

Resources in raising a child with autism in Ethiopia: parents' perspectives

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Thesis submitted in partial fulfilment of the requirements for the degree

Master of Philosophy in Health Promotion, University of Bergen, 2016

Department of Health Promotion and Development

Faculty of Psychology

University of Bergen

Acknowledgement

At first, I would like to extend my heartfelt thanks to my remarkable supervisor, Marguerite Daniel, for guiding me through every step of my education. I am very grateful for your continuous effort in providing me helpful feedback on my thesis work from the beginning until the end. I deeply appreciate how you have always found time to meet and discuss with me to answer all my questions. You have taught me so much that I will take with me and also share with others. I also want to thank all the lecturers and tutors from the HEMIL centre for all their contributions in making this course a great course, and for inspiring me through their work.

Secondly, I would like to thank all my study participants both at Nia Foundation and Nehemiah Autism Center in Addis Ababa, Ethiopia. All of you were amazing group of people that dedicated your precious times to willingly respond to my interview questions and discuss your personal stories with me. I could not have completed this thesis work without your participation. Thank you very much also to the owners and staff of Nia Foundation and Nehemiah Autism Center for allowing me to collect my data at your organization and also for facilitating my data collection process.

I would also like to thank all my fellow students in my department for making my times in Bergen wonderful and memorable. I feel lucky to have met and conversed with such diverse group of people.

I owe a great thank you to my mother, Shewaye Abebe and my sisters, Senetibeb Birhanu and Hagnesh Abebe for your continuous support all the time.

At last, I would like to thank the Norwegian State Educational Loan Fund (Lånekassen.) I couldn't have attended my Master's study at University of Bergen without their financial support.

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Abstract

Background: This thesis contributes to the topic of autism in an African context by studying the experiences of parents raising a child with autism in Addis Ababa, Ethiopia. The majority of publications that focus on autism are based on studies conducted in North American and European nations. There are limited publications available on the topic of autism in an African context and these publications rarely address autism from parents' perspective.

Ethiopia is a nation located in Eastern Africa. The number of children affected by autism is continuously growing in Ethiopia while the awareness of autism in most Ethiopian communities is low to non-existent. In these communities, developmental disorders such as autism are regarded as an evil-spirit phenomenon. In Ethiopia, in addition to emotional and financial challenges, parents raising a child with autism suffer from lack of autism awareness in their communities. This thesis will explore culturally sensitive parent coping mechanisms that would allow managing autism for families in Ethiopia.

Objective: The general objective of this research is to explore the experiences of parents raising a child with autism. The following four research questions are addressed. What were the stressors experienced by parents when finding out about the disorder of their child? What Generalized Resistance Resources (GRRs) do parents identify that strengthened them to cope with situation? Were there any consistent behaviors of the child that contributed for better understanding about the situation? Was there identifiable SOC in the coping process of the parents?

Theoretical framework: For this study Salutogenesis theory was applied, which focuses on the resources that create health rather than focusing on what causes disease. Salutogenesis theory has two main components: Generalized Resistance Resources (GRR) and Sense of Coherence (SOC). By exploring the strengthening and positive resources available to parents that are raising a child with autism, it was possible to identify coping mechanisms that allow for the health and well-being of families with autism.

Methods: This study employed a qualitative research method to acquire understanding of a certain phenomenon through exploration instead of measurement. Among the various approaches used in a qualitative research method, a phenomenological approach was implemented in this study in order to facilitate the understanding of parents' experiences of raising a child with autism as viewed by the parents themselves. Data collection for this study was conducted in two organizations located in Addis Ababa, Ethiopia. The data were collected

through focus group discussions, individual interviews and observations during a three-month period from mid-June to mid-September 2015. Fifteen parents of children with autism and four staff were enrolled in the study. All the interviews were conducted in the local language, Amharic. Therefore, the transcription step involved two steps; transcribing recordings to Amharic and then translating to English. The data were analyzed using the method of thematic network analysis. Permission to do the study was obtained from the required organizations in Ethiopia and Norwegian Social Science Data Services (NSD). Informed consent was obtained from all the participants prior to conducting interview.

Results and discussion: The experiences of parents were grouped into initial stressors and ongoing stressors. All parents reported that their initial stressor was their first experience of observing unusual behavior in their child. After the initial stressor, parents continue to feel additional challenges of raising their child with autism also termed as ongoing stressors. Most parents reported that their ongoing stressors arise from financial constraints and social isolation. Most parents kept their child's situation a secret to avoid stigma, however, some reported to have shared their child's situation to some friends.

When asked about their positive resources, most parents indicated that knowledge and understanding of their child's condition helped them to accept the situation and become stronger. All parents also reported that their belief system is one of their strong resources. In addition, the role of special schools for children with autism was also reported by parents as one of their positive resources. These schools hold monthly meeting for parents to discuss their experiences. Most parents reported that this monthly meeting with other parents who are in the same situation is an important coping mechanism.

Conclusions: The major stressors that were highlighted by participants in this study are the lack of awareness about autism in the society and the lack of facilities designed for children with autism. In relation to positive resources, all parents agree that the two organizations are major resources. Some parents reported financial stability as being an important resource. In addition to external resources, parents highlighted that full acceptance of their child's situation is the most important resource in their coping process. Several of the participants can be said to have built a strong sense of coherence, which is related to the strong belief that they will overcome various types of stressors and build a healthy lifestyle.

List of acronyms

APA - American Psychiatric Association

ASD - Autism Spectrum Disorder

DSM - Diagnostic and Statistical Manual for Mental Disorders

FGD - Focus Group Discussion

GRRs - Generalized Resistance Resources

NSD - Norwegian Social Sciences and Statistics Data

SOC - Sense of Coherence

SRRs - Specific Resistance resources

UN - United Nations

1. Introduction

1.1 Background

Parents raising a child with a disorder such as autism face various challenges in managing the regular parental tasks with the additional responsibilities posed on them due to the situation of their child. Such parents might encounter emotional hardships before they can find the necessary coping mechanisms (Paster, Brandwein, & Walsh, 2009). These parents will go through emotional hardships such as sadness and shock which may lead to anxiety and stress. In addition to their personal struggle, they might also face different kinds of hardships that arise from their society (Paster et al., 2009). Moreover, issues related with the diagnosis and treatment of their child bring additional responsibility on these parents (Johnson, Frenn, Feetham, & Simpson, 2011). Recently, some scholars have continued to debate why publications related to parenting a child with a disorder emphasize so much on the stress factors of parents instead of focusing on ways parents could cope with the situation of their child. Although parents face challenges, other dimensions related with raising a child with a disorder should also be studied and shifting the focus towards parental adjustment to the situation is vital (Barak-Levy & Atzaba-Poria, 2013).

Autism is a neurodevelopmental disorder which refers to those disorders that are noticeable during the early stages of a child's development, often before the child enters school. These disorders are characterized by developmental deficits that impair the normal personal, social, academic and occupational functioning (American Psychiatric Association, 2013). The main signs of autism are demonstrated by impairment in social communication and social interaction, restricted and repetitive patterns of behavior, interests, or activities. These symptoms are normally present from early childhood and may limit everyday functioning of the child (American Psychiatric Association, 2013). Impairment in social interaction and communication are the main manifestations of a child affected by autism. Depending on the developmental stage of the child, additional manifestations such as hyperactivity, aggression and delayed toilet training might also be used as further explanation to the disorder (Neff & Faso, 2014). Although some forms of the disorder can be noticed earlier, autism is observed when a child turns two years old. As immediate care givers, parents are usually the first to recognize the symptoms of their child. The symptoms include poor eye contact, poor communication and social skills (Strock, 2007).

The majority of official reports regarding the prevalence of autism are from United States. According the report by Centers for Disease Control and Prevention (2014), in United States 1 in 68 children are believed to be identified with Autism Spectrum Disorder. In the African context, very few publications discussed the presence and clinical manifestations of autism, however, official estimation of the prevalence of the problem in African context is not yet available (Dixon, Badoe, & Owusu, 2015). For many years, autism was strongly regarded as a disorder that only exists in developed nations. This created a knowledge gap in developing countries such as Africa and made it difficult to provide a solid conclusion about the extent of the problem in most African countries (Bakare & Munir, 2011). In Ethiopia, except predictions provided by some non-governmental organizations, publications about the exact number of children affected by autism is non-existent. Although clear data regarding the prevalence are not yet available in Ethiopia, few private organizations are providing service to children affected by autism. There are two private organizations namely Nia Foundation-Joy center and Nehemiah Autism Center both located in Addis Ababa, Ethiopia. These organizations have been functioning in Addis Ababa for the last few years providing various services to children with autism and their parents.

This study is conducted with parents raising a child with autism in Ethiopia. Ethiopia is a country located in East Africa commonly referred as the Horn of Africa. The country has the second largest population in Africa with an estimated population size of 90 million (Bertelsmann Stiftung, 2016). Ethiopia is among the many countries that ratified the United Nation's (UN) convention on the Rights of Children. The articles complied in this UN Convention, highlights Children's rights that should be ensured for every child in the world. Among these rights are the right to education and right to good quality health care. In the handbook of child rights in Ethiopia prepared by Alemu and Birmeta (2012), the Ethiopian constitution recognizes the rights of children in various aspects among which are the right to know and be cared for by parents and the right to education. The constitution prohibits the infliction of corporal punishment or cruel and inhumane treatment in schools and other institutions responsible for the care of children. However, the applicability of the rights of children in Ethiopia, specifically children born with a certain type of disorder still remains a question.

1.2 Problem statement

According to the description provided by Nia Foundation, the rough estimation of children in Ethiopia that are affected by autism reaches up to 500,000 (Nia Foundation, 2002). This is a concerning figure that requires immediate attention from various groups within a society. The awareness of autism in most Ethiopian communities is low to non-existent. Developmental disorders such as autism are generally attributed to an evil spirit. Due to such spiritual attributions, children with autism are tied up, locked in dark rooms and deprived of their basic rights (Dirbsa, 2013). The impact of autism is not only limited to the children but it also affects parents in several ways. Parents of children with autism are driven to believe that the situation of their children is due to their past sins. As a result, parents blame themselves for their children's disorder (Aynalem, 2014). In most cases, parents' lack of awareness about autism hinders them from searching appropriate diagnosis and treatment for their children. Although there are some parents who are aware enough to send their children to school, most schools may not have a special arrangement for children with autism. In Ethiopia, schools designed to specifically serve children with autism are very few in number compared to the demand of parents to send their children to these schools. Furthermore, these special schools may not be affordable for many parents which adds additional burden for them. In addition, the lack of awareness of autism in a society makes it challenging to provide a conducive environment for children with autism. This results in the children experiencing hostile relationships and isolation from their communities.

1.3 Relevance of the study

Even though there are a large number of autism cases estimated in Ethiopia, the amount of research conducted in that area is limited. There exists a huge research gap specifically on areas related to the perspective of parents who are striving for the better functioning and integration of their children into the larger society. Despite all the societal influences and discriminations, some brave parents still struggle to take their children to school.

The widely accepted definition of health describes health as a state of the physical, mental and social wellbeing (Smith, Tang, & Nutbeam, 2006). Having this definition, it is difficult to separate mental health issues and disorders such as autism from the wide ranging health concept. Consequently, mental health issues need to be addressed like all the other aspects of health. This study will attempt to explore the perspectives of parents raising children with autism. Mainly this paper will be significant in contributing to the observed research gap in this

specific area. In addition, this paper will shed light by exploring culturally sensitive parent coping mechanisms in managing autism for families in Ethiopia.

1.4 Literature review

A large body of research regarding the prevalence of autism has been conducted in United States and other developed countries within the last decades. More research regarding autism contributed to enhanced awareness about the condition in the developed countries (Elsabbagh et al., 2012). Specifically research related with prevalence, clinical manifestations and individuals with autism and other psychiatric disorders has been conducted in the United States. However, most of the publications focus on individuals with the disorder and publications emphasizing on parents raising a child with developmental disorders are still scarce compared to the individual studies (Dykens, 2015). In the past few decades, autism was assumed to be a rare condition that specifically occurs in the western world and its prevalence in developing continents such Africa was debatable. As result, a clear figure regarding the prevalence and manifestation of the disorder in African countries is not yet accessible (Bakare & Munir, 2011). Although consideration about autism has been enhanced in African countries with in the last few years, cultural differences of defining autism in African context has not yet been addressed (Nyarambi & Enwefa, 2011). Even though some studies in Western and Northern part of Africa exist, a huge research gap still exists in Sub-Saharan Africa. Samadi and McConkey (2011) also highlight there is limited information on the identification of children with autism in less affluent countries. Most research in autism has been conducted in affluent English-speaking countries. Being considered as less affluent country, Ethiopia is not an exception for this lack of research about childhood developmental disorders such as autism. Very few publications regarding autism are accessible in Ethiopian context. For instance Master's thesis conducted by Aynalem (2014) viewed the challenges and coping mechanisms of families living with a child diagnosed with autism. Another similar study by Daniel (2014) explored Psychosocial impacts of autism on families and their perceptions on the supports provided at Nia Foundation. The two studies selected Nia foundation as the a site to conduct their study. The perspectives of parents from another service provider can provide a wider view regarding the issue under investigation. In addition, application of Sautogenesis theory can also supplement studies related with autism through shifting the focus towards health.

1.5 Terminology

When researching about the subject of autism, one might come across various terms used to identify the disorder. In some publications, it is termed as *autism*; some writers use *autism*

spectrum disorder and autism interchangeably; other writers use the term *autistic disorder*. According to American Psychiatric Association (2013), Autism Spectrum Disorders (ASD) is a collective name provided to a range of developmental disorders including Autistic disorder (Autism), Asperger Syndrome, Pervasive Developmental Disorder, Childhood disintegrative disorder and Rett syndrome. This study is mainly focused on Autistic disorder (autism) which is considered as the most severe form of ASD (Gentile et al., 2013) These four disorders were separated to promote accurate diagnosis, although they share several similar symptoms. For the purpose of this study, the general and more commonly used term ‘autism’ will be used.

1.6 Objectives and research questions

Overall objective

To explore parents’ experience of raising a child diagnosed with autism.

Sub objectives

- To explore the initial and ongoing stressors experienced by parents after the diagnosis of their child with autism
- To investigate resources that contributed to strengthen parents after having a child with autism
- To examine the existence of SOC in parents during the process of coping with the situation

Research questions

- What were the stressors experienced by parents when finding out about the disorder of their child?
- What Generalized Resistance Resources (GRRs) do parents identify that strengthened them to cope with situation?
- Were there any consistent behaviors of the child that contributed for better understanding about the situation?
- Was there identifiable SOC in the coping process of the parents?

2 Literature review

This section reviews existing literature in relation to the main concept and the research questions of the present study. First, a brief review of literature regarding the history and definition of autism is presented in order to provide an overall understanding of the condition. Afterwards, literature in relation to the experiences of parents raising a child with autism is presented. There are numerous studies that have been conducted regarding autism including its diagnosis, symptoms, treatments and its effect on an individual and societal level. However, limited studies are available in the context of African 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 African context.

2.1 History and definition of autism

The word autism, derived from the Greek word 'autos,' refers to self. The word is reported to have been used since the 1900s. Various scholars used the concept of autism linking it to other mental health issues such as schizophrenia. However, the credit of introducing the concept of autism goes to Leo Kanner, who in 1943 conducted a study that marked the difference between autism and schizophrenia. The study Kanner conducted with children revealed clinical conditions such as being aloof and having a language difficulty manifested at an early age of 3 which he termed as infantile autism (Kita & Hosokawa)

Currently, mental health professionals define autism as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) prepared by the American Psychiatric Association. With the emergence of more research about the symptoms of autism, the definition of autism has been revised. The DSM has updated several diagnostic criteria of autism and other mental disorders. The first and second publications of DSM published in 1952 and 1968 respectively, classified autism under a mental disorder termed as a schizophrenic reaction of childhood type that is characterized by symptoms such as disturbances in reality, stream of thought and intellectual abilities (American Psychiatric Association, 1952). The third publication of DSM provided more tangible diagnostic criteria than the previous two publications. This publication categorized autism under disorders of infancy, childhood and adolescence (American Psychiatric Association, 1980). The fifth edition of DSM classifies autism under a group of neurodevelopmental disorders and describes the diagnostic features of autism as impairment in social interactions and communication skills. Impairment in social interactions includes abnormal use of non-verbal behaviors, lack of developing peer relationships, lack of regards for others, etc. Impairments in communication skills involve delay or lack of spoken language

development, inability to sustain conversation, use of stereotyped and repetitive language (American Psychiatric Association, 2013). This edition of DSM uses the term autism spectrum disorder. This term is an umbrella term that includes four separate disorders; autistic disorder, asperger's disorder, childhood disintegrative disorder and the catch-all diagnosis of pervasive developmental disorder.

2.2 Causes and symptoms of autism

Although various factors are believed to cause autism, the etiology of autism is not clearly understood. Several theories have been proposed by scholars about the causes of autism in the past. The most widely known theory was termed as “refrigerator mothers theory” that was proposed by Leo Kanner in the 1940s. According to Kanner, autism may be triggered by the lack of maternal attachment that mothers fail to provide to their infant (Cook & Willmerdinger, 2015). Following the foundation laid by Kanner, Bruno Bettelheim provided an explanation for the theory and proposed psychological factors, stating that specifically mothers who are unloving towards their infant are the main cause of autism. Bettelheim also stressed out that providing therapy to both the mother and the child can improve the situation (Martin, 2012). In today's time, this theory has been discredited in various publications that studied other factors such the biological causes of autism. However, some studies still argue that most of the studies on this topic report mothers as being responsible for the birth of a child with autism. Connotations such as ‘autism mothers’ has played a widespread role in blaming mothers for the situation of their child (Douglas, 2014). Douglas also argues that the parental blaming approach that started with the “refrigerator mother theory” still continued to create other forms of burdens and blames on mothers of today.

Children with autism display certain characteristics that are observed as symptoms of autism by parents. Among the characteristics that are mostly observed are impairments in social interactions and communication skills, repetitive patterns of behavior, interests and activities (Blumberg et al., 2013). According the publication of National Institute of Mental Health, symptoms of autism may differ from one child to another. However, the generally accepted symptoms can be categorized into social impairment, communication difficulties and repetitive stereotype behaviors (National Institute of Mental Health, 2007). In addition to the characteristics mentioned above, there are cases where autism in children co-occurs with other neurological disorders such as epilepsy. Tuchman, Cuccaro, and Alessandri (2010) discussed the historical views regarding the co-occurrence of epilepsy and autism. Although there are cases where epilepsy and autism co-occur, providing a clear explanation regarding their

association is a challenge. It is still not clearly identified if one disorder causes the other or if there are specific genes responsible for the occurrence of each of these two disorders. Others studies also mention the prevalence of other disorders such as epilepsy and intellectual disability in children with autism. Viscidi et al. (2013) also support that intellectual disability and epilepsy co-exist with autism. In children with autism, the onset of epilepsy was recorded to be higher in the first year of life. With the increment of age, the prevalence of epilepsy in children with autism also increases.

The majority of studies on the causes of autism and the criteria set to identify its symptoms have been documented in developed countries. Only a few studies addressed the causes and symptom of autism in developing countries. Ametepee and Chitiyo (2009) mentioned, that the onset and causes of autism in Africa may not necessarily fit the criteria set in developed countries. They suggest that extensive research should be done to address autism in an African context. There are less studies about the extent of the problem in an African context and studies found in sub-Saharan countries are very scarce (Bakare & Munir, 2011). In Africa, Bakare and Munir (2011) mention that traditional herbalists and spiritualists play a major role in treating illness while it is medical professionals that treat illness in developed nations. Such differences in medical treatment approaches between African nations and developed nations make it a challenge to apply the diagnostic criteria set in developed countries as standard criteria to diagnose children with autism in Africa.

2.3 Parents' reaction to child's diagnosis with autism

Parents pass through challenging moments and react in various ways when discovering that their child has autism. The stressful period of time that parents go through can lead them to blame themselves for giving birth to a child affected by autism. Lutz, Patterson, and Klein (2012) conducted their study in United States focusing on mothers' responses to their child's diagnosis with autism. They interviewed 16 mothers, 10 of which were mothers of children with autism and 6 were mothers of adult children with autism. According to their findings, reactions of mothers to their child's diagnosis with autism was grouped into four major groups; grief & anger, dis-ease and relations-ship, guilt and doubt, and disappointment and sacrifice (Lutz et al., 2012). The most common initial reaction of mothers at the time of diagnosis is feeling of sadness and anger highlighted by self-blaming. Mothers also experienced psychological problems such as fear and anxiety during the initial stages of learning about their child's situation. The reaction of denial was reported by some parents as their first reaction to their child's diagnosis with autism while others reported experiencing feelings of shame when

sharing the news of their child's situation to others (Dababnah & Parish, 2013). In their study performed with participants from Iran, Samadi and McConkey explain that parents' immediate reaction after their child's diagnosis with autism was shock and devastation (Samadi & McConkey, 2011).

2.4 Gender discrepancies in raising a child with autism

Most of the existing literature on parental experiences of children with autism often involves the participation of mothers rather than fathers. There are a large number of studies that concentrate on the various stressful situations of mothers raising a child with autism. For instance, in their effort to gather participants for their study that discusses raising a child with autism in West Bank, Dababnah and Parish report that out of a total of 24 participants, 20 of them were mothers and only 4 were fathers (Dababnah & Parish, 2013). Dababnah and Parish explain this to be a limitation on their study as it limits the understanding of fathers' perspectives on raising their child with autism. As mentioned above, studies about parental experiences of raising a child with autism often revolves around mothers. In most traditional societies, a female family member, often mother, takes care of the needs of others in the family and in turn experiences challenges first hand. Gau et al. (2012), in their study comparing psychopathology measures between mothers and fathers of children with autism, found that the mothers of children with autism displayed more psychopathology than did the fathers. According to Iranian culture, mothers are the primary caregivers to children with autism while fathers mainly provide the financial support for the family (Samadi & McConkey, 2011). A study by Lutz et al. (2012) also focused in studying mothers' experiences about their child's diagnosis with autism.

This study also failed to address fathers' experiences; therefore, it provides half the perspectives of parents' responses. Most studies tend to display mothers as vulnerable to the stress that comes along with giving birth to a child affected by autism. However, some studies pointed out that although mothers of a child with autism clearly demonstrate more stress and depression, fathers also tend to express their stress in ways other than depression. For instance, Fido and Al Saad (2013) studied parenting related stress and concluded that mothers are more vulnerable to stress. However, they pointed out that fathers differ in displaying their stress; therefore, there is a need to develop another measure of psychological health for fathers.

2.5 Coping process of parents raising a child with autism

Several studies have discussed about the strategies used by parents to proceed towards accepting the situation of their child. Lutz et al. (2012) discussed coping mechanisms in their model titled,

“Journey Towards Adaptation”. Their model groups coping mechanisms into four major categories: seeking answers, seeking support, socialization and spirituality; appreciating life; and revising dreams and future planning. Mothers in their study mentioned seeking answers as a coping mechanism through educating themselves and seeking for treatments. This helped them to cope with the grief and anger they encounter due to the situation of their child. In addition to the personal attempts, mothers also seek for support, socialization and spirituality as means to cope with their struggle.

Other coping strategy discussed by mothers is focusing on the positive perspectives and developing appreciation of life as their way of dealing with their child’s situation. In imagining of their child’s future, most mothers discuss the importance of accepting the reality and recognizing the limitations that their child can and cannot become. And these mothers explain that they chose to focus on their child’s happiness, safety and functioning above other kinds of dreams. The role of spirituality as a coping mechanism has been highlighted in this study as mothers mentioned how attending church helped them to find support for their struggle (Lutz et al., 2012). The role of spirituality as a coping mechanism for parents raising child with autism was also mentioned in other studies. For instance, Dababnah and Parish (2013), discussed families of children with autism look to their religion and faith in God for their coping processes. These families tend to accept their child’s situation as the will of God.

In their study that interviewed 138 mothers of children with autism, Weiss et al discuss about family hardiness as a coping mechanism used by some parents (Weiss, Wingsiong, & Lunskey, 2013). They define hardiness as a sense of control over stressors and building the ability to endure life’s challenges. According to their results, family hardiness was negatively related to family distress and positively related to perceived social support and self-efficacy. This study also reports the experiences of mothers and do not address that of fathers. In their study of experiences of Iranian parents of children with autism, Samadi and McConkey (2011) mentioned about two forms of coping mechanisms; problem-focused and emotion-focused. They define problem-focused coping as a mechanism of finding strategies to deal with the problem and emotion-focused coping as a mechanism of ignoring problems and wishing they will go away. Most Iranian parents of children with autism practice emotion-focused coping mechanisms while this type of coping mechanism has been correlated with poor health and increased levels of parental stress. Educating parents about diverse and appropriate means of coping mechanisms is a crucial step in their journey of raising their child with autism.

3 Theoretical framework

Salutogenesis theory was applied for this study in order to explore the resources in parenting a child with autism in spite of challenging situations. Salutogenesis theory is aimed at emphasizing peoples' resources to create health instead of focusing on risks, ill health and disease (Lindström & Eriksson, 2005). Aaron Antonovsky developed Salutogenesis theory in 1979 focusing on assets that maintain peoples' strengths under stressful situations. The two main concepts in Salutogenesis theory are generalized resistance resources (GRRs) and sense of coherence (SOC) (Lindström & Eriksson, 2005). GRRs are resources that an individual uses to facilitate successful management of stress (Antonovsky, 1996). For instance GRRs can be money, cultural stability, and social support (Flensburg-Madsen, Ventegodt, & Merrick, 2005). GRRs can be of different types but all are aimed at supporting individuals to perceive the world as meaningful regardless of repetitive stressful stimuli (Antonovsky, 1996). Effective utilization of GRRs for health development leads to acquiring strong SOC (Lindström & Eriksson, 2006). SOC is the perception of an individual to acquire the ability to maintain balance under any stressful situation that leads towards health (Lindström & Eriksson, 2006). SOC can be further described by its three core components: comprehensibility, manageability, and meaningfulness. Comprehensibility refers to understanding various stressors from internal and external environment as predictable. Manageability is the belief of having necessary resources to overcome stressors. Meaningfulness is individuals' perception that the problem is worthy of commitment (Langeland, Wahl, Kristoffersen, & Hanestad, 2007).

According to Lindström and Eriksson (2006), there seems to be a general predictive relationship between strong SOC with movement towards health. Studies in different parts of Europe such as Sweden and France, demonstrated that SOC directly or indirectly predicts good health. However, some findings in Canada demonstrated that SOC might not always be predictor of good health. As a result, further study on SOC is required to confirm its predictive relationship with.

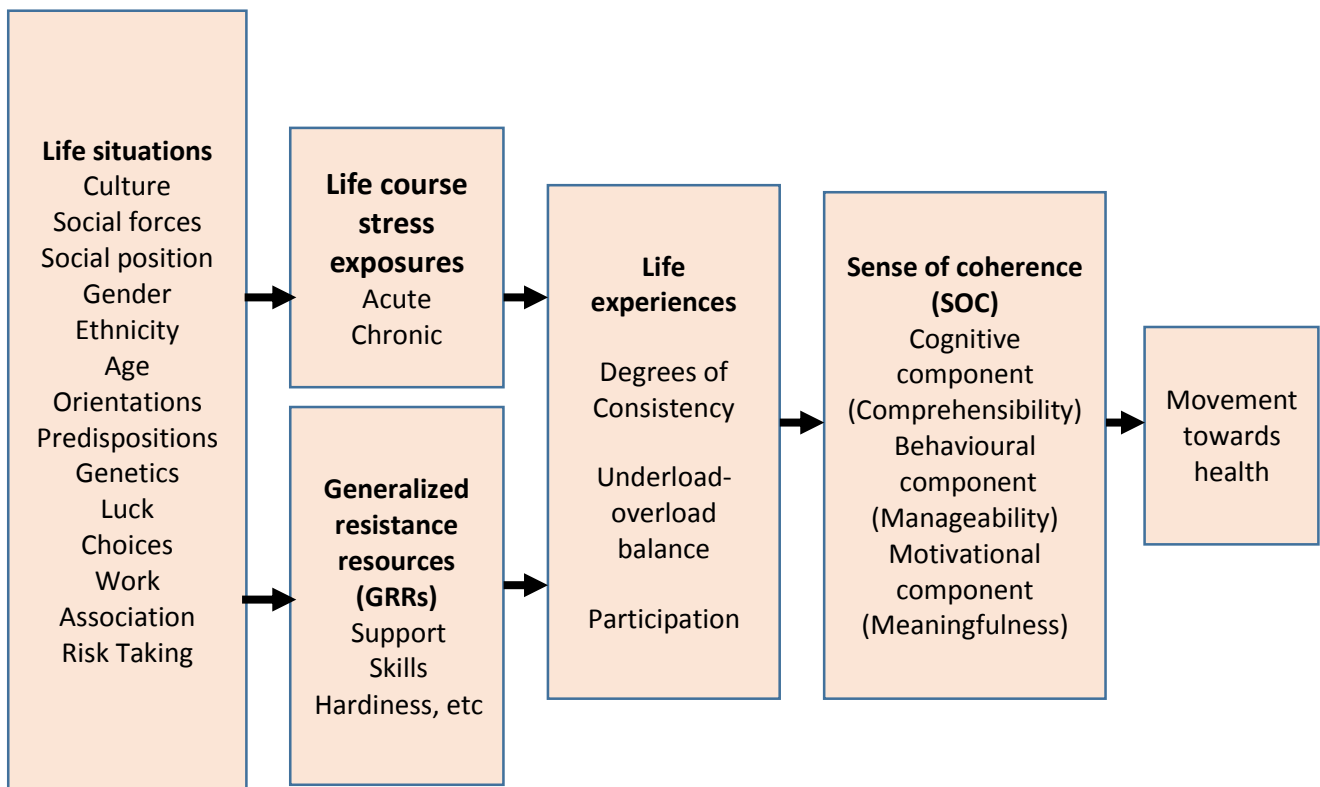


Figure 1: The salutogenic model (adaptation of Mittelmark, 2010)

The model above demonstrates how one's life situation such as culture, social forces, social position, gender, ethnicity, age, genetics and luck, among other factors influence the development of the SOC. These aspects of life situation may give rise to either life course stress exposures or GRRs. For instance, individuals raised in supportive culture will be provided with resources and life experiences necessary to manage stress which leads to perceiving life as comprehensible, manageable and meaningful (Benz, Bull, Mittelmark, & Vaandrager, 2014). Balance between life course stress exposure and GRRs determine the life experiences of an individual. The strength of SOC is shaped by three kinds of life experiences: consistency shows predictable life experiences; underload-overload balance shows balance between resources and stressors; and participation shows involvement in socially valued decision making. When confronted with a stressor, an individual perceives the situation is understandable (comprehensibility), resources are available to cope (manageability) and that it is meaningful to invest effort in engaging challenge (meaningfulness) (Antonovsky, 1990).

As a parent, having a child diagnosed with autism creates several stressors such as societal discrimination and lack of special schools for the children. Weiss, Wingsiong, and Lunskey

(2013), studied mothers raising a child with autism and they highlighted that these mothers often account for high stress levels, anxiety and mental health related issues. Their results demonstrated that parents will face crisis which is distinguished by the disruption of their capacities to cope with the situation indicated by feelings of stress and hopelessness. A Study by Dababnah and Parish (2013) in West bank also demonstrated the vulnerability of parents of a child with autism to various forms of stresses. The stresses mainly arise from community attitudes, negative family environment and financial challenges to meet the demand of their children.

Despite all this difficulties, some parents manage to take their children to school and strive to integrate them with the society. In this study, the existence of GRRs and SOC will be explored from parents' perspective. Internal and external support systems that facilitated their coping processes will be expected to indicate GRRs. The existence of SOC will be explored by its component parts, comprehensibility, manageability and meaningfulness. The parents' responses about the consistent behavior of their child will assist to investigate comprehensibility. Manageability will be assessed through responses about balance between stressors and resources. The involvements of parents in activities that benefit their child are expected to designate meaningfulness. Parents who are able to cope are expected to have strong SOC. Strong SOC indicates that parents are able to tackle stressors and invest their resources to create a conducive environment to their child. The strength of these parents will possibly initiate other parents going through a similar situation and encourage their coping processes.

4 Data and Methods

4.1 Design

This study explored parents' perspectives about raising a child with autism using qualitative research method. Qualitative research was selected for this study with the aim to acquire an in-depth understanding about a certain phenomenon through exploration instead of measurement. The focus of qualitative research is to find explanations for questions such 'what', 'how' or 'why' of an occurrence (Green & Thorogood, 2014, pp. 5-25). Qualitative research investigates a phenomenon considering the context of people's everyday lives. It attempts to understand and explain the world from participants' points of view (Draper, 2004).

One of the approaches of qualitative research, phenomenological approach, is implemented for this study. Phenomenological approach explains the lived experiences of individuals about a phenomenon as described by the individuals themselves (Creswell, 2014). This approach is suited for the current study in order to acquire the experiences of parents raising a child with autism as viewed by the parents themselves. Data collection in qualitative research is conducted using research questions as a system to structure the research. In qualitative research, reality is viewed as socially constructed and findings are expected to consider subjectivity to a certain extent. Qualitative research does not intend to obtain absolute objective findings from the study (Swift & Tischler, 2010).

4.2 Study Area

This study was conducted in two organizations located in Addis Ababa, Ethiopia. The two organizations, namely Nia Foundation-Joy Centre for Autism and Nehemiah Autism Centre, assisted me in participant recruitment and provision of necessary information throughout the study. Nia Foundation is a non-profit and non-governmental organization that provides treatment and education for children with autism. It has been actively working since 2002, reaching out for children with autism in Addis Ababa. In addition to the treatment it provides for children, the Foundation also offers counselling 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.

Nia Foundation has a compound located in a peaceful neighbourhood in Addis Ababa. The compound consists of therapy rooms where various forms of therapies are provided for children with autism. There is also a playground area in the compound for the children to use. The staff

is highly dedicated in training the children to be capable in daily life skills such as toilet training, communication and self-feeding.

The second organization where this study is conducted in is called Nehemiah Autism Center. It is also a non-profit and non- governmental organization that started working in Addis Ababa since 2011. The organization mainly focuses on providing training and treatment to children with autism. It also provides counselling and support to parents interested in the education and development of their child. Furthermore, the organization is involved in developing awareness raising programs in the society. The organization mainly assists parents that lack the financial capacity to cover the treatment of their child with autism by offering free treatment to their child. The compound is located in a refreshing environment. It consists of a playground for the children. The head psychologist of the center played a key role for this study in the recruitment of participants for individual interviews. As mentioned earlier, both organizations are non-governmental organizations founded by self- initiated individuals. Both founders have a child with autism and are striving to reach for parents that are in a similar situation.

4.3 Participants

As mentioned above, this study is a phenomenological study and participant recruitment is aimed to acquire in-depth information. Participants who are expected to provide relevant information for this study have been recruited with certain inclusion and exclusion criteria.

For this study, parents from both organizations and staff at Nia Foundation were recruited as participants. Since my aim in this study is to explore the experiences of parents raising a child with autism, the main participants recruited from both organizations were parents. I also intended to investigate the experiences of the staff in the organizations as the staff work closely with parents. As a result, it was necessary to recruit the staff as participants to provide crucial information. Although time limitation hindered me from accessing the staff at Nehemiah Autism Center, the owner and the staff at Nia Foundation were recruited as participants. Participants were selected with assistance from the head psychologists at Nia Foundation and Nehemiah Autism Centre. These head psychologists played a significant role in serving as gatekeepers at the study site.

The first inclusion criterion was to recruit participants who have a child that is diagnosed with autism and is currently enrolled at these organizations. Therefore, for the first inclusion criteria, parents having a child with other types of childhood disorders were not included in this study.

The second inclusion criterion was to select parents having a child with age two and above. This particular age of a child is chosen based on the description provided by the diagnostic statistical manual for mental disorders (DSM-5). The manual describes autism as a behavioural disorder that is usually manifested after a child turns two years old (American Psychiatric Association, 2013). Although, in some cases, parents report becoming aware of their child's situation since birth, generally the disorder is manifested after a child turns two years.

I intended to look through gender perspectives of raising a child with autism. As a result, participant recruitment also focused on including both mothers and fathers of children with autism. The gatekeepers in the organizations facilitated the recruitment of participants of both genders. Additionally, participant selection also included variety in age groups, economic status and marital status. This was done in order to collect diverse information from individuals of different backgrounds.

Participant	Sex	Age	Marital status	Age of child	Employment status
Lidiya	F	40	Divorced	10	Private job
Azeb	F	35	Married	4 and 4 months	Government job
Hilina	F	38	Divorced	8	Private job
Almaz	F	41	Married	9	House wife
Mekdes	F	37	Married	4	House wife
Tadesse	M	46	Married	6	Government job
Daniel	M	39	Married	4	Private job
Johannes	M	48	Married	10	Government job
Dawit	M	43	Married	5	Government job
Girma	M	46	Married	7	Government job

Table 1. Participants for the individual interview

* All names indicated in the table are pseudonyms

4.4 Methods of data collection

For this study, the main methods applied for data collection were interviews, focus group discussions (FGD) and observations. In total, 15 parents and 5 staff participated in the individual interview and FGD. Specifically, 10 parents from both genders participated in the individual interview. Out of the 10 parents who participated in the individual interview, seven of them were recruited from Nehemiah Autism Centre while three of them were recruited from Nia Foundation. The owner of Nia Foundation was also individually interviewed. Initially, I planned to conduct FGDs with mothers and fathers separately. However, due to some inconveniences that are explained in my data collection procedure, I was able to conduct FGD only with mothers. In addition to parents, the staff at Nia Foundation also participated in FGD. Due to the timing conflicts between my time frame for data collection and the schedule of Nehemiah Autism Center, FGD was not conducted with staff in Nehemiah Autism Center.

In qualitative research, individual interviews are essential to investigate sensitive topics. I used open ended sets of questions to explore participants' experiences through interview. During the interview, the researcher can further clarify the questions in order to direct the participants for further exploration (Tong, Sainsbury, & Craig, 2007). In this study, individual interviews were conducted with parents and the owner of Nia Foundation. I organized sets of questions that cover the main areas of interest (see appendix 5). Individual interview played a key role in allowing participants to freely communicate about their experiences in raising their child affected by autism. For the majority of participants, raising a child with autism is a sensitive topic to discuss and individual interview provided them with the opportunity to talk about their experiences in private.

In the individual interview with parents, the questions addressed the experiences of parents beginning from the onset of their child's diagnosis with autism to the current concerns related to raising their child. Some of the questions were: what were their experiences before the diagnosis of their child with autism? What were their experiences in raising their child after the diagnosis? What resources help them cope with the situation? And, what advice would they provide for other parents that are in a similar situation? The latter question, specifically helped parents to open up more and discuss what they went through so that others can learn from their experiences. The interview guide that I prepared consisted of open ended questions in English. However, all the questions were translated to Amharic, the official working language of Ethiopia. I provided the language options for participants and all of them chose to give the interview in Amharic. This allowed the participants to clearly communicate their ideas and

enabled me to acquire in-depth information from the individual interviews (see appendix 5).

On the other hand, FGD was also conducted to obtain additional views of participants. 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 (Khan et al., 1991). During FGD, the researcher is able to capture diverse information from participants. FGD allows interaction between participants and provides variety of beliefs and opinions regarding the topic of interest (Dilshad & Latif, 2013). In this study, FGDs were conducted with mothers who have a child in Nia Foundation and staff working in Nia Foundation. For the FGD conducted with mothers, I prepared a set of questions designed to capture the social aspects of raising a child with autism instead of personal experiences of participants. The questions were mainly focused on parents' view of the societal perception of autism and how they cope with the challenges they face (see appendix 5). These questions allowed participants to freely communicate their ideas within the group since personal topics were not included in the questions. Prior to conducting the FGD, I attempted to create a conducive environment for participants to facilitate an open discussion within the group.

4.5 Setting

My initial plan was to use the two organizations as settings to conduct my data collection. However, participants preferred various venues to conduct the individual interview. I was assisted by the head psychologists to collect the addresses of each of the participants. Afterwards, I travelled to the selected venues by the participants. Some participants preferred to conduct the interview in their homes while others preferred to be interviewed at their work places. A few of the interviews were conducted in coffee shops as some participants were able to assign some time out of their busy schedule during weekends.

The two FGDs were conducted in the compound of Nia Foundation. To conduct the FGD, the head Psychologist at Nia Foundation assigned a head teacher that closely works with parents. I was aided by this head teacher to access mothers for the FGD during the monthly parent meeting. The FGD with mothers took place in one of the rooms at the Foundation. The quiet setting of the room facilitated a smooth communication between me and the participants in the FGD. The second FGD with staff at Nia Foundation also took place in one of the therapy rooms in the Foundation. Initially, the head psychologist prepared a venue in the compound of the Foundation. However, since the FGD was conducted on weekdays during breaks, it was decided that it will be loud to conduct the interview with the children playing outside. Hence,

the FGD with the staff took place in one of the therapy rooms which was a relatively quiet setting to easily communicate with the interviewees.

4.6 Data collection procedures

To conduct the individual interviews, I travelled to various venues selected by participants. Individual interviews were conducted with 10 parents from different social and economic backgrounds. Moreover, I conducted an interview with the owner of Nia Foundation. Prior to conducting the interview, I translated the interview questions and the consent form into Amharic language. After translating took place, I began scheduling appointments with participants. Since some participants lived far away from my residence, transportation challenges delayed me from being punctual to some of the interviews. However, I was able to conduct all the individual interviews with the cooperation of the interviewees. The individual interview with the owner of Nia Foundation was conducted in the owner's office. Although the owner of the Foundation has a busy schedule, I was able to find time to conduct the interview after several rescheduling of appointments.

The parent meeting that takes place every month at Nia Foundation provided me with the opportunity to access parents at the same location. The head psychologist at Nia Foundation assigned a head teacher that works closely with parents to help me facilitate FGD with parents as they come to the organization to attend the monthly meeting. The head teacher played a key role in the selection of mothers to participate in the FGD and assisted by providing an explanation to mothers regarding their roles in the FGD. After the necessary preparations were completed, I was able to conduct the FGD with the mothers before they start their monthly meeting. The participants in the FGD knew each other and comfortably discussed their ideas in front of each other.

Initially, I planned to conduct FGD with fathers on the same day after the monthly meeting took place. However, the meeting lasted longer than anticipated and the majority of the parents left the compound right after the meeting. Those that remained after the meeting were not willing to spend extra time to participate in the FGD. Since the full willingness of participants is necessary to collect data, I refrained from conducting FGD with fathers on that day. I planned to conduct the FGD with fathers some other time. However, inaccessibility of fathers made it challenging to gather them for FGD. I realized that most fathers are often the breadwinners in their families and are occupied at work most of the time. Due to the reasons outlined above, it was not possible to conduct FGD with fathers as initially planned.

Conducting FGD with staff at Nia Foundation was relatively an easier task compared to the other data collection procedures. As the staff who participated in the FGD were therapists at the organization, they were always accessible and are well informed about autism. This facilitated a smooth communication between me and the participants.

Although observation was not used as a specific method on its own, it was part of the study throughout the process. I was able to capture essential nonverbal cues from participants while conducting interviews and FGDs. Moreover, I conducted some of the individual interviews in the participants' residence in the presence of their child affected by autism. I had the opportunity to directly observe the participants' interaction with their child. I was also able to observe how the staff interact with parents at the organization. This was provided me additional views that are used to enhance the findings of this study.

I used a tape recorder during the interview and the FGD. The recording was performed in order to record all the necessary information without missing important points. In addition, using the tape recorder allowed me to be fully engaged with participants during the interview and FGD without interruption to record responses.

4.7 Data management and analysis

The data gathered were manually transcribed by me. Since I conducted the interview in a local language, transcription included two steps. The first step was transcribing directly from the native language and the second step was translating it to English. The transcribed data were carefully kept in a password protected personal computer and it is accessible only by the researcher and the supervisor during the study period. A back-up of the transcribed data was saved in a memory stick and kept in a place that can only be accessed by the researcher.

There are various data analysis methods in qualitative research. For this study, thematic network analysis was used as a main method of data analysis. Thematic network analysis is a form of analyzing text data though systematically organizing themes from a text into a web like network structure. Thematic network analysis takes series of steps to organize themes from a text into a network that will later be used for interpretation (Attride-Stirling, 2001).

In this study, the following series of steps were used to analyze the data.

Step one: Understanding the transcriptions

After the data transcription took place, I repetitively read through the interviews and FGDs and also listened to the recordings. I also referred to notes taken from observations during the data collection. This allowed me to attain the necessary preparation prior to coding the data.

Step two: Coding the data

After being familiar with the data, coding took place. Coding the data involved grouping the data into meaningful pieces of texts. Coding the interviews took place with colleagues which allowed to acquire varied perspectives other than me. Each code from me and the colleagues were written individually. Then colleagues and I took time in in trying to avoid repetitive ideas in the coding the interviews. Then codes from me and colleagues were compared and those that best fits for each interview were selected through discussion.

Step three: Identifying themes

Afterwards, identification of themes from the coded texts was performed. In using thematic network analysis, identifying themes begins from extracting the basic themes that comes out of the coded data. In identifying the basic themes, repetitively mentioned issues were grouped into basic themes. For instance, financial constraints and inaccessibility of proper treatment were issues that were continually mentioned in this study and were grouped into basic along with other basic themes. The basic themes were then registered into a table and prepared for the next step of the analysis (see appendix 1).

Once all the basic themes were identified, grouping them into organizing themes took place. In this step, similar issues raised in the basic themes were clustered into an organizing theme that summarizes the ideas into a structured form. This was essential step in acquiring a more advanced level of information through organizing the fragments of assumptions in the basic themes (see appendix 1).

The final process in theme identification is classifying the organizing themes into global themes. Global themes are useful in summarizing and providing an interpretation for the collection of all the other themes. They provide a concluding statement about the analysis through reducing the organizing themes into a short representations (Attride-Stirling, 2001). The main issues in

the organizing themes were deduced into the global themes by carefully grouping them in a way that can broadly capture the analysis.

Step four: Constructing the thematic network

After all the basic themes, organizing themes and global themes has been identified, the web-like thematic network was drawn to explore interaction between themes. The thematic network is essential in clarifying the interpretation process for me and the reader.

4.8 Validity, Reliability and generalizability

Researchers make every effort to present credible findings to readers and establish trustworthiness. The trustworthiness of a qualitative research has been a debatable issue in the past. Especially, for those unfamiliar with qualitative approaches, it has been a challenge to identify what distinguishes a ‘good’ qualitative research from that which has been less thoroughly conducted (Pilnick & Swift, 2011). Since qualitative and quantitative research approaches differ in their basic assumption, the technique used to assure trustworthiness in each of the research approaches also varies. The main aim in qualitative research is exploring the perception of individuals regarding certain social issues instead of quantifying a phenomenon (Green & Thorogood, 2014). As a result, application of the main concepts of trustworthiness, validity, reliability and generalizability are also structured based on the assumptions of a qualitative research. Alternative terms such as truth value, consistency and applicability are provided to refer to validity, reliability and generalizability in qualitative research.

Validity as defined by Long and Johnson (2000), is the accuracy of the findings or terms. It reviews whether a measuring factor or instrument actually measures what it is intended to measure. In qualitative research, some scholars apply alternative terms such as truth value to refer to validity. Truth value refers to realizing the existence of multiple realities in qualitative research. Qualitative researchers utilize different methods to enhance the truth value of findings by presenting findings that acquired from various evidences (Noble & Smith, 2015). Some of the methods used to enhance truth value of findings include triangulation and respondent validation. Triangulation, according to Brink (1993), is the use of multiple data sources, methods, investigators, theoretical perspectives and approaches for the study of a single phenomenon and checking the correspondence among them. In using triangulation, researchers go through a systematic process of employing various data collection methods. As a result, several forms of evidence are presented from different data collection methods instead of a single point of view from a single method (Creswell, 2014). However, data gathered using

different methods is not aimed to produce similar findings from each method. It is rather used provide multiple views of the issue being studied (Barbour, 2001).

In this study, I attempted to use triangulation in two ways. One way that triangulation was used is through the collection of data using different methods. The methods used to collect data were interview, FGD and observation. Triangulation is an important strategy in strengthening the findings of a study in qualitative research. The employment of multiple methods of data collection plays a key role in presenting diverse realities and minimizing researcher bias (Afzal, Azeem, & Bashir, 2008). Moreover, the use multiple methods enhances in-depth knowledge regarding a certain phenomenon and allows the researcher to produce rich amount of data (Hussein, 2009) . Another way that triangulation was used in this study is through the collection of data from multiple sources. Although the main aim of this study is to acquire experiences of parents raising a child with autism, the staff at Nia Foundation also provided additional information which was recorded as data from additional sources. Moreover, the owner of the organization also participated in an individual interview. Since she has been running the organization for more than 10 years and has been in close contact with parents from various backgrounds, she provided essential information for the study. These additional interviews with the owner and staff were important to ensure triangulation for this study.

The widely accepted definition of reliability is the repeatability of results of a study. When the same results are repeated by other researchers conducting the same experiment using similar methods, the results are viewed as reliable. However, social occurrences studied under qualitative study are often difficult to repeat. Hence, qualitative study focuses on producing results consistent with the collected data instead of repeatability of a study (Merriam, 1995). In qualitative research, clear explanation of concepts and procedures of the study is important in assuring the reliability of the study (Pilnick & Swift, 2011). As Long and Johnson (2000), suggest peer debriefing is a method to ensure reliability in a qualitative research. Peer debriefing refers to communication of findings with colleagues to acquire additional perspectives and explanations at various stages of a study. For the current study, I was communicating with the supervisor about the general flow of the data collection process. After the data has been collected, there was an ongoing communication with supervisor in order to review different perspectives and receive educational support on the topic of the study. Moreover, the use of audio recorder to fully capture participant's explanations and consistent use of interview guides for all the interviews also contributed to present reliable findings in this study.

As mentioned above, the interview in this study was conducted in Amharic language. Afterwards, the transcription of the interview from the tape recorder to documents, followed by translation of the responses from Amharic to English took place. After the transcription process, I performed the process of coding with my two classmates to ensure Intercoder reliability. Intercoder reliability refers to the agreement between two or more coders in the process of coding a transcribed data. This type of reliability confirms that the coding process does not only reflect the researcher's view but is a result of an agreement between the coders (Kurasaki, 2000). Using more people in the coding process, assists the researcher in improving the consistency of the coded information (Mays & Pope, 2000). In this study, coding interview together with classmates played a key role in ensuring the application of Intercoder reliability and minimizing researcher bias.

The challenge to secure reliability in this study involved the process of translating interviews from Amharic to English. In some of the interviews, participants mention a word that maybe challenging to find an equivalent term for in English. In order to enhance the accuracy of the translation, I shared some of the translated interviews to a colleague who speaks both Amharic and English. Incorporating the feedback from another individual who speaks both languages was vital in enhancing the reliability to the translated interviews.

Generalizability is considered as the extent to which the information gathered from participants can be representative of the larger population. In qualitative research, it refers to the extent to which a theory developed within one study can be exported to provide explanation for the experiences of other individuals who are in comparable situations (Horsburgh, 2003). The findings from this study can be utilized as a source for other studies involving individuals in similar situations and it can also provide valuable recommendation for the two organizations.

4.9 Role of the researcher

In qualitative research, the researcher's position such as personal characteristics, gender and personal experiences may have an impact on the study. The researcher's background and understanding of the world affects the data collection and interpretation which reflects on the final conclusion of the study (Berger, 2013). By being aware of how personal positions influence the study, it is possible for the researcher to critically look at the role he or she has in the study. This plays a key role in expressing how the researcher adds value to the research and addresses his or her limitations in knowledge. Hence, clear communication of personal roles enhances the quality of the research study (Guillemin & Gillam, 2004).

My personal position, specifically my educational background, might have affected this study in various ways. Initially, due to the varied backgrounds of my participants, explaining the overall aim of the study to some of the participants was a challenge. However, I tried to spend more time to provide my explanations in simple terms to my participants until they were able to understand my overall aim and able to communicate their experiences.

In relation to my educational background, being a Masters student was viewed in different ways by the participants. Some participants were excited to see that students are studying more about autism. These participants expressed that more studies can provide better awareness of autism to their society. However, other participants have the belief that people with a higher educational background are not contributing enough regarding the issue of autism. These participants were critical of my background. However, having a background in psychology, I took a series of counselling courses in the past. Such courses have provided me with good listening skills that helped to improve my interaction with participants. The participants were able to express their opinions without being interrupted by me. Throughout the data collection procedure for this study, I tried to let the participants feel that they are experts in the topic and highlighted to them that I am just an interviewer recording their experiences. Moreover, the fact that the study was conducted in a culture that I am well aware of allowed me to have smooth communication with participants.

4.10 Ethical considerations

Prior to the data collection step, the proposal for this study was submitted to Norwegian Social Sciences and Statistics Data (NSD) (see appendix 1). The proposal passed through all the necessary requirements and a permission was provided ahead of the data collection step. In Ethiopia, National ethical clearance for research is still at its developing stage. Even though there are various levels of ethical approval in Ethiopia, the majority of them are applicable for large scale projects instead of Masters study at individual level (Cochrane, 2015). For the purpose of this study, proper oral consent was acquired from both organisations through submitting the proposals, NSD permission paper and official letter from the supervisor to both organizations. The head psychologists at both organizations carefully observed the proposal and NSD permission before allowing me to conduct the study. In addition, proper discussion regarding the type of research procedure was conducted between me and the head psychologists at the organizations. Additional national level permission was not required by the organization. It was sufficient for me to present the permission from NSD and official letter from the supervisor to be allowed to conduct the study. I began conducting the study once full permission

was acquired from both organizations.

In relation to ethical consideration of participants, I have prepared an organized informed consent form (see appendix 3 and 4). The informed consent form clarified the goals of the study and the nature and duration of activities that were performed during the study. It was clearly stated in the consent form that the data the participants provide will only be gathered by me. No attempt was made to coerce participants to be part of the study. The written consent ensures the confidentiality and anonymity of participants. However, it was clearly stated to the owners of the organizations that anonymity cannot be insured for them since they can easily be identified due to their position at the organizations. The consent form was prepared both in the English and Amharic languages. The participants were allowed to sign using their language of preference.

5 Findings

This chapter is organized based on the structure that emerged from analysis which shares certain similar features to the specific objectives of the study (see appendix 6). According to the structure that emerged from analysis, the main stressors and resources of parents raising a child with autism are the global themes. These global themes comprise several organizing themes which in turn are classified into the basic themes. Primarily the stressors analyzed from the data are explained and the resources associated to raising a child with autism are explained following the stressors. In addition to the findings from analysis of data, my personal observations are also presented the finding below.

5.1 Stressors associated to raising a child with autism

The results acquired from the data analysis resembled one of the sub objectives of exploring the stressors parents face in the process of raising a child autism. Various stressors were mentioned by participants during the individual interview and the FGD. These stressors have been a major challenge to parents in the process of raising their child. Based on the information provided by parents and staff at Nia Foundation, the main stressors that are observed on parents are categorized into initial and ongoing stressors.

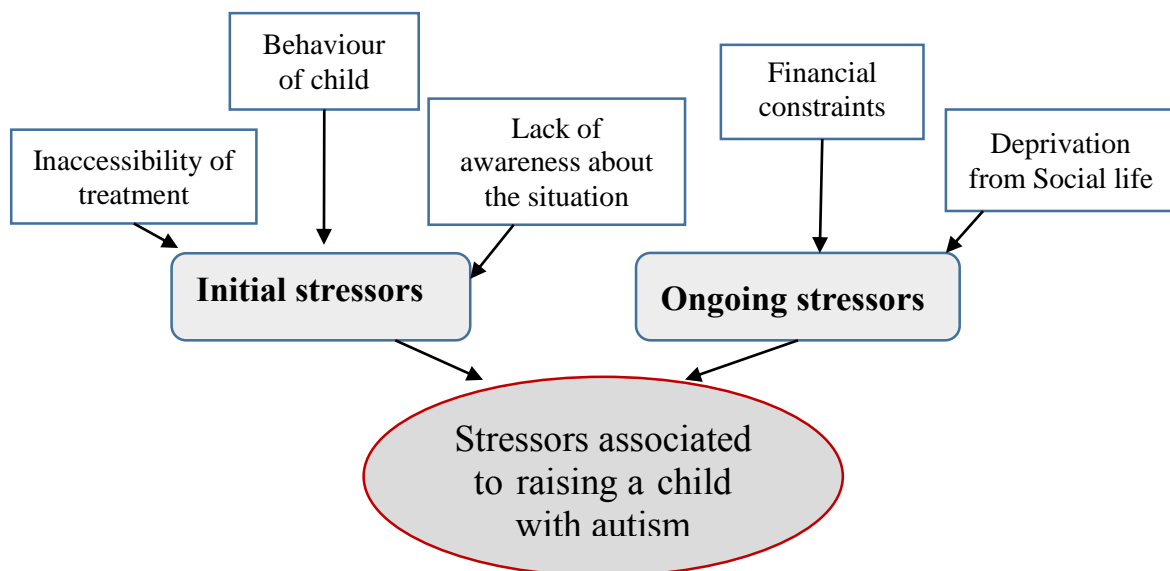


Figure 2. Stressors associated to raising a child with autism

5.1.1 Initial stressors

Initial stressors are those stressors that parents faced during the early stages of identifying the situation of their child. At this stage, parents are in continuous process of recognizing diverse symptoms on their child. Most parents who participated in the individual interview stated during the first years of observing the situation of their child, they went through a lot of emotional instability and confusion in their lives. Their description shows that even though there is individual difference in the duration of time they remained within such emotional instability and confusion, all participants experienced these initial stressors. The basic themes that emerged from the initial stressors are behavior of the child, inaccessibility of treatment and lack of awareness.

All parents who participated in this study mentioned the behavior of their child as one of the primary symptoms of the situation of their child. They reported the first experience of observing their child demonstrating unusual behavior created a major stress in their lives. For parents who participated both in the interview and FGD, identification of such behaviors greatly affected their day to day activity in several ways. This was observable both from their words and also from their gestures as they explained their first experiences of raising their child. The behaviors that were repeatedly explained by parents as a main symptom can be summarized as hyperactivity, impairment in speech and preference of isolation.

Hyperactivity of the child is mentioned as a behavior noticed by the majority of parents. Most of them explained their child being hyperactive, very energetic and difficult to manage. This was a stressor to most of them as they are not able to easily manage their child because of the extreme energy and aggression the child demonstrates. Furthermore, hyperactivity of the child usually co-occurs with additional difficulty such as lack of sleep at night. With the exception of one participant, all of them confirmed they were unable to sleep at night during early identification of the situation. Staying awake the whole night was a daily routine of parents in order to keep an eye on their child. For instance, Lidiya, a mother who participated in the individual interview mentioned the situation of her child as follows.

Raising him was very difficult especially at those times when we were aware that he has autism. He doesn't sleep at all so I have to be awake all night, he was very energetic and does not sleep at all...

Johannes, a father who I interviewed also explained

Before we knew about her situation her illness was very difficult to manage. We were not able to sleep the whole night and day. She uses to fall down every time so we were standby

every time to look after her. We were just like soldiers who is on duty 24 hours. It was very difficult.

In addition to participant's explanation, I was able to observe children with autism as I went to the compound of Nia Foundation and Nehemiah Autism Center. Some of the children I saw are highly energetic and restless. However, I was also able to observe some children that looked inactive. This was general observation I took while I visited the schools but I experienced a close contact with a child affected by autism during one of the interviews I conducted. For this interview, the participant, Hilina, preferred her home as a venue. During the interview her 8 years old boy was lying in a bed while she was sitting next to him. I witnessed how restless the boy was and how alert Hilina looked throughout the interview.

Another behavior that is mentioned as initial stressor by participants is inability of the child to speak. Most of the participants discussed how their child failed to make sounds at the expected age when other children speak. For some this was taken as a sign that some disorder is affecting their child. Aster who participated in the FGD described her situation as follows

My daughter was normal but then we started observing that she was unable to speak and she was very aggressive. Then I took her to hospital assuming maybe she has some other complication within her brain. The doctors told me her brain is normal and functioning well but it shows there is autism.

However, for some participants it took them some time to realize their child is affected by a disorder. For instance, Azeb, a mother that I interviewed explained that she and her husband were aware their child could not speak but since other children in comparable situation were able to speak after the expected age, they assumed their child would also speak. Most parents rely on information from relatives and the neighborhood. This delays parents taking their child to hospitals at the appropriate timing. Azeb described her experience as follows

... we have heard that some children might be slow to speak so we thought our son might also be like that. Even my niece started talking when turned 2 years and 8 months so we were expecting that would also be the case of our child.

According to the information from the participants, the speech impairment is not only limited to the inability to make sounds. For some participants, the child is capable of making sounds and words. Nevertheless, they only know how to repeat one word over and over again. For instance, Almaz another participant explained the situation of her child as follows.

I started seeing that my daughter cries and shouts continuously so I was worried. In addition, she keeps saying the same words over and over again.

In general, the different ways the speech impairment is manifested was reported as a stressor to parents. Speech impairment created a communication barrier between the parents and the children and this made it difficult for parents to clearly understand the needs of their child. Parents in this study stated their children cannot express their feelings and there were times where parents failed to identify when their child was sick.

For the majority of parents who participated in this study it was a huge challenge to help their child socialize with other children. Most of the participants explained during social gatherings where children get together, they observed their child prefers to stay segregated at all times. If parents attempt to persuade him to socialize, the reaction of their child would be extreme aggression and crying. Girma explained how his child prefers isolation as follows

Usually her daily routines are consistent. She is isolated and does not want mix up with people, she has some kinds of toys that she like and she spends very long time playing with them. If she hold one toy she can hold that for days and does not allow anyone to take it from her.

Lidiya also stated

...when he sees people he cries and he becomes very disturbed. Even celebrating birthday is the most disturbing thing for him. I remember before I was aware of his situation, I prepared his first year birthday and called people to celebrate and he was very disturbed by that.

The effect of the isolation of the child is also reflected on parents. Parents reported they stayed at home in order to take care of their child and this left them isolated from public places in order to keep the interest of their child. The intensive care such children requires also plays a role keeping parents isolated at all times. For instance, the head teacher who participated in the FGD with staff clarified her views as follows

These children require a lot from their parents and most of all they require their time. In most cases we see a mother who quitted her job to stay with her child. If one should take care of these children, it is difficult to go out and involve in the society.

Additionally, the staff also reported usually parents who are in continuous conflict with themselves and the society come to them for help. They described that since parents cannot attend any social gatherings because of their child, there is a distance observed between parents and the society.

Another theme raised under initial stressor was parents' inability to get proper treatment for their child. Although some of them mentioned certain hospitals that provide treatment for children with autism, it was not satisfactory compared to the situation of the child. The majority referred to the lack of proper treatment as more stressful than the actual disorder the child is facing. Azeb described her experience in the individual interview as follows

In general, I would not even call it diagnosis it only helped us to know his situation but there was no treatment provided for him.

Azeb highly emphasized that although taking the child to hospital was useful to be aware of the situation, it provided them nothing more than that. Other participants also share this view and discussed on how proper treatment is a necessity for children with autism. For instance, Daniel, who was part of the individual interview described

There were times that me and my wife decided not take him to hospital again because whenever we go there we are not able to find a specialized doctor in this area.

Other participants also explained that although hospitals were helpful to become aware of the situation, they do not provide sufficient treatment after the diagnosis. This can be due to the shortage of skilled therapists that work around the area of autism in hospitals. In order to access therapists, parents are forced to take their children to centers such Nia Foundation and Nehemiah Autism Center. As reported by the staff, these centers have limited space and cannot accommodate large number of students at once. As a result, parents have to wait in queue for several years to get their child enrolled at the centers.

Based on the response gained from participants, lack of awareness about autism was mentioned as initial stressor by parents and the staff. Some parents explained they have not heard of the word itself until the situation happened to them. Most parents were not aware about the symptoms of the disorder and the possible treatments for a child with autism. In addition to this, most of them were also not informed about which school to take their child to. For some parents, it took them considerable amount of time to discover the existence of a school with a special accommodation for Autism. For instance, Lidiya explained

In general, he started going backwards in everything. I didn't have much awareness back then but his father is pharmacist and he knows. He always used to ask me why is this boy going backwards but I didn't understand till a certain point. I assumed that it is typical behavior of kids since they always like new things I thought my child was also doing that

Johannes also highlighted how lack of awareness stopped them from accessing proper treatment for their child made them to keep their child away from proper treatment.

At the time we did not have much awareness so we did not take her to hospital but we were just using holy water from church.

The fact that parents are less informed about the situation of their child made them to rely on information from neighborhood and family members. Parents indicated they wasted a lot of time before seeking professional help for their child. This deprived the children with autism from accessing school and other forms of treatment at the appropriate time. Eden, who participated in the FGD mentioned that people gave opinions that are not usually helpful for the child or the parent. This participant explained in the beginning she was not aware about autism which led her to be advised by people in her neighborhood. Since the situation of her child is interpreted as a spiritual possession in the neighborhood, it was very difficult for her to communicate with people.

People usually advise me to treat him traditionally such as using holy water since it is associated with evil spirit. Whenever we take him out with us people refer to him as 'that sick kid' since no one knows the case specifically as autism and it is all the result know lack of awareness and I hope this will change.

The staff at Nia foundation also shares this view that although they are working hard to reach parents, there is still huge gap in awareness about the disorder. The staff discussed that there is a lot to do to raise awareness in parents and also in the society.

The lack of awareness about what autism is also a stressor. Awareness about the disorder is in a very early stage and people are recently finding out about autism but if parents and society are aware on how to treat and teach these children, guidance can be provided at home to them.

The staff also described having prior knowledge and information about the situation can help people to stay prepared. If not, children with autism will keep on suffering from inhuman treatments such as tying and locking them inside a room, segregating them from the society and also attributing the disorder to evil spirit.

5.1.2 Ongoing Stressors

The second category under stressors is ongoing stressors faced by parents raising a child with autism. Ongoing stressors refers to the existing challenges faced by parents after the child joined school. These stressors are still part of day to day life of parents and are more than the capability of what the school can offer. The major themes identified under ongoing stressors are financial constraints and deprivation of parents from social life.

I. Financial constraints

Parents who participated in this study are from a wide range of backgrounds. Some are financially stable and monetary issues are not a major challenge to them. Specifically, three participants from the individual interview confirmed they earn sufficient amount of money to cover expenses of their child. Out of five mothers who participated in the FGD, two of them mentioned that issues related with money are not a major concern for them. However, the remaining three mothers explained how monetary issues are a major challenge in raising their child. According to the owner of Nia foundation, economic constraint contributes a lot on the difficulty of raising a child with autism.

Autism and poverty is a disaster; it creates huge problem. This is because it makes it difficult for them to move on in their lives. Imagine a mother cannot work since she has to stay with her child 24 hours and the child with autism requires everything; her time, her energy and everything constantly.

Participants who found financial constraint as a major stressor discussed the imbalance between what they earn and what the child demands creates tension in their homes. Based to the information from the staff who participated in FGD, to supply the demands of children with such developmental disorders it requires more money. In order to teach them at home parents will need more space, toys and various other things. Nevertheless, most parents with financial constraint do not even own a house. They usually rent a small affordable in a compound where other people live. In addition to the problems they face with what they earn, they also face difficulty living in a compound with others since people do not tolerate their aggressive child. The speech therapist who participated in the FGD explained

When there is issue of poverty attached to this situation that makes it difficult. When there is poverty a mother or father needs to work and earn a living but they cannot simply do that because there is nobody to care for the child and as you know these children need special care.

Most parents described that the issue of financial constraints created other associated challenges in their lives. In order to earn a living parents, need to work and during working hours they need a safe place where they can keep their child. However, people around them are not willing to be in charge of a child who is not manageable and communicates with difficulty. For some, even their own family are not willing to provide any kind of support. This chain of challenges forced some participants to lock their child at home. Some parents mentioned, especially during weekends, they need to work extra hours to earn better money. As a result, they are forced to lock the child inside in order to keep him/her from harm.

Financial constraints are reflected in various aspects of the participant's lives. For instance, most participants mentioned that transporting their child has been a major challenge to them. Most of them do not own a private car and they are forced to use public transport to take their child to school. For instance, Johannes mentioned

The basic problem we have is when we try to move our child from one place to another. At these moments where we try use public transport holding her it is very difficult and we become so sad as parents. She is not manageable and then she will shout and disturb other people inside and this is very difficult.

Even though the schools provide transport service, it is accessible for households that are nearby and parents who reside far away still struggle with issues related to transporting their child. Moreover, although parents want to take their child to different places on weekends, those who don't own a private car face challenges to move with their child and prefer to keep them at home.

However, some participants have different view related to transportation issues. They discussed they are able to access support from family members in transporting their child to school and this allowed them to work and earn a living. For instance, Lidya mentioned

My family support me a lot. Especially my sisters have always been with me and they always take my child to school. I am able to work because my sister looks after him when I am not around.

Another participant Azeb also discussed that her family provide support to her by transporting her child to and from school. Although she struggles with other financial issues related with meeting the needs of her child, her family eased part of the challenging through providing her with such support.

II. Deprivation from social life

The other ongoing stressor mentioned by most participants is their deprivation from social life due to the situation of their child. Parents in this study explained they are not able to attend any social events with the presence of their child. According to their explanation, when their child is not at school they are forced to remain at home since are the only one to take good care of him/her. Even if they want to attend social events with their child, the challenges they face in managing their child makes them to prefer staying at home. For instance, for Hilina, who is a

single mother, raising her son is an enormous challenge in her life. Among several difficulties she faced, she mentioned her deprivation from social as the most challenging aspect.

What makes it most difficult is that I do not have any social life because of him. I cannot go anywhere with him because of his behavior, even when I walk with him on the street I see people pointing fingers at me.

Another participant Mekdes, also explained her situation as follows

You know how social gatherings such as weddings and birthdays are valued in our culture. For some people it is a disgrace if they call you to attend and you could not go. In my case, only few of my close friends can understand the situation I am in but others think I am just using my child as reason not to attend events.

Some participants mentioned sometimes the deprivation from social life is not only resulted caused by the behavior of the child but by the parent's fear of societal attitudes. Meron, one of the participants in the FGD, explained they sometimes predict people will mistreat their child and they prefer to keep him locked at home. She mentioned whenever she thought of attending social events, she creates stressful images of people's negative attitude and always remained at home with her a child.

Usually I prefer to remain at home. Whenever I think of going outside with him I picture negative images of the neighborhood talking about me and staring at me. But during the few times I took him outside everyone was not negative as I expected but I still prefer staying at home because I know I will not be able to tolerate if someone says something bad to him.

Participants also highlighted their deprivation from social life is also manifested at times they want to prepare family or friendly gatherings at their home. Whenever they want to call their friends and relatives at their homes, usually people are not comfortable with the behavior and the presence of the child. They reported that as a parent they always prioritize their child; as a result, they prefer not prepare any events at home.

5.2 Resources associated to raising a child with autism

Based on the data collected from participants, resources are different ways parents use in order to strengthen themselves and proceed to find solution for their child. Various resources were mentioned by parents and staff. The resources are mainly organized into role of schools, acceptance of situation, role of religion and small progress of the child. The basic themes under each category are explained below.

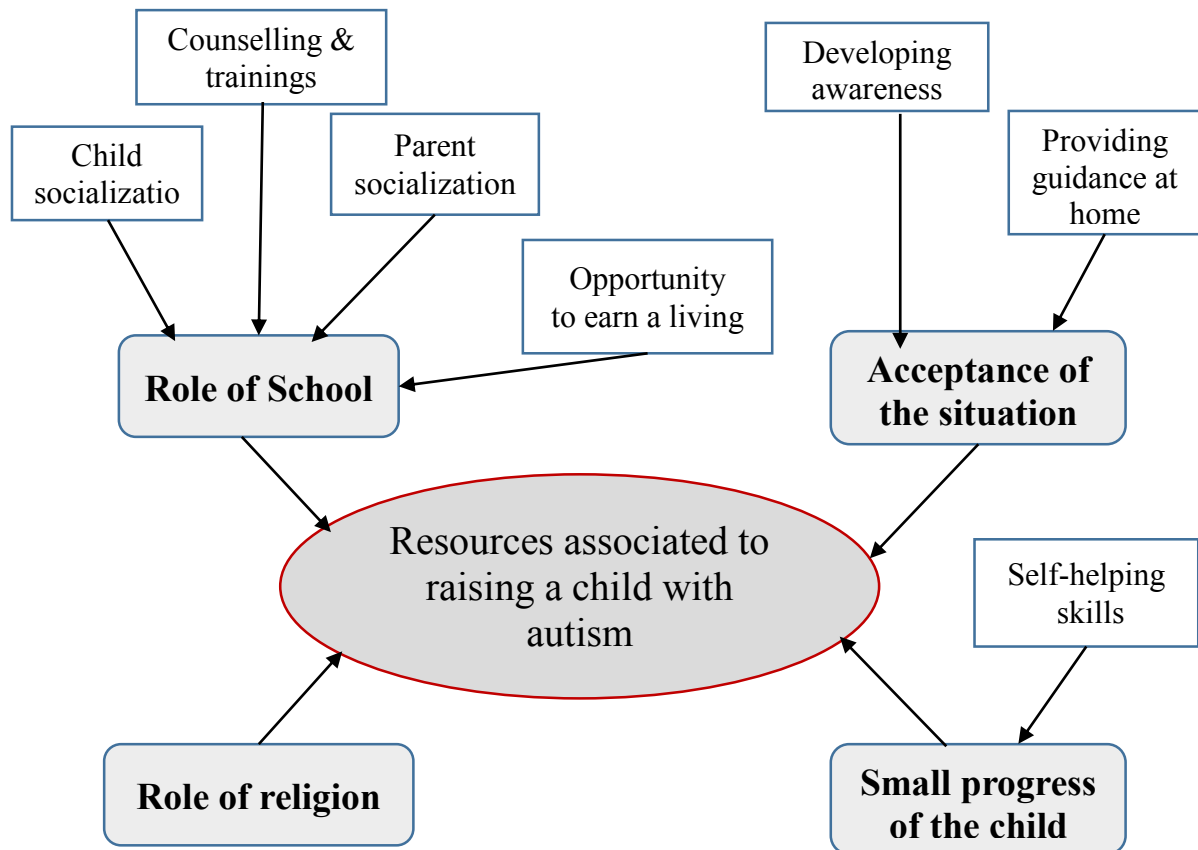


Figure 3. Resources associated to raising a child with autism

5.2.1 Role of schools

Parents who participated from both Nia foundation and Nehemiah Autism Center pointed out how their life changed after their child joined these schools. According to the information parents provided, the schools play a vital role in helping their child to be manageable. For majority of the participants these schools were viewed as a relief from the stressful day to day activities of raising their child. Most of them described the different types of changes they experienced once their child joined school. The main points raised by parents and staff included child socialization, counselling and training to parents, parent socialization and getting opportunity to earn a living.

The interview and FGD with both parents and staff confirmed that schools play essential role in helping children with autism socialize with other children in a similar situation. All parents mentioned that they observed significant change in relation to the socialization of their child.

Prior to joining the school their children were highly isolated are not able to easily socialize with other children. Tadesse, a father who participated in the individual interview mentioned the following about how school has improved the situation of their child.

As you can see there are other kids in the compound we are living in. These kids are not affected by autism. Before joining school, our son used to see them as a complete stranger and he never gets close to them. Now that he joined school he has started to get along with them and sometimes he even tries to play with them. This is huge progress.

Almaz also mentioned how school changed her child and also recommended other parents to allow their children to join school.

These children are different from us but segregating them worsens the situation. They should mix up with people. Otherwise if you keep them isolated they will become extremely wild. In my case a lot has been changed since he joined the school. So I highly recommend for parents to help their children to join school.

The owner of Nia foundation also highlighted that although it is difficult for parents to access school for their children with autism, parents find relief as they allow their child to join her foundation. They use it as a medium to cope such stressful situation.

Well they see our organization as means to cope since they don't have any other option other than bringing their child here. They cannot find many schools designed for this purpose.

Almost all parents in this study recommended that other parents in similar situation to allow their children to go to school. They reported that as a child with autism started to learn to socialize, both parents and the children benefited. It is explained by most parents as an exciting experience to see their child play with other children. For some parents, it was reported the most hopeful thing they acquired from allowing their child to join school.

According to the majority of participants, counselling and training are provided in Nia foundation and Nehemiah Autism Center. For parents these played an essential role in helping them to become well aware of the situation. Parents in this study strongly mentioned the counselling and training programs allowed them to understand autism and to identify ways to treat their child at home. As mentioned by the staff counselling and trainings are provided by the staff in the organization and invited guests also provided various trainings until recently. Aster, who participated in the FGD described prior to taking these trainings, she was not aware on how to guide her child. However, after the continuous trainings she took from the organization a lot has been changed.

I have benefited from the trainings provided at this organization. At this organization training is provided not only for parents but also siblings and anybody who is in close contact with the child affected by autism can attend the trainings. It was really helpful and it helped to learn many things about treating my child.

Based on the information from participants and staff, the trainings provided at the organization are not only centered towards immediate family members such as fathers and mothers. Anyone who has a responsibility towards the child with autism are included in the trainings. Siblings, aunts and uncles and also house keepers are invited to take trainings. Parents reported the trainings they took from the organization made them more relieved especially during weekends where they have to remain at home with their child.

Another theme raised by parents and staff as a coping mechanism to parents is the monthly meeting of parents at Nia foundation. During this monthly meeting parents are provided with all the necessary information about the status of their child and they discuss in depth about how to support their child with the staff and the owner of the organization. The majority of parents mentioned they take this monthly meeting as an opportunity to discuss and socialize with other parents in a similar situation. This allowed them to realize they are not the only one raising a child with autism and this greatly enhances their strength. For instance, Eden, one of the participants in the FGD described the importance of the monthly meeting as follows:

It is always easier to communicate with someone who is in a similar situation as mine. I really look forward for this monthly meeting because I can discuss with other people who can understand my situation clearly.

Meron, who recently enrolled her child at the organization, explained how helpful she found communicating with other parents as follows:

At first I was very scared to bring my child here because I never expected to see large number of parents in this compound. It was at my first monthly meeting that I was able to realize that I am not alone. There are many parents more than my expectation.

During my data collection I was also able to attend one parent monthly meeting. I have clearly observed how parents discuss the situation their child freely in the compound. They were sharing ideas and looked very comfortable in discussing the issue among each other.

It was mentioned by the majority of parents after their child was enrolled in school, it provided them the time to work and earn a living. Most of the participants mentioned before their child joined school, it was difficult to leave the child at home in order to work. This was a major challenge to most parents as they cannot provide the needs of their child. Especially, the two

single mothers who participated in the interview emphasized how challenging it to raise their child without any support from the fathers. Specifically, Hilina who is a single mother in poverty explained how she was able to work and provide her son after he joined school.

I used to lock my child at home before I knew that schools exist for such situations but after I took him to school I see the changes he is making. At least he will be able to move his body and I will have some time to go out and work.

Eden also reported the significance of schools in relation to earning a living as follows

To be honest I cannot imagine what I would do if my child did not go to school. The benefit is for both of us. He is improving a lot and I find a little break while he is off to school. Now I even started a half day job which helps me to supply his needs.

In addition to providing time and space for parents to earn a living, Nia foundation also offers additional support for parents under low economic status. According to the information provided by the staff, Nia foundation has been working to support women with severe financial constraints. The organization provides certain amount of initial capital for women who are living in extreme poverty and they allow them to start small business as per the preference of parents. Once parents are involved in producing different products, the foundation also strives to find a market to sell their products.

Moreover, the two organizations selected for this study are striving to raise awareness within the society in various ways. For instance, Nia Foundation attempts to raise awareness of autism among parents through ways such as organizing workshops, forming family support groups, providing professional counselling and trainings. Although such awareness raising programs are highly beneficial to parents, they are only limited to parents who have a child enrolled in the organization. In order to access parents outside of the organization, Nia Foundation began broadcasting a radio program in a national radio station. This radio program is called ‘Yagebagnal’ when translated to English it means ‘it concerns me’. According to the owner of the organization, a lot has been achieved in relation to communicating message about autism through this radio program.

On the other hand, Nehemiah Autism Centre also collaborated in a project with a nationally recognized mineral water company called Ambo. The company sponsored Nehemiah Autism Centre for a three-month duration to use Ambo bottles with attached necktie. The attached necktie includes a description about the project and explanation about spending a portion of the profit to assist the centre. The aim of such promotion was to communicate the message about autism by distributing the bottles to restaurants and selling the mineral water to consumers. In

addition, the project was broadcasted at a national level through various forms of media such as radio, television and electronic media such as internet. This collaboration with Ambo Mineral Water Company was a huge action by Nehemiah Autism Center to open up the issue of autism to the public.

5.2.2 Acceptance of the situation

The main resource discussed by parents, the staff and the owner of the organization was how accepting the situation plays important role in strengthening parents raising a child with autism. Specifically, the staff and owner of the organization highly emphasized the importance of acceptance in helping parents to acquire better understanding about the situation of their child. Mainly, enhancing awareness and providing guidance at home were themes raised under the importance of acceptance.

Some parents mentioned acceptance of the situation led them to comprehend the situation of their child. This was found to be important step in raising a child affected by autism. As discussed by parents and staff, if one is able to learn how to accept the situation it is less challenging to stand the stressors that come along for their child. For instance, Azeb, a mother of a boy affected by autism highlighted how accepting the situation helped her through her journey of raising him as follows:

When parents are unable to accept the situation it will not be helpful for the children so acceptance is basic. If you accept is early then you will move on to finding solutions to your child.

This mother looked very strong and hopeful that her child will progress. As I interviewed her she kept mentioning how people should not exaggerate autism and the best approach is to quickly proceed to helping the child. The issue of acceptance was also raised in the FGD with staff, a therapist at the organization, discusses the role acceptance plays in helping these children.

If parents are able to accept it, they can easily overcome the problems they face. I see acceptance as more important than economic stability and other factors. It simplifies many things for the child, for parents and even for us working here.

The owner of Nia foundation also added voice to the relevance of acceptance by mentioning how they provide parents counselling and trainings in order to make them accept the situation and provide help to their child.

As we see it sometimes the case of having a child with autism will lead to divorce and we work on how to make them strong to accept their child and be strong enough to raise

the child and help them transform this strength into a better way of life. So we strive to avoid all the anger, frustration, feeling of “why me” and all the denial.

As it was mentioned by most participants and staff being aware and informed is best option to provide better treatment to the child. In order to work towards the progress of the child first parents should be able to accept the situation of their child. Based on the information they provided, it is after accepting the child against all the difficulties that parents proceeded to gather information about autism in general. They strived to enroll their child to school and to have better understanding on the situation rather than being frustrated by their child.

Some parents and staff who participated in FGD explained how acceptance was helpful in making them prepared to provide all the support and guidance at home for their child. Parents mentioned before accepting the situation life was stressful to most parents as they were not aware on how to treat their child at home. Some mentioned this resulted from the lack of knowledge about treatments provided at home but after accepting the child unconditionally, it simplified the process of treating the child at home. Aster described

In the beginning me and my husband were confused. We had no idea what we can provide him at home. But at the end of the day we needed to accept the child because he is fully our responsibility so now we are strongly working at home to see improvement on our son.

A staff at the FGD also explained the importance of acceptance in making parents prepared to support their child at home.

I think the main step towards raising a child affected by autism is accepting the situation. If parents deny things it will only lead to frustration but those who are able to accept can find ways on how to train and how to teach their child at home.

Daniel, another participant, also clarified that once he realized the situation is not going to change he and his wife decided to provide all the time their child needs.

We give him all the time he needs. Of course I work to earn a living but after work I always go back home. My wife actually quitted her job and when our child goes to school, she always tries to read different ways to support him at home.

Acceptance was explained as the first step towards solution by the majority of parents and also the staff. Staff described that the duration of time that parents accept the situation differs from one parent to the other. In the foundation they come in contact with different parents. The staff

highlighted that those parents who accepted the situation early are usually highly engaged in the matters of their child and actively participate to work towards solution for their child.

5.2.3 Progress of the child

Parents who participated in this study emphasized the minor improvements they observed in their child was a major resource for them to strengthen themselves and work towards further progress. Parents and staff discussed various types of changes children with autism attain once they joined school. These progresses are vital source of strength for parents, mainly the child's development of self-supporting skills such as toilet training, eating independently and making sounds were the main themes raised by parents and staff.

It was highlighted by most parents and also staff that toilet training of the child with autism is viewed by parents as a major success. For the majority of parents who participated in this study raising a child with autism, teaching skills such as toilet training are found challenging. For some parents, the child was toilet trained in his early years but failed to recall the toilet training after diagnosed by autism. This situation was reported as a major stressor and it left parents hopeless. After their child joined school, the therapists tolerantly work to train the children capable of self-helping skills such as toilet training. As the child was able to re learn such essential skills, parents reported it retained their hope again and made them strive to achieve for more progress. For instance, Dawit, a father who participated in the individual interview described seeing his child being toilet trained was a pleasing experience. As he explained how encouraged he was he said

During his first two years our son was normal. It did not take much time to toilet train him but after his third year things started to change. Me and my wife were frustrated at the time...now we observe he is being well trained since he joined this center. It is a big step for us.

Another participant, Mekdes, also described how excited she was to see the progress of her child.

My child was very difficult starting from his early years. I was completely hopeless that he will remain like this forever...I am very thankful for the staff who are so patient make him toilet trained and am surprised how they are capable of fixing these things.

The staff also explained various trainings are provided for children in order to improve their self-helping skills. According to staff, by the time they arrive at the foundation most children were difficult to manage and parents usually feel hopeless about their children. However, after

few trainings the children will usually become manageable and well trained. This is considered as an enormous achievement for both parents and the staff.

Another progress raised as a resource by most parents was eating independently. Most parents reported that before being trained at the foundation, their child was not able to eat without their support. Observing their child trained in such skills was seen as massive progress to parents raising a child with autism. For instance, Almaz, a mother who participated in the individual interview reported her case as follows:

For other parents who are raising a normal child this small progress will occur at the appropriate timing which is very exciting. But when comes to raising a child like mine everything is delayed so whenever I see any significant change it really gives me hope that my son will get better one day.

For the married couple Dawit and Adey, observing their child eating on his own created great expectation in the development of their child.

He used to throw his plate and I used to cry every day because I did not know what to do. Even when I tried to feed him he was not willing to swallow. Now there are changes at least he can hold a spoon and eat for himself. I hope to see better changes.

Although parents observe minor changes, they reported these minor changes such as seeing their child feeding himself is what gave them a light to work for more progress. The staff also reported they properly train the children how to open their lunch box and eat by themselves. Although it is challenging to train children with autism, they described their strong commitment to their career as a driving force to work on these children.

An additional theme raised as a small progress by parents and staff is the child's ability to make sounds. For most parents in this study, their child's inability to speak was one of the first symptoms they observed. Some mentioned they felt their child will never be able to speak again and these was stressful situation for parents. After continuous trainings with speech therapists at the foundation, parents were able to see their child making sounds. With extensive training some children are able to make words, count numbers and construct sentences. Although these process of teaching the children might take considerable amount of time, parents reported seeing their child making sounds and words provided them with hope. One participant explained,

I assumed my son will remain mute for the rest of his life and I was starting to give up...I have no words to explain how thankful I am for the therapists. Now I have seen him making sounds I expect to see him constructing words and sentences.

The staff at the FGD discussed that children with autism mainly show delays in everything but that do not display they cannot be trained.

There are different degrees of autism, from mild to severe. We work on these children according to their degree. We train them to make sounds and depending on their degree of disorder, we teach them to construct words and sentences. We even have students who are well trained and joined regular school with other children without autism. These children can be trained.

During the data collection, I was invited to attend a semester closing ceremony at the foundation. The children presented different skills they have been learning during the semester. I was able to observe some children who could count numbers, construct words and sentences. I witnessed how parents were excited at the ceremony since they are aware how tiresome it is to train children with autism. The staff also explained although the process was tedious, the main issue to recognize is the children are trainable.

5.2.4 Role of religion

The belief in God as a means to cope with the stress was evident in the description of most parents. All participants described their hope in God and their expectation to see their child get better with the help of God. For instance, Azeb mentioned how she is relieved to think of the power of God.

But with God's willing...I have great hope in God I will see him changed.

The majority of the parents repeated how they rely on God and how they use their religion as a main medium to release their stress. Some described sometimes they try to take their child to church and attend the ceremony with their child. Although they usually cannot stay long since their child is restless, they reported they always feel better with taking their child to church. Meron explained her situation as follows:

Sometimes I take my daughter to church. She might shout and continuously repeat what the priest says. I see people around me being disturbed by her presence but nowadays I do not mind. I want her to be blessed so I try not be attentive of the people around me.

Additionally, some parents described specific activities they perform within their religion. For instance, using holy water in addition to medications was a method repeatedly mentioned by participants. Drinking holy water in the morning is a commonly performed activity in Ethiopian

Orthodox Church. For Hilina, who is a follower of Ethiopian Orthodox religion, holy water gives her better relief than taking her child to hospital.

I always make my child drink holy water every morning. I do hope that one day my child is going to be normal. I am strong because God helped, walked with me throughout my journey of raising my child.

In general, the statements from parents manifested the importance of their religion as a resource to cope with their stress.

6 Discussion

Grounded on the findings from the data collection of 10 interviews and 2 FGDs, there are major issues that emerged out of the explanation from parents raising children with autism in Ethiopia. This chapter attempts to discuss these major issues. The findings are also briefly presented in relation to the theoretical framework applied in this study that is Salutogenesis theory. The main components of Salutogenesis theory such as life situations, generalized resistance (GRRs) resources and sense of coherence (SOC) are discussed in this section. In addition, existing literature are also referred to compare and contrast the findings from this study.

6.1 Major issues based on findings

6.1.1 Social Isolation

Social isolation is one of the challenges affecting a majority of parents raising a child with autism. Participants in this study repeatedly stated that the situation of their child affected their social life by isolating them from their society. It was found that social isolation was experienced in various forms. One form of such social isolation entails isolation of parents by their society due to lack of basic knowledge about autism. This type of isolation has been shared by the majority of the participants in this study. Other studies also discussed such form of isolation involving lack of knowledge. In their study titled, “Challenges faced by parents of children diagnosed with autism spectrum disorder”, Ludlow, Skelly, and Rohleder (2011) discussed that parents raising a child with autism are vulnerable to judgment from others. Their results revealed these parents suffer from judgments due to the misunderstanding of others about the behavior of their child with autism. This misunderstanding involves others labelling children with autism as being badly behaved and viewing parents as lacking the ability to discipline their child. Meirsschaut, Roeyers, and Warreyn (2010) also highlighted on the experiences of mothers raising a child with autism. In their study, participants mentioned that they are surrounded by individuals with little understanding about autism. They discussed that they are easily criticized by others and are in turn led to avoid social gatherings. Moreover Bashir, Kurshid, and Qadri (2014) conducted a study in India that discussed parents’ social isolation in the process of raising a child with autism. Their findings emphasized various major changes in their lives after giving birth to a child with autism. Among these changes in their lives, social isolation has been experienced by a majority of the participants. Having their child as the centre of attention and criticism left parents isolated and greatly affected their mental and physical wellbeing.

The findings from the present study also revealed the existence of social isolation from the community. The majority of the participants confirmed that the unusual behavior their child displays are not well understood within their neighborhood. Therefore, parents are forced to attend events without their child. However, attending social events alone is also impossible to most participants. This is due to fact that the majority of participants do not have anyone to take care of their child at home. Hence, they are required to remain at home instead of attending social events. Some participants discussed although they suffered from social isolation in the past, at the time this study was conducted, the isolation from their community is reduced to a certain extent. Some mentioned they believe the awareness raising programs conducted within the last few years created a difference. As a result, their communities were becoming better at accepting their situation.

Another form of social isolation explored in this study involves self-imposed isolation whereby parents hide the situation of their child and isolate themselves from the society with their own assumption that they might be singled out. Parents usually attempt to hide the situation through locking their child at home and segregating the child from the society. This type of isolation usually is initiated by the parents themselves. Some of the participants in this study indicated such form of isolation because they are concerned about what others may think about them. Neff and Faso (2014) discussed that parents raising a child with autism suffer from various challenging situations such as judgment and disapproval from others which in turn can lead to parents' feeling of self-blame. Desai, Divan, Wertz, and Patel (2012) had similar findings about parents raising a child with autism in India and their refusal to send their child out in the community to play, celebrate events or visit places. Such characters of parents, according to Desai et al. (2012), could result from parents' negative past experiences or expected fears of being isolated within communities.

In the present study there are mixed views regarding self-imposed isolation. Some participants discussed they suffered from self-imposed isolation when they first found out about the situation of their child. Hence, they tried to segregate their child and themselves from any social gatherings. However, they mentioned they no longer isolate themselves from their environment rather they openly discuss about the situation. On the other hand, few other participants discussed they still prefer not to communicate the situation of their child within their community and developed self-imposed isolation from their fear of societal judgment.

Individual differences were observed in relation to disclosing the situation of their child within their community. The majority of the participants were able to communicate their experiences in managing challenges such as social isolation. However, there were some other participants who struggled to freely communicate about their past experiences. In managing challenges related with social isolation, personal strength of individuals plays a great role. Neff and Faso (2014) highlighted in their study that managing stress related to self-blame depends on the personal characteristics of parents raising a child with autism. The authors referred to such personal characteristics as self-compassion that refers to being less tight on oneself during challenging situations, being conscious about others in similar situation and being mindful about one's thoughts. According to the authors of this study, higher self-compassion results greater well-being. Altieri and von Kluge (2009) also highlighted that having transformed views of life allows parents to gain personal benefits from raising a child with autism. Some parents in Altieri & Kluge's study mentioned how their level of compassion and patience has grown as they began to cope with their child's situation.

The findings from the current study also supports some of the studies conducted in western culture. For instance, parents in this study also mentioned how they learned to manage their emotions on difficult situations related with raising their child. This ability of parents demonstrates self-compassion that parents developed though time. In addition, self-compassion is also described by being aware of other people in similar situation in order to be able to manage one's stress. The finding from this study also revealed that as parents started to become aware about other parents in comparable situation, they began to transform their views about having a child affected by autism. As a result, it allowed them to be more focused towards improving their child.

6.1.2 Awareness about the situation

According to most participants in this study, the various forms of challenges in raising their child resulted from lack of understanding about autism. Most parents spent years making their own assumptions instead of working towards seeking a proper treatment for their child. Moreover, various spiritual attributions regarding the situation of their child also prohibited them from seeking proper treatment for their child. Samadi and McConkey (2011) conducted a study in Iran and reviewed the importance of information to parents raising a child with autism. The absence of information can lead parents to grasp unclear concepts about the causes and treatments of autism. They also compared how sources of information differ between affluent

and less affluent countries. For less affluent countries, the main source of information was found to be other parents that are in a similar situation while self-researching using books and websites were reported as the main sources of information for affluent countries. Midence and O'Neill (1999) reported a major finding regarding parents' lack of awareness about the autism in general and the situation of their child in particular. They emphasized how the lack of understanding about autism and their child's situation leads parents to confusion and self-blame. It can also complicate communication between parents and greatly affects marital relationships.

In the current study, a participant mentioned that her husband was more aware about autism and that allowed them to design a better life for their child including finding early treatment and appropriate school. Some participants also discussed about their personal attempts to research and understand about autism. They mentioned that reading has helped them by widening their views on the subject. However, other than these few exceptions the majority of participants confirmed that they were not well informed about the situation during the initial stages. This study has been conducted in the capital city of Ethiopia where the majority of the people have access to broadcast media such as radio and television and print media such as newspapers and brochures. However, there is less information broadcasted in these media regarding essential health topics especially topics involving behavioral disorders.

6.1.3 Acceptance and adjustment

Acceptance plays a key role in allowing parents to take action and seek treatment to their child affected by autism. In this study, the role of acceptance in moving towards action has been repetitively highlighted by parents and staff. Accepting the situation of the child is approaching half way closer to the solution of the issue. A significant difference was clearly observed between those parents who fully accepted the situation of their child and those who are still struggling to accept the situation of their child. Some of the parents who accepted the situation are fully committed to provide a better future for their child. Although acceptance depends on the personality of an individual, both organizations are highly engaged in supporting parents using various trainings and counselling sessions. It is very fortunate that both organizations are owned by women who also happen to have a child affected with autism. This provides a ground for parents to easily communicate their issues with the owners. It also makes it easier for the owners to share their experiences with parents about the journey of raising their child. Even though there are individual differences in accepting situations, other factors such as socio-economic status and support from family and friends also facilitate acceptance. As stressed by

staff who participate in this study, those parents without economic constraints can rapidly accept and cope with the situation. This is often due to the lack of restrictions they face in order to meet the demands of their child. Parents who accepted the situation of their child easily move on to seeking ways to provide help.

Existing studies confirmed the role acceptance plays in strengthening parents in their journey of raising a child with autism. Hoogsteen and Woodgate (2013) discussed parents raising a child with autism pass through a phase of emotional breakdown prior to attaining a certain level of acceptance. Their findings confirmed that after certain period of time of sadness, parents were able to accept the situation in order to proceed towards solution. Lutz et al. (2012) also confirmed that mothers raising a child with autism pass through several stages until they reach to the level of adaptation. They mentioned that that adaptation takes places through a journey of grief and anger. However, once mothers reach to the level of adaptation, they tend to work for a better future of their child. Altieri and von Kluge (2009) also highlighted that despite the emotional hardships and personal struggles parents experience, in the end they proceed to pulling all their resources for the improvement of their child.

The results from the present study also demonstrates that acceptance is a process and it requires certain amount of time until parents internalize the life altering situation of their child. Although time is necessary element in the process, individual differences in accepting and adjusting to the situation rapidly were observed in participants of the current study. Acceptance and adjustment are facilitated by integrated support from spouse, family and community. However, it is also personal process where parents communicate with themselves and examine their personal strength at such a challenging situation.

6.2 Discussion in relation to Salutogenesis Theory

The following section discusses the findings in the light of theoretical framework selected for this study that is salutogenesis theory. Salutogenesis theory views health as a movement along a continuum from disease to health. The main aim of this theory to focus on factors that cause movement towards health instead of factors that causes disease. Even though people are constantly exposed to various stress (stressors) factors throughout their lives, they are able to endure and proceed to health. Salutogenesis theory aims to study such factors that leads people to move towards health. The theory can be applied at individual, group, and societal level (Lindström & Eriksson, 2005).

6.2.1 Life situation

In salutogenesis theory, the life situation refers to the various aspects in the life of an individual which can result in either a stressor or a resource. Aspects of life such as culture, social forces, social position, gender, ethnicity, age, genetics and luck play a key role in creating either a stressor or a resource in the life of an individual. These aspects of life situation may give rise to either stress exposures or generalized resistance resources (GRRs). For instance, individuals raised in supportive culture will be provided with resources and life experiences necessary to manage stress which leads to perceiving life as comprehensible, manageable and meaningful (Benz, Bull, Mittelmark, & Vaandrager, 2014).

Based on the responses acquired from participants, among the various aspects of life situations, culture gender and economic status are mainly emphasized in this study. Culture was viewed as both a resource and a stressor for participants. For some participants, culture affected them in an adverse way and worsened their challenging life of raising a child with autism. As mentioned by most participants, they were not able to take their child to hospital early. This is due to common trend to rely on information from neighborhoods rather than going to hospitals to get treatment. Participants mentioned they have observed their child was not able to speak but they collected information from neighborhood and relatives that some children make words at a later age. This made them to assume their child is also in a similar situation. As a result, they preferred to wait for situations to happen rather than trying to take actions for the treatment of their child.

For other participants, the strong rooted Ethiopian culture of family support has helped them throughout their journey. In Ethiopia, in addition to immediate family members such as mother, father and siblings, extended family members assist in raising a child. Some participants mentioned that they find it helpful to be able to leave their child with a relative while they perform their daily activities. The role of social support in families raising a child with autism was also highlighted in the findings of Greeff and Van der Walt (2010). This paper discussed when families are able to find support in their community they can easily adapt to their difficult situation as compared to families that are not able to obtain any community support.

Gender differences were also observed in this study. In most cases, fathers are the breadwinners in the family. As a result, if a child with autism has to remain home, it is the responsibility of the mother to quit her job and take care of the child. Meirsschaut et al. (2010) studied experiences of mothers with a child affected by autism and their findings revealed that, mothers

were unable to perform normal family activities since family life with a child with ASD has to be very structured and planned. Mothers also mentioned job and career adjustments they made to care for their child. A study conducted in Taiwan by Gau et al. (2012) reflected on the employment differences of mothers and fathers raising a child with autism. Results from this study suggest mothers raising a child with autism have lower employment rate in order to provide full time care for their child. Another study by Brezis et al. (2015) conducted in India, provided a training program aimed to empower parents raising a child with autism. Their results indicated that the traditional role of mothers in India is primarily being caregivers for their child. As a result, mothers are usually more involved with childcare than fathers. However, this study also confirms that fathers have a problem focused approach and focus less on blame. This ability of fathers not to focus on blame plays an important role in improving family relationships.

In addition to employment differences in the family, raising a child with autism also affects marital relationships. Two of the participants in this study reported that they faced marital problems leading up to a divorce after they had a child with autism. The responses from staff at the organization also confirmed that divorces after giving birth to a child affected by autism frequently happen in families. It is reported as being a common trend for the fathers to leave the mothers with the child. A study by Gau et al. (2012), also discusses that raising a child with autism creates low marital happiness and difficulties within the married couple.

In the current study, even though household burdens are placed on mothers, most fathers who participated in the study were well informed about the situation of their child. Some of the fathers clearly communicated the daily routines and behavior of their child. This demonstrates there is certain level of commitment by the fathers in raising the child with autism.

6.2.2 Generalized resistance resources (GRRs)

One of the main concepts in salutogenesis theory is generalized resistance resources (GRRs). GRRs are resources that facilitate individual's successful management of stress (Antonovsky, 1996). There are different types of GRRs such as Money, Knowledge, experience, self-esteem and social support (Lindström & Eriksson, 2006). As individuals are able to utilize these resources, they can be able to resist stress and perceive the world as meaningful regardless of repetitive stressful stimuli (Antonovsky, 1996). In this study, support systems such as family, school, economic status and religion are discussed as major resources by the majority of the participants.

Family support

According to the responses from some participants in this study, family served as a major support system in challenging situations related to raising a child with autism. For some participants, family members such as cousins, siblings of parents and other family members provided enormous support in transporting their children to and from school. Such type of support was mentioned as a major support by some participants. The importance of family was also confirmed in the paper by Ludlow et al. (2011). According to their study on parents raising a child with autism, the findings show that parents who were able to get support from extended families were able to better cope with the situation. Although it is challenging to acquire adequate family support, those who were able to get help were found to better cope and have positive experiences. Lutz et al. (2012) also discussed the role of family support in coping process of parents raising a child with autism. This study mentioned how mothers seek for people to support them and the challenges they face whenever they fail to get support from family members. Hall and Graff (2011) further explained the importance of family support. According to their study, parents raising a child with autism are likely to depend on family support. This study also emphasized that parents tend to rely on support and care from spouse. In addition to spousal support, parents also depend on support from parents' relatives of kin.

The findings from the current study also corroborates with the studies mentioned above. Although most parents find it a challenge to find family support, those who were able to access it were better in coping with their situation.

Belief system

For most participants their belief system has greatly helped them throughout their journey. They mentioned different types of religious activities that allowed them to strengthen themselves. Most parents mentioned that they attend church and some mentioned that they also try to take their child to church. According to participant parents, their belief is a source of hope and positive expectations. Various other studies also highlighted the role of belief system serving as a resource. Myers, Mackintosh, and Goin-Kochel (2009) stated in their finding how parents found their spiritual life enriched due to the situation of their child. Parents in this study stated that they are able to see their child as a unique gift provided to them and they viewed autism as a calling to get closer to their spiritual life. The study by Greeff and Van der Walt (2010) also highlighted parents' viewed their faith in God as a main factor to facilitate their adaptation process. Their faith has allowed parents to have purpose and meaning in their lives. Faith in God was rated by the families in this study as an important factor contributing to

adaptation. Dababnah and Parish (2013) mentioned belief system in related with acceptance with the situation. Some of the participants in their study confirmed that their condition as a situation given from God in which they have no control over.

The findings from the current study revealed how parents utilized their belief system as resource to accept the situation of their child. Most parents who participated in this study are part of a community where disorders such as autism are attributed to evil spirit. The majority of them suffered from such perceptions with in the community. However, parents were able to use their belief system as a way to strengthen themselves in order to accept the situation of their child. It was mentioned by majority of parents that it is 'God's will' for them to give birth to a child with autism. For most of them this is not irreversible situation and the only way to see their child grow is to accept the situation.

Economic status

A resource emphasized by both parents and staff in this study was the role that economic status plays in raising a child affected by autism. According to the participants, children with autism have special needs that require enormous investment. Similar to other children, parents need money to satisfy the needs of their children that include balanced diet, school fees and other needs. Those with relatively better economic status can at least provide the material demands of the child. However, parents with no sufficient source of income are likely to be challenged to meet the demands of their child. Such findings were also confirmed in various publications. For instance the findings from Weiss et al. (2013) revealed that parents raising a child face different demands that require adequate income. As parents fail to meet these demands, it can lead them to crisis. In a study by Dababnah and Parish (2013) that was conducted in West Bank it was stated that parents raising a child with autism experienced financial hardships to meet their children's needs. In total, these intimidating financial, psychological, and caregiving burdens led parents to feel embarrassed about their child's condition. While the parents in this study demonstrated resilience, the findings overall revealed they are vulnerable to further psychological, emotional and financial stressors. Myers et al. (2009) stated in their findings how parents mentioned struggles in relation to different costs while raising their child such as therapies, special schools, and special diets. In their study, most parents met these enlarged needs with just one income.

According to the staff at Nia Foundation who participated in this study, economic status can be a resource for those with sufficient income and a stressor for those with insufficient source of

income. This led the organization to design income generating activities that benefit parents to organize themselves in a support group. Financially challenged parents are supported by the organization to start their own small businesses in order to support themselves and their family. These income generating activities are effectively empowering parents financially by allowing them to acquire better economic status to resist the stressors they face.

The availability and utilization of the points mentioned above serves as a GRR to the majority of parents in this study facilitating their coping process. Moreover, parents in this study were also able to access a resource that is specific to their situation. As discussed by Mittelmark et al. (2016) such resources are termed as specific resistance resources (SRRs).

Schools as a Specific Resistance Resources (SRRs)

Specific Resistance Resources (SRRs) are resistance resources that are available for specific situations and people are able utilize them to manage their particular stressors. Specific resistance resources are enhanced by actions taken by individuals and groups having the intent to contribute in the creation of health promoting environments (Mittelmark et al., 2016).

Based on the information acquired from participants, the two private organizations Nia Foundation and Nehemiah Autism Center are serving as an SRR mainly focusing on children affected by autism and parents raising these children. The children enrolled in these organizations are those specifically affected by autism and related disorders. These children benefit from services provided by the centers such as the integrated rehabilitation service, education and training. Moreover, parents benefit from the organization in other forms such as being provided with a school where they can enroll their child. This plays an important role in allowing parents to cope with stressors related with the placement of their child with autism. The organizations also provide parents with a certain amount of free time that can be used for working and earning a better income. These organizations are also serve as a venue where parents facing similar stressors discuss their issues together and support each other for the better future of their children. In addition, the organizations are also making an effort to work hand in hand with the public to raise awareness of autism in the society. Such efforts greatly contribute for the creation of supportive environments for children affected by autism and their parents.

Although, these schools serve as a major support for parents, there are challenges they face. It was highlighted by the staff that there are a great number of students that are on waiting lists for entrance to the schools. Due to the shortage of sufficient space, the schools find it difficult

to accommodate large number of students at once. In addition, both schools are located in the capital city which makes it difficult to address children with autism residing outside the capital city. It was stressed by the staff and the owner that more government intervention is necessary to achieve the desired change. The staff also highlighted that children with autism require more space and materials which requires considerable investment.

6.2.3 Sense of coherence (SOC)

Parents who participated in this study continually mentioned how they were confronted with various types of stressors. However, what is common to all these parents is their ability to overcome these stressors and come out in public.

The sense of coherence refers to the strong belief an individual retains despite the exposure to stressors. Stressors can result from different incidents that arise from internal and external environments. However, individuals develop the ability to perceive these incidents as predictable, resources are accessible to manage and it is a meaningful commitment (Antonovsky, 1993). The SOC is a concept which is universally meaningful and observable across lines of gender, social class, region and culture. SOC refers to factors which always are the foundation for successful coping with stressors (Antonovsky, 1993). SOC can be defined by three sub dimensions namely, comprehensibility, manageability and meaningfulness. Comprehensibility which refers to understanding various stressors from internal and external environment as predictable. Manageability is the belief of having necessary resources to overcome stressors and meaningfulness and individual's perception that the problem is worthy of commitment.

Comprehensibility

Comprehensibility refers to understanding different types of stressors from internal and external environments (Lindström & Eriksson, 2006). In this study, most participants mentioned during the initial stage of awareness about the situation of their child, they observed different types of stressful behavior in their child. Such observations kept them confused and stressed until they started to observe and record repetitive behavior of their child. The predictable behavior the child demonstrates was considered as the crucial sign to understand about the situation of their child. The staff at the organization also mentioned that they provide individual training to the children since this will allow them to easily follow each child according to the specific needs he or she demonstrates. Understanding the behavior of a child is important for parents in their life long process of raising their child. Understanding goes hand in hand with fully accepting

the different behavior of the child. Although it depends on the severity of the disorder, children with autism are generally trainable. When parents are able to accept the behavior of their child, their goal shifts towards working on behaviors that can be improved through time. When parents integrate understanding with acceptance, they tend to seek small progress of their child and intensively work for a better future.

Manageability

Manageability refers to the belief of having all the necessary resources to overcome the stressors. In this study, it was clearly observed that once parents were aware about the situation of their child, they search for various alternatives to find help for their child. Parents' belief of having the resources to overcome their situation appears after understanding of the situation. It is normal for families to deal with issues such as time, financial and social management issues with a presence of a child in their lives. For parents that have a child with autism, managing time, finance and social aspects of life is even more important. If parents understand that a child with autism requires more time, they will find ways to live their lives by spending more time with their child despite other social obligations. Parents who understand their child's situation will also know that they require better finances for major expenses such as health care and school fees. This will allow them to focus on their savings. Parents also have to manage stressors involving in their social life. This goes hand in hand with managing their time. Parents who understand their child's situation, will benefit by attending selected social activities rather than attending all.

Meaningfulness

Meaningfulness refers to the commitment of parents to strongly believe that their child's behavior will progress for the better as long as they continue their effort. In this study, some participants reported that they devote a lot of time towards their children's situation. They spend most of their time attending regular meetings at their schools, discussing with other parents in similar situation and personally researching about autism. The staff who participated in this study mentioned that a small number of students with mild autism have managed to join regular schools with other students. Some of the parents indicated that they are hopeful their child will join regular schools one day if they continue their efforts.

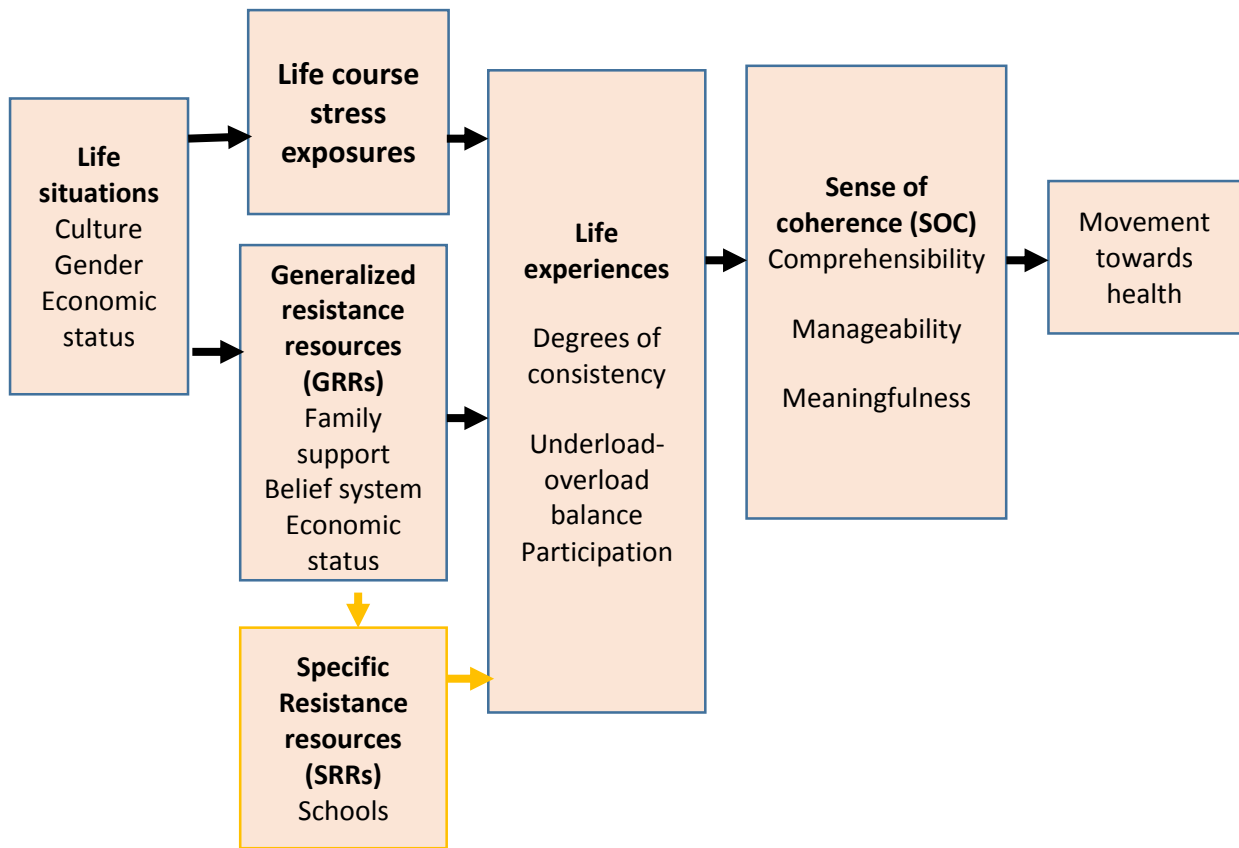


Figure 4: The salutogenic model applied to parents raising a child with autism in Ethiopia

7 Limitations, conclusion and recommendation

7.1 Limitations

Some of the factors that might have affected the quality of the data collected are acknowledged in this section. A major limitation in this study is the failure to conduct FGD with fathers. Although, I initially aimed to conduct FGD with both mothers and fathers, it was not possible to conduct the FGD with fathers due to several factors. The personal experiences of fathers were addressed during the individual interviews conducted. However, fathers' experiences regarding their social lives were not captured due to the inability to conduct the FGD. This might have impacted the quality of the data since I was not able to acquire the perspective of fathers in FGD which can limit observations about gender differences.

Another limitation to mention is related to the two interviews conducted with a couple at their homes. In both of those interviews the fathers dominated the interview to a certain level and discussed more about the issue. This could not provide the opportunity for the wives to clearly communicate their ideas. This possibly affected the data that can be gathered from the mothers if they were to provide the interview independently.

Moreover, this study is limited to parents who have a child enrolled at schools designed for children with autism. However, acquiring the experiences of other parents who did not have access to enroll their child at school would have added value to the data.

7.2 Conclusion

This study was conducted with parents raising a child affected by autism using qualitative research. The study was focused on exploring stressors that these parents experience and identifying the resources that help them overcome the stressors. Furthermore, the study employed the concept of salutogenesis theory in order to investigate the existence of sense of coherence (SOC) in parents raising a child with autism.

In exploring the first objective, several types of stressors were observed in parents who participated in this study. Out of these stressors, lack of understanding and inaccessibility of facilities are the major points that are considered to challenge parents. This study confirmed that lack of understanding about autism is a main factor for many aspects stressors on parents raising a child with autism. The majority of parents had no understanding about autism before the diagnosis of their child. This challenged parents in managing the behaviours of their child. Moreover, limited understanding about the disorder delayed parents from finding diagnosis to their child in the appropriate time. Lack of understanding about autism within the society also

creates additional stressor to parents by contributing to the social isolation that parents face due to the situation of their child. Although parents are striving to integrate their child with autism into the community, they still struggle from the societal judgment they face. Hence, they tend to deprive themselves from any social life.

The few participants who had a little understanding about autism were better in making an effort to find diagnosis to their child at an early stage. However, inaccessibility of health professionals specialized in childhood developmental disorders and the lack of proper treatment were exhausting to parents. The findings of this study also demonstrate that facilities designed to accommodate children with disorders such as autism are not easily accessible to parents. There are only few private organizations in Ethiopia that are making effort to provide education and treatment to children with autism. Moreover, these organizations are located in Addis Ababa, the capital city of Ethiopia. As such, they are not easily accessible to children affected by autism that are residing in other parts of the country. Although the number of children affected by autism in Ethiopia is not clearly stated, it is obvious that these private organizations currently have limited capacity to accommodate large number of children at once.

In relation to resources, it was observed in this study that parents utilize resources to manage various stressors they face. Mainly the two organizations, Nia foundation and Nehemiah Autism Center, are viewed as a resource for the majority of parents. These organizations played a key role in serving as a centre that trains children with autism. They also provide parents with a central location to discuss with other parents that are in a similar situation and foster support among each other in various ways. In addition to the above resources provided by the organizations, some participants also report financial stability as a resource for the stressors they face when raising their child with autism. Parents that are raising a child affected by autism need to provide for all the needs of their child the same as parents raising a healthy child. However, the extra need that children with autism require pushes parents of such children to be able to provide more. Those who are reported financial stability as a resource have the capacity to meet the demands of their child and seem to better cope with the situation compared to parents that are under financial constraints.

In addition to the external resources that parents acquire from the two organizations, another essential resource identified is parents' acceptance of the situation of their child. Acceptance is process that requires certain amount of time and it greatly differs from one individual to another. Parents' ability to accept the situation of their child plays an important role in supporting their commitment towards their child. The role of acceptance was also reflected on the application

of the salutogenesis concept, SOC. Sense of Coherence was identified in the majority of the participants manifested through its basic components: comprehensibility, manageability and meaningfulness. Specifically, comprehensibility indicates parents understood the behaviors demonstrated by their child and linked acceptance along with comprehensibility. Incorporating understanding with acceptance equipped parents with the necessary preparation to seek for support and continue their attempt for the progress of their child.

Though it was not part of the main objectives, gender differences were also observed in this study. Among participants in this study were divorced single mothers. Most of the participants physically remain with their children and take responsibility of caring for them while the fathers leave home and provide from afar. In such family situations, the single women explained the heavy burden of caring for their child with autism. Most of these women also blame themselves or are blamed by others regarding the situation of their child. In most studies regarding gender and autism, such blame outcomes were discussed to be a result of lack of awareness about autism. The single women in this study also reported that they face financial and emotional stressors as a single parent raising a child with autism. On the contrary, this study also came across fathers who were well informed about autism and the daily routines of caring for children with autism. These fathers explained that they understand their child's situation and work with their spouse to make a better life for their child instead of blaming their wife.

In summary, this study explored parents raising a child with autism in Ethiopia are exposed to various forms of stressors. However, this did not prohibit them from coming out in public and allowing their children to join schools. The SOC evident in the majority of parents is also facilitating the journey of parents towards the health of their children and themselves. Professionals in Nia Foundation and Nehemiah Autism Center are also working hand in hand with parents for the improvement of their children.

7.3 Recommendations

The findings from this study clearly demonstrate that parents raising a child with autism pass through various stressful situations. Lack of government intervention regarding health issues such as autism posed additional responsibility on few individuals who are running organizations for children with autism. The two organizations that are currently functioning are only limited to the capital city Addis Ababa. With more government intervention, the number of institutions that provide service to children with autism can be enhanced and children living outside of the capital city can also be addressed. Since children are the upcoming work forces that build a

nation and the world at large. Children with disorders such as autism have much to offer for their nation and the outside world if they are provided with a conducive environment specific to their situation.

Considering the heterogeneity of Ethiopia, conducting a study in other parts of the country is highly recommended. Further research with parents raising a child autism residing outside of Addis Ababa can provide a varied understanding about the magnitude of the issue.

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Appendices

Appendix 1. Ethical clearance from Norwegian Social Science Data Services (NSD)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Høgskoleplassen gate 2
N-5007 Bergen
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Fax: +47 55 58 06 50
nsd@nsd.uib.no
www.nsd.uib.no
Org nr: 585 321 884

Marguerite Daniel
HEMIL-senteret
Universitetet i Bergen
Christiesgt. 13
5015 BERGEN

Vår dato: 15.08.2015

Vår ref: 43465 / 1 / MBB

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 13.05.2015. Meldingen gjelder prosjektet:

43465	<i>Resources in raising a child with autism: parents' perspectives</i>
Behandlingsansvarlig	Universitetet i Bergen, ved institusjonens øverste leder
Daglig ansvarlig	Marguerite Daniel
Student	Mahlet Gebre

Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektet opplever endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig.

Vennlig hilsen

Vigdis Namtvedt Kvalheim


Marie Strand Schildmann

Kontaktperson: Marie Strand Schildmann tlf: 55 58 31 52
Vedlegg: Prosjektvurdering
Kopi: Mahlet Gebre, Fantoft studentbolig, 5075 BERGEN

Personvernombudet for forskning



Prosjektvurdering - Kommentar

Prosjektnr: 43465

Based on the information we have received about the project, the Data Protection Official cannot see that the project will entail a processing of personal data by electronic means, or an establishment of a manual personal data filing system containing sensitive data. The project will therefore not be subject to notification according to the Personal Data Act.

The Data Protection Official presupposes that all information processed using electronic equipment in the project is anonymous.

Anonymous information is defined as information that cannot identify individuals in the data set in any of the following ways:

- directly, through uniquely identifiable characteristic (such as name, social security number, email address, etc.)
- indirectly, through a combination of background variables (such as residence/institution, gender, age, etc.)
- through a list of names referring to an encryption formula or code, or
- through recognizable faces on photographs or video recordings.

Furthermore, the Data Protection Official presupposes that names/consent forms are not linked to sensitive personal data.

If the participants will be contacted by the student/researcher, we presuppose that the Duty of confidentiality is not in conflict with this method and that the contact information used for recruiting participants is not connected to the other data.

Appendix 2 Letter from supervisor



UNIVERSITETET I BERGEN
Det psykologiske fakultet

Department of Health Promotion and Development
The Faculty of Psychology
University of Bergen
PO Box 7807
5020 Bergen
Norway

25 March 2015

To Whom it may concern,

I am the academic supervisor for Mahlet Gebre who is currently doing an International Master's in Health Promotion. I confirm that she will be travelling to Ethiopia from mid-June until mid-September 2015 in order to carry out fieldwork. The data she will collect in Ethiopia will be an essential part of her Master's thesis.

Yours sincerely,

Marguerite Daniel
Director, International M.Phil. in Health Promotion

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Appendix 3. Informed consent forms in English language

i. Explanation of the study for participating adults

This study investigates the resources for parents raising a child with autism. Despite all the challenges in raising a child with behavioural disorders such as autism, some parents are found to cope with the situation better than others. It is the intention of this study to explore the resources that particularly strengthen parents' ability to cope with such difficult situations. If you agree to participate, you will be involved in an interview and in a focus group discussion divided into two groups, female and male groups. The interview is expected to last one hour and each of the focus group discussions are expected to last an hour and a half.

The collected information will be given back to the organizations so it can contribute to improving the organizations. Your experiences with the organizations will provide essential information to this study. If you agree to participate in this study, your own name will not be used in the written report and it will not be possible to trace who provided which information. Whatever is said in the interviews or activities will not be passed on to other people in the community. Recordings of the interviews or group discussions will be destroyed after they have been transcribed.

If you agree to participate in this study, you are free to withdraw at any time or may refuse to answer any of the questions asked to you.

If you agree to participate, please read and sign the statement below.

Thank you for your cooperation.

Mahlet Gebre

Contact mobile number- +479739807/+251911646206

Email address- mahletbirhanu14@gmail.com

ii. Informed consent form for parents

The purpose of this study has been explained to me and I understand what it is about. Participation involves two focus group discussions and interview.

It has been made clear that if I agree to participate in the study, my own name will not be used and, in the written report, it will not be possible to trace what has been said by me. Whatever is said in the interviews or activities will not be passed on to other people in the community. Recordings of the interviews of group sessions will be destroyed after they have been transcribed.

I am free to withdraw at any time or may refuse to answer any of the questions asked of me.

Name _____

Signature _____

Date _____

iii. Informed consent form for staff

The purpose of this study has been explained to me and I understand what it is about. Participation involves interview.

It has been made clear that if I agree to participate in the study, my own name will not be used and, in the written report, it will not be possible to trace what has been said by me. Whatever is said in the interviews will not be passed on to other people in the community. Recordings of the interviews will be destroyed after they have been transcribed.

I am free to withdraw at any time or may refuse to answer any of the questions asked of me.

Name _____

Signature _____

Date _____

Appendix 4. Informed consent form in Amharic language

ለተሳታፊዎች አጭር የጥናቱ ማብራሪያ

ይህ ጥናት ኦቲዝም ያለባቸውን ልጆች የሚገነባዘቡ ቤተሰቦች ላይ ያተኩራል። እንደ ኦቲዝም ያሉ የማሕበራዊ ግንኙነት እና የተግባራት ክህሎትን አዳጋች የሚያደርጉ ሁኔታዎች ላይ ያሉ ልጆችን ማሳደግ አስቸጋሪ እንደሚሆን ቢጠበቅም፣ አንዳንድ ቤተሰቦች ግን ሁኔታውን ክሌሎች በተሻለ መቋቋም ሲችሉ ይታያል። በዚህ ጥናት ቤተሰቦች በተለየ መልኩ ብርታት ሆኗቸው ሆኔታውን ለመቋቋም የሚያስችሏቸው ጉዳዮች ላይ ትኩረት ይደረጋል። በጥናቱ ለመሳተፍ ከፈቀዱ ከ30 እስከ 50 ደቂቃ በሚደርስ ቃለመጠይቅ ውስጥ እንዲሳተፉ ይጠበቃል። በቃለ መጠይቁ ወቅትም ተገቢውን መረጃ ለመሰብሰብ ድምጽዎ የሚቀዳ ይሆናል።

ከቃለ መጠይቁ የተሰበሰበው መረጃ በዋናነት ለመመረቂያ ጽሁፍ ማሟያ የሚውል ሲሆን በተጨማሪም ለነህምያ ኦቲዝም ማዕከል ተጨማሪ ግብዓት እንደሚሆን ይጠበቃል። በማዕከሉ ልጆቻችን በማስተማር ሒደት ውስጥ ያልሆኑትን ልምድ መግለጫም ጠቃሚ መረጃ ሆኖ ይገለገላል። ለመሳተፍ ፈቃደኛ ከሆኑ የእውነተኛ ስምዎ በጥናቱ ላይ አይገለጹም። በመሆኑም መረጃውን መስጠትዎን ማወቅ የሚቻልበት መንገድ አይኖርም። በቃለ መጠይቁ ወቅት የተቀዳው ድምጽዎ በፊርማ ከተገለጠ በኋላ ወዲያውኑ የሚሰረዝ ይሆናል። በማንኛውም ሰዓት ቃለ መጠይቁን ማቋረጥ እንዲሁም መመለስ ለማይፈልጋቸው ጥያቄዎች ምላሽ ያለመስጠት መብትዎ የተጠበቀ ነው።

ለመሳተፍ ፈቃደኛ ከሆኑ እባክዎን ከዚህ በታች ባለው ቦታ ላይ ፊርማዎትን ያጉሩ

ለትብብርዎ አመሰግናለሁ

ማሕሌት ብርሐኑ ገብራ

ስልክ ቁጥር 0947 508009

የኢሜይል አድራሻ mahletbirhanu14@gmail.com

የፊቃደኝነት ማረጋገጫ

የዚህ ጥናት አላማ የተገለጸልኝ ሲሆን በቃለ መጠይቅ ውስጥ ተሳትፎ እንደሚኖረኝ ተረድቻለሁ። ለመሳተፍ ፊቃደኛ ከሆንኩ የእውነተኛ መጠሪያ ስሜ ስለማይገለጸ የተገኘው መረጃ ከእኔ መሆኑ የሚታወቅበት መንገድ እንደማይኖር ተረድቻለሁ። በቃለ መጠይቁ የገለጸኳቸው ሐሳቦች በማሕበረሰቡ ውስጥ ለሚገኙ ሌሎች አካላት ተላልፎ እይሰጥም በቃለ መጠይቁ የተቀዳው ድምጹም በፅሁፍ ከተገለበጠ በኋላ የሚሰረዝ ይሆናል።

ቃለ መጠይቁን በማንኛውም ሰዓት ማቋረጥ እንዲሁም ምላሽ መስጠት ለማልፈልጋቸው ጥያቄዎች ምላሽ ያለመስጠት መብቴ የተጠበቀ ነው።

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Appendix 5. Interview guides

i. Interview guide to parents

1. How did you receive the diagnosis of your child?
1. What were your experiences before diagnosis of your child with autism?
2. What are your experiences in relation to raising your child after the diagnosis?
3. What resources help you cope with the situation?
4. Can you share the daily routines of your child?
5. What advice would you give to another parent raising a child with autism?
6. If there is anything that is not covered in the questions above that you would like to explain more?

Thank you for your participation!

ii. Interview guide to staff

1. What is your role in the organization?
1. What are the services provided by your organization?
2. How do you describe your relationship with parents who have children enrolled in the organization?
3. What stressors are faced by parents raising a child with autism?
4. What helps these parents to cope?
5. How does enrolment in your organization affect these parents?

Thank you for your participation!

iii. Focus group discussion questions

1. What are the perceptions in the community regarding the situation of children with autism?
2. How do *fathers* of children with autism experience such attitudes/perceptions?
3. How do *mothers* of children with autism experience such attitudes/perceptions?
4. How do parents raising a child with autism interact in the community?
5. What types of societal institutions serves as a support system for parents in the community?

Thank you for your participation!

Appendix 6. Codes and themes that emerged from data analysis

Table 1. Analysis of stressors associated to raising a child with autism

Codes	Basic themes	Organizing themes	Global themes
Hyperactive and energetic child	Behavior of the child		
Prefers being alone			
Demonstrates abnormal behavior			
Child remains unfriendly			
Unable to make words			
Repetitive actions			
Child does not sleep at night			
Child is difficult for toilet training			
Child does not respond to his/her name			
Not aware where to get treatment	Inaccessibility of treatment	Initial stressors	Stressors associated to raising a child with autism
No proper treatment for the child			
Lack of professionals specialized on autism			
Available professionals do not provide the necessary information about autism			
Never heard of the word autism before			
No awareness in the neighborhood			

Parents are not aware about autism	Lack of awareness about the situation		
Condition of the child is not acceptable in the society			
The neighborhood associates the child's disorder with evil spirit			
People point fingers on the child			
Difficulty to meet the special needs of the child	Financial constraints	Ongoing stressors	
Forced to work extra hours to earn better income			
Unable to afford health care			
Cannot afford to own a car and challenged to move to places with the child			
Unable to afford a house and forced to pay for rent			
Unable to leave the child at home to attend social events	Deprivation from social life		
Unable to take the child to any social events			
Difficulty to prepare events at their homes			

Table 2. Analysis of resources associated to raising a child with autism

Codes	Basic themes	Organizing themes	Global themes
Child learns to socialize with other children	Child socialization	Role of schools	Resources associated to raising a child with autism
Child slowly learns to play with other children			
Child learns not to perceive other children as strangers			
In depth understanding about autism	Counselling and trainings		
Learning ways on how to manage the child at home			
Trainings are also provided to siblings and other care givers			
Accessing other parents at the monthly parent meeting	Parent socialization		
Being aware about the existence of other parents in a similar situation			
Meeting other parents with similar situation at the schools			
Learning from the experiences of other parents			
Being able to work once child joined school	Opportunity to earn a living		
Accessing some relief to earn a living after sending the child to school			

Participating in income generating activity designed by Nia Foundation			
Accepting the reality of the child	Developing awareness	Acceptance of the situation	
Starting to learn about autism			
Searching schools for their child			
Managing to reduce their stress			
Striving to support their child at home	Providing guidance at home		
Believing that child can progress at home treatment			
Making the necessary preparation for home treatment			
Child begins to toilet train	Self-helping skills	Small progress of the child	
Child learns to feed him/herself			
Child learns to respond to his/her name			
Child slowly learns to make sounds and words			
Great hope in God		Role of religion	
Taking the child to attend church			
Strong belief in the power of religious activities such as holy water			

Appendix 7. Brochures from Nia Foundation and Nehemiah Autism Center

Joy Center for Children with Autism is the first organization in East Africa to open a center and serve children, adolescents and youth with Autism and Related Developmental Disorders and by far the strongest one of its kind in Ethiopia.

Our Nia
To see children with autism and related disorders having ample opportunity to develop their ability and reach their potentials so that they can be independent, productive and socially accepted members of the community

Mission
Through education, trainings, therapy and awareness creation programs, Joy center strives to brighten the future of persons with autism and their parents

Services we Provide
We are actively engaged in services such as but not limited to;

- ◆ Provision of holistic rehabilitation, education, and training services for children with autism and related disorders
- ◆ Conducting diagnostic and educational assessment for children with Pervasive Developmental Disorders (PDD)
- ◆ Empowering parents, siblings, caretakers, professionals in the field, social workers and the public at large
- ◆ Collaborating with government schools found in Addis Ababa and Oromia towns to increase educational access for persons with autism .


Autism in Ethiopia
Thousands of children with autism in Ethiopia are still the most forgotten and vulnerable ones. Most children with autism in Ethiopia are deprived of their rights for education and rehabilitation because of lack of awareness as they are considered to be useless and unworthy to invest on. They are underprivileged of their very basic rights, even the one to enjoy the day light, the sun shine and their freedom to unite with the society.

It is more likely that Parents, particularly mothers become disabled themselves, burdened and most probably have no or very low incomes as their child's disability directly constrains their ability to work and make a living. This shows that it is not only the child who is affected but their parents as well. The impact of the child's disability creates psycho-emotional and financial distress on parents too.

Statistical evidence on the extent and prevalence of the problem is not sufficiently available in Ethiopia at the moment. Since Autism is found throughout the world and amongst all nations, nationalities and social classes, Ethiopia is not an exception. If one in every 166 children are diagnosed with autism globally, we could fairly say that with Ethiopia's population of more than 94.1 million, we can estimate to have over 550,000 children suffering from autism and related developmental disorders, with no access to rehabilitation, education and training.


Furthermore, in a country like Ethiopia; most attitudes towards mentally challenged persons are not positive. The full acceptance of the rights of children with no discrimination is the key. It necessitates positive attitudes. On the other hand, even if attitudes are changed, a lot still need to be done in the society to facilitate the inclusion of children with autism to encourage them in the regular school system and create access to rehabilitation, education and training.

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**Nia Foundation
Joy Center for
Children with
Autism**

**Understanding
Autism
Awareness Matters**





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NEHEMIAH AUTISM CENTER
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**Together we can change the
lives of autistic children
in Ethiopia!!**

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