1016/j.acap.2014.03.011

APPENDICES

Appendix A: Interview Guide for Mothers of Children with Autism

Part I: Back ground information about mothers

1. Age__________

2. Marital Status: Married ________ Single________ Divorced________

Widowed_________ have

3. Educational Level: Literate_______ Primary education ________ Secondary

Education_________ Collage and above_______ Illiterate ______________

4. The standard of living of the family to accommodate the child____________

5. Occupation:

a. Employed at governmental organization_________

b. Employed at private or NGO________

c. Daily laborer_________

d. House wife_________

e. Business person______

f. Others (specify)_______

6. How many Children do you have? Do you have other child with developmental problem?

____

Back ground information about the child with autism

· Sex: M_______ F_______

· Age ________

· Birth order __________

· Age when first diagnosed with autism_____________________

Appendix B:In-depth Interview Guide: Amharic Version

የቃለ ምልልስ ጥያቄዎች

1. ልጅዎ ኦቲዝምጋር እንደሚኖር ካወቁ ምን ያክል ጊዜ ይሆናል ?
2. ልጅዎ ወደ ጆይ የኦቲዝም ማዕከል ከገባስ ምን ያክል ጊዜው ነው ?
3. ከኦቲዝም ጋር የሚኖሩ ልጆችንና ሌሎች ልጆችን በማሳደግና በመንከባከብ መካከል ያለው ልዩነት ምንድን ነው ?
4. ከኦቲዝም ጋር የሚኖሩ ልጆችን በማሳደግና በመንከባከብ ሒደት ውስጥ የእናቶች ሚና ወይም ሐላፊነት ምንድን ነው?
5. በተራቁጥር 4 ላይ የገለጹት ሐላፊነት በራሳቸው በእናቶች ኑሮ ወይም ህይወት ላይ ምን አይነት ተጽዕኖ ወይም ጫና አለው? ኢኮኖሚያዊ ፣ ማህበራዊ ፣ ስነልቦናዊ ወይም ሌላ ?
6. እናቶች በተራ ቁጥር 4 ስር የተገለፀውን ሐላፊነት እና በተራ ቁጥር 5 የተገለጸውን ጫና በራሳቸው አቅም መወጣትና መቋቋም ይችላሉ ብለው ያስባሉ? ቢያብራሩት ?
7. እርስዎ ልጁዎትን ወደ ማዕከሉ ሳያስገቡ በፊት እናቶች ኦቲዝም ያለባቸውን ልጆች በማሳደግና በመንከባከብ ሒደት የ3ኛ ወገን ድጋፍ ያስፈልጋቸዋል ብለው አስበው ያወቃሉ ? እንዴት? ምን ዓይነት ድጋፍ?
8. ልጅዋን ወደ ጆይ ኦቲዝም ማዕከል ያስገቡት እንዴትና በምን ምክንያት ነው?
9. ልጅዎን ወደ ማዕከሉ ለማስገባት ሲወስኑ ወይም ባስገቡት ወቅት ከማዕከሉ አገኛለሁ ብለው ያሰቡት ጥቅም ምንድን ነበር ?
10. ልጅዎት ወደ ማዕከሉ በሚገባበት ወቅት ማዕከሉ የሚሰጠው አገልግሎት ከልጅዎ ባለፈ ለእርሰዎ እንደሚጠቅም አስበው ያውቃሉ? ምንምን ጥቅም?
11. ለልጅዎ በማዕከሉ የሚሰጡ አገልግሎቶች ምንምን እንደሆኑ ቢገልፁልን?
12. ለእርስዎ በማዕከሉ የሚሰጡ አገልግሎቶች ካሉ ምንምን እንደሆኑ ቢገልፁልን ?

13. በማዕከሉ ለእርስዎም ሆነ ለልጅዎ የሚሰጡት አገልግሎቶች /ተራ ቁጥር 11 እና 12/ በእርስዎ ኑሮ እና ህይወት ላይ ምን ዓይነት ውጤት አላቸው /…….? ማህበራዊ ፣ኢኮኖሚያዊ ፣ ስነልቦናዊ፣ ሌላ
14. በማዕከሉ የሚሰጡት አገልግሎቶች በህይዎትዎ ላይ የፈጠሩትን /ያመጡትን ለውጥ መጀመሪያ ልጅዋን ወደ ማዕከሉ ሲያስገቡ ካሰቡት አንፃር እንዴት ያነፃጽሩታል? በዝርዝር ቢገልጹልን?
15. ልጅዎ ወደ ማዕከሉ ከገባ/ች በኋላ በእርስዎ ህይወት ላይ ለውጥ ካለ ቢገልጹልን ?
16. ልጅዎ ወደ ማዕከሉ ከመግባቱ በፊትና ከገባ በኋላ በእርስዎ ህይወት ላይ ያለውን ማህበራዊ ፣ ኢኮኖሚያዊ ፣ስነልቦናዊና ሌላ ለውጥ በንጽጽር ቢገልጹልን?
17. በአጠቃላይ ከእርስዎ ልምድ በመናሳት የኦቲዝም ማዕከል ልጆቻቸው ከኦቲዝም ጋር ለሚኖሩ እናቶችና ምን ይጠቅማል ?
18. ተጨማሪ መግለጽ የሚፈልጉት ነገር ካለ?

ቃለ ምልልሱን ጨርሰናል! እናመሰግናለን!

Appendix C: Focus Group Discussion Guide: Amharic Version

<u>የመወያያ ጉዳዮች /ጥያቄዎች/</u>

1. ኦቲዝም ያለባቸው ልጆች እናት መሆን ወይም ማሳደግ ምን አይነት የስነ ልቦና ማህበራዊ ኦኮኖሚያዊ እና ሌሎች ተያያዥ ተፅዕኖዎች አሉት ?
2. በተራ ቁጥር አንድ ላይ የተጠቀሱት ነገሮች በእናቶች ህይወት ላይ ጫና አለው ? ካለው ምን ዓይነትና በምን ያክል ደረጃ?
3. ልጅዋን ወደ ማዕከሉ ከማስገባትዋ በፊት ወይም በሚያስገቡበት ጊዜ ከማዕከሉ ምን ዓይነት አገልግሎት አገኛለሁና በህይወቴ ላይ ምን ዓይነት ለውጥ ይፈጥራል አስበው አበር?
4. ወደ ማዕከሉ ካስገቡ በኋላ ማዕከሉ ለእርሰዎ እና ለልጅዎ ምን አይነት አገልግሎት እየሰጠ ይገኛል?
5. በተራ ቁጥር 4 ላይ የገለፃቸው አገልግሎቶች በህይወትዋ ላይ የፈጠረው ለውጥ አለ? ካለ ምን ዓይነት ነው ? መጀመሪያ ልጅዋን ሲያስገቡ ካሰቡት አንፃር በተለይ እንዴት ይገልፁታል ?
6. በጠቅላላው ልጅዋን ወደ ማእከሉ ከማስገባትዋ በፊትና ካስገቡ በኋላ ያለዋትን ሁኔታ በመገምገም የኦቲዝም ማእከሉ ኦቲዝም ላለባቸው ልጆች እናቶች ጠቀሜታ /አስተዋፆኦ አለው ብለው ያስባሉ ? መልስዎ አወ ከሆነ ጠቀሜታዎቹ ምን ምን እንሆኑ በዝርዝር ይግለፁልን።

* * *

በውይይት ውስጥ ንቁ ተሳታፊ በመሆን ሀሳባችሁንና ስሜታችሁን ስላጋራችሁን ከልብ እናመሰግናለን፡

Appendix D: Mothers Agreement Form and Short Discription: Amharic Virsion

ህሊና መሸሻ እባላለሁ። በአዲስ አበባ ዮኒቨርስቲ የሶሻል ወርክ የድህረ ምረቃ ተማሪ ስሆን የመመረቂያ ጥናት በማከናወን ላይ እገኛለሁ። የመመረቂያ ጥናት የኦቲዝም ማዕከላት ኦቲዝም ላለባቸው ልጆች ወላጆች ውስጥ ለማሳተፍ እናቶችን ኦቲዝምላለባቸው የኦቲዝም ማዕከል እንዲስፋፋ ለማድረግ ያግዛል ተብሎ ይታመናል።

እርሰዎም በዚህ ቃለ ምልልስ ወቅት ለሚነሳው ጥያቄዎች ትክክለኛና ግልፅ የሆኑ መልሶችን እንዲሰጡ እየጠየኩበቃለ - ምልልስ ወቅት ኦቲዝም ካለበት ልጅዎ ፣ ከእርስዎ ፣ ከቤተሰብዎ እና ከኦቲዝም ማዕከሉ ጋር የተያያዙ ጥያቄዎች እንደሚነሱ አስገነዝባለሁ ። በቃለ ምልልሱ መልስ የሚሰጡት እርሰዎ በተረዱት መጠን ብቻ ሲሆን ያልፈለጉትን ጥያቄ ያለመመለስና መብት እንዳለዎት ቃለ መጠይቁን በየትኛውም ስርዓት ማቋረጥ እንደሚችሉ እገልፃሁ።

በዚህ ምልልስ የሚሰጡ መልስ ለጥናቱ አላማ ብቻ የሚውል ፣ በሚስጥር የሚያዝ እና በምንም ሁኔታ ማንነትዎ የማይገልፅ መሆኑንና ቃለምልልሱ በድምጽ የሚቀዳና ወዲያውኑ ወደ ጽሁፍ ተገልብጦ የድምጽ ቅጂ የሚሰረዝ መሆኑን አሳውቃለሁ። ቃለ - ምልልሱም ከ30 እስከ 45 ደቂቃ ሊፈጅ ይችላል።

ከላይ የተመለከተውን ማብራሪያ አንብበውና ተረድተው ለቃለ ምልልሱ ፍቃደኛ ከሆኑ ቀጥሎ ባለው ማረጋገጫ ፊርማዎን እንዲያስቀምጡ እጠይቃለሁ። ከልብ አመሰግናለሁ።