

**An-Najah National University**

**Faculty of Graduate Studies**

**Parents' Experience during the Diagnostic Process of Autism  
Spectrum Disorder in the West Bank  
A Descriptive Phenomenological Study**

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**This Thesis is submitted in partial Fulfillment of the Requirements for  
the Degree of Master in Public Health, Faculty of Graduate Studies,  
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The block contains three handwritten signatures. The first signature is in black ink and is partially obscured by the 'Signature' label. The second signature is in blue ink and reads 'Bihan Qaimari'. The third signature is in blue ink and is partially obscured by the 'Signature' label.

بسم الله الرحمن الرحيم و الصلاة و السلام على سيدنا محمد سيد المرسلين

الهي احمذك و اشكر فضلك حمدا كثيرا طيبا مباركا فيه .

الى من احمل اسمه بكل افتخار ... الى من ساندني بكل الحب و العطاء.... الى من يحمل اسمه كل معاني الهيبة و الوقار ... ارجو من الله ان يمد في عمرك و يجعلك دائم الرضا عني ...

والدي العزيز

الى ملاكي في الحياة... الى معنى العطاء و الحنان ... الى فرحة عمري و شبابي ... الى سر الوجود و بسملة الحب ... الى من علمتني معنى الطموح ... الى من اتطلع لان اكون ظلا لرقبيها و انعكاسا لانجازاتها الادبية ... الى من كان دعائها سر نجاحي و تفوقي ... اغلى البشر

امي الحبيبة

كما و اتقدم بخالص العرفان و الامتنان الى ملهمتي .... الى انسانة دعمتني معنويا و قربي منها اضاف لي الكثير ... الى انسانه يحمل اسمها كل معاني التفاؤل و الامل ... الى من تجسد الرقي و الذكاء برونقه بشخصها و انجازاتها .....الى

خالتي العزيزة امال ابو شمس

الى انسان عزيز على قلبي استمد منه قوتي و طموحي في الحياة ... الى انسان رائع كروعة يافا و بياراتها

جدي العزيز خليل ابو شمس

الى توأم روحي ورفقاء حياتي .... الى اخواتي الاحباء نيفين و نادين و اخي الحنون نمر.

الى حبيبي و رفيق دربي ... الى معنى الحنان و الطيبة...الى شريكي في الطموح.... الى من ساندني بكل ما للكلمة من معنى .... الى من ارى التفاؤل بعيني و اختصر السعادة في ضحكته ....

زوجي الحبيب

الى كل من مد لي يد العون لأخطو في طريق العلم .....شكرا لكم...

و اسمحوا لي ان اهديكم بحثي هذا.

## الشكر والتقدير

افضل الحمد و الشكر لله عز و جل و عونہ لي لإخراج هذا البحث في صورته النهائية

الشكر جزيل الشكر الى استاذتي الفاضلة و مشرفتي و صديقتي ... الى من امدت لي يد

العون....الى انسانية فريدة من نوعها ....الى من وثقت بقدراتي على اتمام هذا البحث على افضل

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الى استاذي الفاضل ... الى من علمني التميز و ان اطمح لأعلى المراتب العلمية... الى من طبع

بصمة لا تنسى على شخصيتي و طريقة تفكيري للأفضل .... لأنه الافضل يستحق جزيل الشكر

دكتور زاهر نزال

ال كل الاساتذة الافاضل في الصرح العلمي الكبير لكلية الدراسات العليا قسم الصحة العامة

و الشكر كل الشكر لأهالي الاطفال الذين سمحوا لي بكل حب مشاركتهم خبراتهم و قصصهم

الشخصية و لم ييخلوا بالحديث عنها ... لقد كنتم النواة الاساسية لإتمام هذا البحث .... لكل ام و

اب شارك بتجربته لكم مني كل الشكر و الحب.

الى معهد النجاح للطفولة و جميع القائمين عليه الذين ساعدوني في الحصول على معلومات

خاصة لإتمام هذا البحث ... اتمنى لكم كل التوفيق و الازدهار و التميز.



## الافرار

انا الموقع ادناه مقدم الرسالة التي تحمل العنوان :

Parents' Experience during the Diagnostic Process of Autism Spectrum  
Disorder in the West Bank  
A Descriptive Phenomenological Study

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## List of Abbreviations

<b>ABA</b>	Applied Behavior Analysis
<b>ACI</b>	An-Najah Child Institute.
<b>ADD/ADHA</b>	Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder
<b>ADI-R</b>	Autism Diagnostic Interview Revised
<b>ADOS-G</b>	Autism Diagnostic Observation Schedule –Generic
<b>ASD</b>	Autism Spectrum Disorder
<b>ASQ</b>	Autism Screening Questionnaires
<b>CARS</b>	Childhood Autism Rating Scale
<b>CAST</b>	Childhood Autism Spectrum Test
<b>CDDs</b>	Child Development Disorder
<b>CHAT</b>	Checklist for Autism in Toddlers
<b>DABDA Model</b>	Denial, Anger, Bargaining, Depression, and Acceptance (Kubler -Ross model in grieving)
<b>DSM-5</b>	Diagnostic and Statistical Manual for Mental Health Disorders (fifth edition)
<b>IEP</b>	Individualized Education Plans
<b>IIP</b>	Individualized Intervention Programs
<b>LD</b>	Language Disabilities
<b>M-CHAT</b>	Modified Checklist for Autism in Toddlers
<b>MMR</b>	Measles, Mumps, and Rubella Vaccination
<b>Montessori KG</b>	Montessori Kindergarten
<b>OT</b>	Occupational Therapy
<b>PDD</b>	Pervasive Developmental Disorder
<b>PECS</b>	Picture Communication System
<b>RRBs</b>	Restricted Repetitive Behaviors
<b>SCQ</b>	Social Communication Questionnaire
<b>SI</b>	Sensory Integration
<b>SL</b>	Speech and Language Therapy
<b>SSRI</b>	Selective Serotonin Reuptake Inhibitor
<b>STAT</b>	Screening Tool for Autism in Toddlers and Young Children
<b>TEACH</b>	Treatment and Education of Autistic and Related Communication-Handicapped Children

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**Abstract**

ASD (Autism Spectrum Disorder) is one of the crucial subjects in the mental health sector, and it is a universal, rapidly-growing disorder. The aim of my study is to investigate and describe the experiences of the parents going through the process of diagnosing autism spectrum disorder in the West Bank. Briefly, my specific objectives are to describe: how an autism diagnosis affects families; the psychological impacts on parents; and the physical burden associated with it. I also investigated the consequences of diagnosis of autism spectrum disorder on couples' lives, family dynamics and the effects of community stigma. In order to explore the aim, the Giorgi methodology was adopted, and the design that I used was a qualitative phenomenological descriptive design. I conducted the study on 12 parents of children with autism in the West Bank. Semi-structured face-to-face interviews were conducted to elicit parents' experiences. A thematic analysis of the data identified 4 core themes and 14 sub-themes representing the vital challenging elements of the parents' experiences: diagnosis, stigma, grief, and family challenges. This study is unique in being a pioneer in the field of ASD in the West Bank. It highlights the needs of children and their families throughout the process of diagnosis and afterwards. This study fills a gap in current research on ASD.

**Key words:**

Autism spectrum disorder (ASD), diagnosis, parents' experiences

**Definition of Concepts:**

**Cognitive burden**

**Psychological burden**

**Social support**

**Autism spectrum disorder**

# Chapter One

## 1. Introduction

Autism Spectrum Disorder (ASD) is a universal, rapidly growing disorder, and the experience of the parents going through the diagnosing process is exceptional. This study is unique in being a pioneer in the field of ASD. It describes the experiences of parents of children with ASD and understands how they cope with the diagnosis; it also highlights the needs and challenges facing children and their families throughout the process of diagnosis.

### 1.1 Background

In the Occupied Palestinian Territory (OPT), mental health disorders are extremely prevalent; around one third of Palestinians are in need of mental health interventions. However, these health issues remain under-acknowledged and under-resourced; indeed, mental health services receive some of the least funding of all areas of health interventions. (Abdel Hamid, Samir & Eyad, 2004).

AUTISM, a word that came from the Greeks meaning 'self' describes the condition of the autistic person as the 'isolated self'. This term has been in use for 100 years, and a Swiss psychiatrist named Eugene Blender was the first one to use it to describe a group of symptoms of Schizophrenia. Beginning from 1940s, and more so in the 1960s and 1970s many researchers in the US started using the term AUTISM to describe emotional

and social problems. In the 1980s, 1990s, and until now, the role of behavioral therapy was and is the primary intervention for autism and related conditions. However, medication treatment is added as needed.

Autism is currently the core of many debates in the sector of childhood developmental services. Autism Spectrum Disorder (ASD) and Autism are both general terms for a group of complex disorders of brain development. Autism appears to have its roots in very early brain development. However, the most obvious signs and symptoms of autism tend to emerge between 2 and 3 years of age. ASD is characterized by three areas of deficits: social, communication, and restricted behaviors and interests. Social difficulties include impairment in interactions and ability to form relationships or making friends, lack of automatic social responses and lack of eye contact.

Communication impairment include verbal communication (difficulties in understanding language), and non-verbal communication (the use of pictures, gestures, pointing, nodding, pictures, and showing).

Restricted behaviors and interests include compulsions, stereotyped movement, and strong reactions (positive or negative) to sensations such as smell, touch and sight; in addition to repeating words or phrases, sometimes children flap their hands and rock their bodies (Autism History, 2013).

Diagnosis of ASD: First of all, according to (Facts about ASD, 2014) all children should be screened for developmental delays and disabilities during regular well-child doctor visits at 9, 18, and 30 months. Children

with ASD should visit the doctor at 18 and 24 months. Additional visits may be required from the pediatrician if the child is at high risk (e.g. having a brother or sister or other family member with ASD). If autism symptoms are present, the doctor will begin an evaluation by performing a complete medical history, and physical and neurological exams. Although there is no laboratory test for autism, the doctor may use x-ray and blood tests to determine if there is a physical, genetic or metabolic disorder causing the symptoms. If the doctor finds that there is no physical disorder, the child should be referred to a specialist in childhood development disorders (psychologists and psychiatrists), who will build his/her diagnosis on the child's level of development, and observations of child's speech and behavior.

Regarding screening tools for infants, CHAT (Checklist for Autism in Toddlers) is one of the screening tools for infants that is composed of 5 yes-no items, and used by the pediatrician or family doctor at the 18-month developmental checkup. MCHAT (Modified Checklist for Autism in Toddlers) is a list of 23 yes-no questions about a child's usual behavior for parents of 16 to 30 month-old children to answer. STAT (Screening Tool for Autism in Toddlers and Young Children) is a 20-minute interactive screening measure that consists of 12 items and is designed to assess children of 24 to 36 months? (Diagnosis Overview, 2014).

In addition, there are some screening tools for school-age children: SCQ is a parental questionnaire with 40 yes-no items, ASQ is a 27-item,



yes/somewhat/no-style questionnaire meant to assess the symptoms that are characteristic of high-functioning ASDs in children and adolescents, and the Childhood Autism Spectrum Test (CAST), also known as the Childhood Asperger Screening Test, detects Autism Spectrum Disorders (ASDs) in 5 to 11 year-old children by using a parental questionnaire to measure social and communication skills (Diagnosis Overview, 2014).

Diagnostic tools which can be applied as early as 18 months are: ADI-R (Autism Diagnostic Interview Revised), ADOS-G (Autism Diagnostic Observation Schedule-Generic), and CARS (Childhood Autism Rating Scale) (Diagnosis Overview, 2014).

ASD includes five subtypes: autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder, and Asperger syndrome.

Autistic Disorder, also called classic autism, has significant language delays, plus social and communication challenges, and unusual behaviors and interests.

Asperger Syndrome is considered as the high functioning end of the spectrum. Adults and children usually have milder symptoms than those with autistic disorder.

Pervasive Developmental Disorder, called PDD-NOS and Typical Autism is characterized by only social and communication challenges.

Rett Syndrome and Childhood Disintegrative Disorder are rare types of autism. (Facts about ASD, 2014).

In May, 2013 in the publication of the new DSM-5 diagnostic manual, these autism subtypes were merged under one umbrella diagnosis of ASD. "The Diagnostic and Statistical Manual of Mental Disorders (DSM) is a classification of disorders with associated criteria designed to facilitate more reliable diagnoses of these disorders. DSM-5 is also a tool for collecting public health statistics on mental disorder morbidity and mortality rates." (DSM-5, 2013, p. xii). Also, according to the DSM-5 Neurodevelopmental disorders are classified into: Intellectual Disability, Communication Disorders, Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder, Specific Learning Disorder, Motor Disorders, and other Neurodevelopmental disorders. Briefly, according to the American Psychiatric Association (2013), "Autism spectrum disorder is a new DSM-5 name that reflects a scientific consensus that four previously separate disorders are actually a single condition with different levels of symptom severity in two core domains. ASD now encompasses the previous DSM-IV autistic disorder (autism), Asperger disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. ASD is characterized by 1) deficits in social communication and social interaction and 2) restricted repetitive behaviors, interests, and activities (RRBs). Because both components are required for diagnosis of ASD, social communication disorder is diagnosed if no RRBs are present"

(American Psychiatric Association/Highlights of Changes from DSM-IV-TR to DSM-5, 2013).

**Epidemiology of Autism:** Just as there is no one type of autism, many authors agree on the fact that autism can be multi factorial. Some of the causes can be attributed to genetics and environment; however, there hasn't been any study that has confirmed specific causes yet.

**Genetics:** Some studies that are based on twins and family show that autism is highly inheritable. It is shared among 50-70% of identical (monozygotic) twins, compared with 0-10% of fraternal twins (Folstein & Rosen-Sheidley, 2001). Another study mentioned that 1-6% of children diagnosed with ASD also have a sibling who is diagnosed with autism, a much higher rate than the general population (Chakrabarti & Fombonne, 2001). Autism, in some cases, is known as syndromic autism due to its link with a particular syndrome, Fragile X syndrome, which is a well-defined genetic disorder; a significant proportion of individuals with Fragile X syndrome develop autism (Rogers, Wehner & Hagerman, 2001).

**Environment:** A study by Hallmayer et al. (2011) found that environmental causes are responsible for 58% of ASD. The two main factors are:

**Vaccinations:** Vaccinations is a controversial issue which received a great deal of media and research attention as a potential cause of autism. Studies failed to establish any association between autism and the Measles, Mumps,

and Rubella (MMR) vaccination (Plotkin, Gerber & Offit, 2009; Hornig, et al., 2008; Doja & Roberts, 2006).

Drugs: Some studies considered a link between some drugs and the causes of autism. These drugs are Selective Serotonin Reuptake Inhibitor (SSRI) (Croen, Grether, Yoshida, Odouli & Hendrick, 2011), and Ethanol (Landgren, Svensson, Strömmland & Grönlund, 2010). Other studies found a correlation between the consumption of lead and mercury and the causes of autism (Mutter, Naumann, Schneider, Walach & Haley, 2005). Furthermore, some associated the deficiency of certain vitamins (vitamin D deficiency and folic acid deficiency) to the causes of autism (Mostafa & Al-Ayadhi, 2012; James et al., 2004).

### **Treatment and Interventions:**

Although research has shown that there is no absolute cure for autism and it is a lifelong condition, it was proven that early intervention does positively affect the progress of the condition and lessens associated complications (Treatment Interventions). A child who receives intervention at an early age (highly recommended by the age of 3), will highly benefit and will show progress when compared to a child who does not get any. The areas of intervention therapy involve multiple intervention strategies based on individual needs, for example:

Educational interventions, such as ABA (Applied Behavior Analysis) which is based on psychological approaches of behavior modification (Treatment

Interventions), and TEEACH (Treatment and Education of Autistic and Related Communication-Handicapped Children), which is an educational intervention based on structured teaching' (Panerai, Ferrante & Zingale, 2002). Other interventions are: speech and language therapy, occupational therapy (which focuses on improving functional motor skills), and physical therapy (based on improving the child's motor skills) (Treatment Interventions).

Dietary interventions have also been used to treat autism such as Gluten-free diets and Casein-free diets (Treatment Interventions). Pharmacological interventions are antidepressant and anti-anxiety medications, and mood stabilizing medications such as (SSRI) paroxetine, fluoxetine, and Risperdal, which is FDA approved (Autism-Medication, 2014).

**Distribution of ASD:** Prevalence studies of autism spectrum disorders done in recent years have been the center of debate because of a highly significant increase of estimates of the total prevalence of pervasive developmental disorders.

While the prevalence of ASD was estimated at 6 per 1,000 in a population of school children in 2005 (Fombonne, 2005), the last prevalence in the United States, released by the Center for Disease Control, recently estimated that about 1 in 88 children has been identified as having ASD. A new CDC report released on the 27 of March, 2014 estimates that the prevalence has become about 1 in 68. Baio (2012) also found that ASDs are reported to occur in all racial, ethnic, and socioeconomic groups. ASDs are

almost 5 times more common among boys (1 in 54) than among girls (1 in 252) (Baio, 2012). An association was found between diagnostic changes and the increased prevalence of autism. As King & Bearman (2009) found, the chances of a person being diagnosed with autism were higher during times when the practices of how to diagnose autism had changed.

Prevalence of ASD (worldwide): According to a recent study by Hughes (2011), prevalence tracked across the world was as following from the highest number of cases to the lowest: Japan, United States, and the United Kingdom.

Prevalence in Arabic countries is high in Saudi Arabia, Egypt, and the UAE.

In Palestine, there are no published articles about the prevalence of ASD and no reported cases have been recorded. Representatives of both WHO and the Palestinian Ministry of Health stated to the researcher that ASD is a newly discussed topic and there are currently no statistics available (Massad & Al-Sharif, Personal contact, May 16, 2014).

Despite all the difficulties that make it hard for an autistic child to live normally, some of them excel in visual skills, music, math and art. Worthy of note at this point is one of the most famous people with autism around the world (Dresden, 2013). Her name is Temple Grandin, PhD who is now the most accomplished and well-known adult with autism in the world. Her fascinating life, with all its challenges and successes has been brought to the



screen through her work in publishing books about ASD (Grandin & Panek, 2014).

During the process of diagnosis of ASD, parents often go through a lot of difficulties and frustration in order to find a specialist able to give a diagnosis for their child. In fact, the study findings revealed that in the West Bank there is a lack of specialized professionals in diagnosis of Child Developmental Disorders, and rehabilitation services are often low quality with no evidence-based practices. As many parents expressed this thing through the study especially in the Diagnosis results as the reader will see later.

Many parents must move from one place to another, and travel from city to another, seeing different doctors, specialists, and sometimes frauds, to find diagnosis and answers for their worries. During that entire journey, they also go through a lot of feelings such as grief. Acknowledging that their child is affected by ASD is itself a loss, the loss of the dream to see their child growing, learning, working and getting married like a normally developed child.

According to the DABDA model (Denial, Anger, Bargaining, Depression, and Acceptance, Kubler-Ross model of grieving): the-5-stages-of-loss-and-grief), grief is a personal process that is not limited in time and it doesn't have a 'right' way of doing it. It has 5 stages and they are as follows: Denial, Anger, Bargaining, Depression, and Acceptance (Axelrod, 2014 ).

Taking into consideration that all people grieve differently, some of them may mask their emotions or keep the grief internal, others maybe outwardly emotional, in one way or another. We can state that all the parents of children with ASD of our study experienced at least one or more of these stages in a personal way (The-5-stages-of-loss-and-grief).

## **1.2 Aim of the study**

The aim of this study is to investigate and describe the experience of the parents going through the process of diagnosis of autism spectrum disorder in the West Bank. In short, the specific objectives are to describe:

1. How autism diagnosis affects families.
2. The psychological effects on parents.
3. The physical effect on parents.
4. The effect on couples' lives.

## **1.3 Problem statement**

In the West Bank there is a lack of specialized professionals working in the field of childhood developmental disorders. Also centers and services often misdiagnose the symptoms, letting parents float for long periods of time from place to place, from specialists to doctor, from one country to another one waiting for the right diagnosis and the consequent rehabilitation plan. In this study, these experiences of the parents of ASD children will be documented and researched since the participants will be recruited from the An-Najah Child Institute (ACI). The ACI is a specialized care institute for

children with special needs belonging to An-Najah National University, Nablus, West Bank. It opened its services in 2013. In addition, it is a pioneer in specializing in diagnosis and intervention as ACI offers early detection, diagnostic and rehabilitation services to children with developmental disorders.

The purpose of phenomenological research is to describe specific phenomena of interest as they are lived and experienced by individuals. The focus of phenomenological studies is on understanding what an experience means within the context of people's lives. This is referred to as capturing the lived experience.

## **1.4 Significance of the Study**

Autism is one of the crucial subjects in the mental health sector, and it is a universal, rapidly-growing disorder, with unidentified causes that are still being researched. Although there is no proven cure for autism, early intervention should be considered as a method of controlling it (Treatment Interventions). The significance of this study is to set the base for a pioneering study in the domain of parental experience with dealing with Autism Spectrum Disorder, and to describe the parents' experience going through the process of diagnosis of autism, to understand how parents cope with the diagnosis of ASD. Lastly, this research will provide additional information in order to create effective services to have an early and scientific based diagnosis.

## **1.5 Research questions**

1. What did the parents do when they first noticed that their child has different behaviors from the normal development of a child?
2. What is the process that leads to the diagnosis of ASD in Palestine?
3. How did parents feel during this process?
4. How does diagnosis of autism spectrum disorders affect the life of a Palestinian family?

## Chapter Two

### 2. Literature Review

Autism Spectrum Disorder is a rapidly growing disorder and increasingly recognized topic in scientific research and literature thanks to scientific improvement in diagnosis and early assessment. There are a considerable number of qualitative researches with different methodologies and theories. And this chapter highlights the main qualitative researches in this field in details below. Over the past years, researchers have been exploring the lived experiences of parents with ASD children. They tried to collect snapshots to exhibit the daily realities through the diagnosing journeys and beyond and investigate the meaning of having a child with autism.

One study titled *"I Wouldn't Change Anything" The Everyday Realities of Living with ASD* is focused on the reality of living with autism. It specifically aimed to shed light on different practices, attitudes, behaviors, and methods of engagement of families in the realm of ASD (Molina Jr, 2014).

Parenting is a very hard job to do; parenting a child with autism is even harder. Raising a child with ASD is accompanied with a lot of challenges and burdens. By identifying these burdens, we can introduce effective interventions that will meet the parents' needs and ease their journey with their children.

Research has found that the burdens are present at different levels: cognitive, financial, psychological, and social.

Sen & Yurtsever (2007) conducted a study to examine the difficulties that the parents of children with disability experience. They concluded that parents and other family members of people with disabilities need information about the specific disability their loved one has been diagnosed with, as well as social support and financial aid due to the expected additional expenses of care and treatment.

In another study, Papageorgiou & Kalyva (2010) addressed the basic needs and the expectations of the parents who have children with ASD. The parents of children, who were diagnosed with ASD, were asked to answer a self reported questionnaire. The results showed that the needs of parents were most prominently cognitive in that they indicated a need for information about autism, including the latest advances in the field; the second most prominent need was practical support, followed by support from other parents with children with ASD. The least most prominent need indicated by participants was that of psychological support.

In his research, Aziz (2014) also targeted the needs of the parents of children with ASD in Saudi Arabia, which he found fell into 4 categories: cognitive, financial, psychological and social needs. He selected 58 families from the Institute of Intellectual Education, and the Saudi Society for Autism in Jeddah.



A study conducted by Desai, Wertz & Patel (2012) investigated the lived experience of 12 parents of children with ASD in Goa, India. The results showed that the parents have many concerns during the diagnosis process for their child, such as new challenges, learning how to care for the child, specifically in addressing his/her basic needs, and supporting the child in finding his/her place in life.

All these studies have agreed that the burdens are present in different levels and they are: cognitive, financial, psychological, and social support.

## **2.1 The cognitive burden**

A survey by Chamak, Bonniau, Oudaya & Ehrenberg (2011) focused on French parents of children with ASD. Parents with diagnosed children had to fill out a questionnaire and be interviewed. They were asked about their views regarding the diagnostic process related to their child, the results were that approximately one third of parents of with children diagnosed with ASD and almost all parents of adults with ASD were not satisfied with the diagnostic process. Participants indicated that their dissatisfaction was due to delays in being provided with the diagnosis, and the way the practitioners provided the diagnosis without attention to the feelings of the families. Many parents also voiced frustration with the challenges faced in obtaining the diagnosis, such as changes in diagnoses, necessity of obtaining the diagnosis abroad, and the length of the process and the toll it took on the family.

Crane, Chester, Goddard, Henry & Hill (2015) proved the importance of the cognitive burden in their study which was conducted in the UK on the parents experiences through the diagnostic process by filling an online survey. The results showed that more than half of the participants of the study were not satisfied with the diagnostic process. They specifically stated the following aspects as causes of their dissatisfaction: length of time to receive diagnosis, lack of information presented at diagnosis appointment, the behavior of the practitioner diagnosing, lack of support after the diagnosis, and the stress of the process in general. In addition, Mackintosh, Myers & Goin-Kochel (2005) aimed to discover the source of information that the parents obtain about the diagnosis for their child. This was an online survey for parents of children with ASD. The results indicated that the most used source was other parents with children with ASD, followed by ASD specialists, doctors, teachers, family members, friends and spouses. Subsequently, web pages, and ASD support group meetings were found as sources of information, followed by newsletters, books, conferences, and workshops.

## **2.2 The Financial Burden**

Hsiao (2013) conducted a study composed of 236 parents of children with ASD, and he investigated the economical status of families and the relationship between the families of the autistic children and the professionals, and he found that "the two variables which contributed greatly to the quality of family life were family income and age of the child

with ASD". Similarly, Sharpe & Baker (2007) surveyed families of children with autism, and the results showed that "financial problems was positively associated with use of medical interventions, having unreimbursed medical or therapy expenses, and having relatively lower income".

### **2.3 The Psychological Burden**

Abbott, Bernard & Forge (2013) conducted a study based on a qualitative methodology to explore the experiences of nine sets of parents of children with autism spectrum disorder. The major theme that emerged was the frustration that parents had experienced leading up to the diagnosis. However, two families expressed anger that the diagnosis had taken so long to achieve. In addition, in another study by Kourkoutas, Langher, Caldin & Fountoulaki (2012) that used a focus group of 24 parents of children with autism spectrum disorder, aimed to reveal effects and impacts of autism at different stages of the child developmental process. The results showed that there is a lot of stress and troubles that the families experience every day when dealing with an autistic child.

In their study, Brobst, Clopton & Hendrick (2009) stressed the impact of the psychological burden by comparing 25 couples with autistic children and 20 couples with children with other developmental disorders. They found that parents with children with ASD indicated more child behavior issues, stress from parenting, and less satisfaction in their relationships than parents of children with other developmental disorders.

Dumas, Wolf, Fisman & Culligan (2009) also assessed the differences in parental stress, dysphoria and child behavior problems between 150 families. The results of their study indicated that parents of children with autism and other behavior disorders had higher amounts of parenting stress than parents in other study groups. Also of note is that mothers, specifically, had higher levels of dysphoria than those in other groups, which was hypothesized to be related to the difficulty of parenting ASD children as opposed to personal dysfunction.

Hastings, et al. (2005) did a systematic analysis of psychological functioning in parents of children with autism, regarding the mental health differences between mothers and fathers. The study resulted in the fact that mothers of autistic children had reported to have much higher levels of depression than fathers did.

However, Oprea & Stan (2012) found that there are positive impacts identified by mothers' responses to a questionnaire-based survey, and these impacts were the hope that the child could recover, and determination to help the child. Similarly, Ogston, Mackintosh & Myers (2011) found that hope can protect against stress and other psychological issues due to the fact that mothers in their study who indicated higher levels of hope, also showed less worry.

## **2.4 The Social Support Burden**

Woodgate, Ateah & Secco (2008) conducted qualitative interviews with 16 families of children with autism and the study aimed to explore the everyday experience of the parents of autistic children. The major findings were that parents felt a sense of disconnect from the family, found that the social system was not supportive, felt nostalgic about their previous, 'normal' way of living, and indicated that there was a lack of understanding in their communities.

Another study interviewed 20 parents using a qualitative approach with thematic analysis of the data. The authors agreed on the fact that parents must face the challenges of judgment from others, a lack of support, and that they are in need of coping strategies and other kinds of support. They also found that the child's challenges were on-going, which impacted the parents' ability to deal and feelings of well-being. The findings did reflected that parents who had support from other family members were better able to cope as were parents who had a positive experience with the school system (Ludlow, Skelly & Rohleder, 2011).

## **Chapter Three**

### **3. Methodology**

This study employed a qualitative research approach, particularly one grounded in phenomenology, which allows one to get at the core of an individual's lived experience of a particular phenomenon. The goal of this type of research is to provide a chance for parents to describe their own personal experience and to understand how these experiences attribute meaning to events. This study will explore the phenomenological experience of parents who went through the process of diagnosis of ASD for their child.

Descriptive Phenomenological Analysis (Smith & Osborn, 2003) was used because it fits the stated goals and purposes of this study. As a qualitative methodological approach, it seeks to understand how parents' experiences attribute meaning to the events of their lives. It also recognizes the active role of the researcher in the investigation process, specifically the subjectivity and personal biases that she or he will invariably bring to the study.

The main question that this study seeks to explore is: "What is the phenomenological experience of parents who went through the process of diagnosis of ASD for their child?" A semi-structured interview format was utilized to explore the various aspects of the parents' experience going through the process of diagnosis of ASD for their child. Participants were



selected using purposive sampling, and they were adult parents of children diagnosed with ASD located in the West Bank.

### **3.1 Design**

The design used is a qualitative phenomenological descriptive design. This design is used to study the lived experience of people by describing the aspect of this experience and by focusing on what exists. This design does not focus on interpretation of the experience, but it uses it as an indicator for the peoples' thoughts and feelings (Giorgi & Giorgi, 2003). Semi-structured interviews were conducted with parents of children diagnosed with ASD.

### **3.2 Setting**

Participants were recruited from the An-Najah Child Institute (ACI), and all the interviews took place in the center. Referrals to the center were made either by parents or school teachers through a referral form designed for this purpose.

The ACI is a specialized care institute for children with special needs belonging to An-Najah National University, Nablus, West Bank. ACI offers early detection, diagnostic and rehabilitation services to children with developmental disorders. The diagnosis of ASD is done by a team of specialists led by a clinical psychologist. The institute offers psychological support services with the presence of two clinical psychologists, a mental health nurse, and therapists for speech and special education, in addition to the inclusion services that are applied through the Montessori program. (Dr

Russo. Director of the Clinical Services, personal communication, June 3, 2015).

### **3.3 Study Population**

Parents with diagnosed children of ASD who are registered in the ACI.

### **3.4 Participant samples**

Those individuals who are identified as parents of children with a diagnosis of ASD were considered appropriate for participation in this study. Purposive sampling (Smith & Osborn, 2003; Mertenz & McLaughlin, 2004) or the selection of participants based on the presence of shared characteristics was utilized to identify participants for this study. Purposive sample sizes are often determined on the basis of theoretical saturation (the point in data collection when new data no longer bring additional insights to the research questions). Purposive sampling is, therefore, the most successful when data review and analysis are done in conjunction with data collection or smaller sample sizes.

### **3.5 Sample size**

The sample size for this study was 12 parents who have at least one child diagnosed with ASD (Guest, Bunce & Johnson, 2006).

### **3.6 Inclusion criteria**

All parents who have at least one child diagnosed with ASD and the diagnosis was done in the ACI.

### **3.7 Exclusion criteria**

1. Parents who have children diagnosed with mental disorders other than ASD.
2. Parents who have children diagnosed with ASD in western countries.

### **3.8 Selection of study instruments**

The interview process was conducted using a semi-structured interview guide with different themes and underlying issues chosen from the purpose and questions of the study. The interview guide acted as a support for some important issues that were necessary to be remembered during the interview. It also served as a guide to the order of the themes that were to be addressed. The open questions allowed interviewees to speak freely. The interview guide was used as a checklist to ensure that all the themes were taken into account rather than an inflexible set of questions to be followed strictly. This helped the interviewees generally feel relaxed and natural. All interviews were recorded on audio tape based on the participants consent and were then transcribed.

### **3.9 Data collection**

#### **Procedure**

The participants who met the selection criteria of the study were contacted by telephone and were briefed on the researcher , the study and its aim, and were asked to volunteer in the research ,Once potential participants were

identified, which constituted the study sampling frame (Mertenz & McLaughlin, 2004), the researcher ensured that they had the informed consent documentation. This included a description of the study, eligibility requirements, and the purposes, risks, and confidentiality issues associated with this study (see Annex 1). The researcher also presented demographic questions (see Annex 2) that requested information regarding name, address, telephone number and/or email address, gender identification, age, and level of education. After reviewing the informed consent, the participants were given the opportunity to ask any questions regarding participation in the study. The individuals who agreed to participate had to return a signed copy of the informed consent as well as a completed demographics questionnaire to the researcher. All information contained in the consent form and the questionnaire were kept separate from all interview material. Participants were then contacted via telephone to schedule an interview appointment. Interviews were scheduled on a first-come, first-serve basis, due to the small number in the sampling frame

## **Interview**

All interviews were conducted face to face in a private location. At the beginning of the interview process, the informed consent was reviewed and participants were provided with an opportunity to ask any remaining questions.

Participants then completed an audio-recorded, semi-structured interview about the phenomenological aspect of their experience, which lasted

approximately 30-40 minutes. A series of predetermined questions served to guide the inquiry, rather than provide a rigid structure to the interview (Smith & Osborn, 2003). The questions were supplemented as appropriate in order to explore particular areas in more depth. The core interview questions, which represent the backbone of the interview, were also provided. (See Annex 3).

Sound quality should was good on all recorded interviews, which allowed the interviews to be easily transcribed. The interviews were transcribed verbatim and all identifying features were removed to ensure anonymity. All interviews were first listened to before being printed. Some quotes were saved in their original form.

### **3.10 Data Analysis**

Phenomenological psychologists analyze the data utilizing a systematic and rigorous process. Data analysis consists of four consecutive steps where each step is a requirement for the next. Prior to the analysis, each interview was transcribed verbatim. All steps in the analysis were performed within the phenomenological reduction (Englander, 2012; Giorgi, 1985b; Giorgi, 1997).

Step 1: Getting the sense of the whole statement by reading the entire description.

Step 2: Discriminating meaning units within a psychological perspective.

Step 3: Transforming the subject's every day expressions into psychological language.

Step 4: Synthesizing transformed meaning units into a consistent statement of the structure of the phenomenon.

### **3.11 Pilot Study**

The above method was tested in a pilot study. The pilot study involved one participant. One individual who met the selection criteria of the study was contacted. The selection was voluntary and based on ethical considerations; the interviewee (a mother of an 8 year-old autistic child) was informed about the study orally and in writing (see Annex 1). The consent form was available at the interview. Both the harms and benefits of being part of this study were explained to the participant. The interview was conducted in a closed private room in the ACI and was recorded on tape after the participant's permission, and then the text was treated in accordance with the above analysis.

After the pilot interview, it was noted that there was a need for some modifications regarding the time of the interview, the way of asking the questions, and the interview guidance questions. As a result some questions were removed and others were added.

The reason behind the deletion of certain questions was that the corresponding responses gave information not related to the aim of the current study. On the other hand, the reason behind the addition of other

questions was that they gave additional information about the diagnosing journey of ASD, the challenges that the parents went through, and the accessibility and the quality of the current health care services regarding the diagnosis.

The final number of questions became 9 guidance questions, which were tested carefully, and the time specific for these questions was 30-40 minutes.

### **3.12 Reliability and Researcher Bias**

Because of the active role of the researcher in an interpretive approach (Smith & Osborn, 2003), several steps were taken to mediate the effects of personal biases and assumptions that might have play part in the interview process. This helped to ensure the most objective approach to the data. The first step was to reflect upon and record the researcher's own perceptions, assumptions, and biases about the nature of parents' experiences or expectations for the research process. This included beliefs, attitudes, cultural and religious and judgmental issues which were thought to possibly affect the research. Since autism is a very sensitive and stigmatized issue in Arabic culture to which the researcher belongs, the researcher hoped to, by making herself aware of her own attitudes, become a better listener who tried to put herself aside and take the dialogue partner seriously.

During each interview, process notes were kept, detailing the researcher's reactions to participants' experiences, impressions of how open a participant

seemed to be to the interview process, and any effects either the researcher's presence or the interview itself seemed to have on the participant. A summary of the impressions were offered to the participant to ask if the researcher's understanding accurately reflected their perspective (adjustments were made, if necessary). This check helped to establish credibility (Mertenz & McLaughlin, 2004), and ensure reliability of the data.

All interviews were recorded on a tape and transcribed verbatim. This makes the survey more credible than if the researcher had only taken notes during the interview (Robson, 2002).

Credibility of the data may be related to whether respondents tell the researcher the truth (Malterud, 2002). In this study, the researcher is looking for the experiences of parents with autistic children. An experience is subjective and thus true to the one who tells it. The analysis model of Giorgi was followed (Giorgi, 1985b), as described in the greatest attempt to be true to the stories of the parents.

In addition the non verbal clues of the parents such as facial expressions, sighs and bursting into tears were also observed and taken into consideration.



### **3.13 Ethical Considerations**

In the study, a procedure for the protection of the human subjects through the researcher's university subjects was followed, which was approved by An-Najah National University's Research Ethics Boards.

The participants, who met the selection criteria of the study, after deciding to be a part of the study, were approved by telephone from us; information about the study, including its aim and objectives was briefly explained to them. The participants signed a consent form (Annex 1), and received further information from the researcher for more clarity. Both verbal and written consent was obtained from all participants.

The interviews were conducted in a private room, where only the participant and the interviewer were present. The interview was recorded after taking the participants' permission, adding that no participants could be recognized after the text processing. Information on both records and prints were all strictly confidential and were stored in a closed cabinet.

The data was stored until the analysis was completed, and, upon the end of the study, all interview materials were deleted. The voluntary nature of the study was explained to the participants, so the participants understood that their participation was voluntary and that they could withdraw at any time, and that they were free to keep their nameless identity.

Participants were also informed about the benefits of being part of this study, as research has shown that talking about painful or difficult

experiences can be helpful. For instance, after talking or writing about a difficult life experience, people in general can experience a sense of emotional release, a greater sense of understanding, and in some circumstances, can even experience health benefits.

In terms of the possible harm of participation in the study, the participants were also informed completely, since the risks of participating in this research study were expected to be small. If participants had experienced discomfort as a result of the interview, they were asked to inform the researcher at any point during/after the interview. The participants were able to stop the interview at any time, with or without reason.

Participants were able to discuss any issues that came up due to their participation in the study with their primary therapist. In the case that they did not have one, the clinical psychologists of the ACI were available for debriefing and psychological support. The participant's safety was the highest concern; and all necessary steps were taken to keep this commitment.

The participant's identity and personal information were protected through the whole study. No names were reported. Our goal has been to sustain an ethical researcher behavior, which does not relate only to data, but also our personality, sensitivity, and dedication to moral issues and actions.

## **Chapter Four**

### **4. Results**

The purpose of this study was to investigate and describe the experiences of the parents during the process of diagnosing autism spectrum disorder in the West Bank. My specific objectives were: to describe how autism diagnosis affects families, the psychological, and the physical impacts on parents, as well as investigate the consequences of diagnosis of autism spectrum disorder on couples' live, family dynamics, and the effects of community's stigma. In order to explore this, the methodology of Giorgi was adopted, and the design that was used was a qualitative phenomenological descriptive design.

The selected sample was comprised of 12 parents of children with autism, and they were recruited from the ACI; semi-structured interviews were conducted to elicit parents' experiences for about 30 to 40 minutes each.

#### **4.1 Interviews results and analysis**

In total, 12 interviews were conducted. Participants were aged between 25 and 62 years old. They were all married, nine of them were females and three were males (based on the fact that the majority of the participants who volunteered to take part in the study were women, in addition mothers are considered as more caring and sympathetic and were involved in bringing their children to the sitting of the study); six participants lived in Nablus; the other four lived in West Bank villages, while just two of the participants

were from refugee camps. The demographic data of the participants are presented in Table (1).

The analysis of the data was based on the Giorgi method of phenomenological qualitative research.

**Table (1): Demographic information about the parents of the autistic children**

No	Gender	Age	Place of birth	Place of residency	No# of children in family	Age of the child when he/she diagnosed	Education level
1	Female	44	Nablus	Nablus	2	5 years	Diploma
2	Female	42	Nablus	Qouseen Village	7	1 year	9 <sup>th</sup> grade
3	Female	31	Kuwait	Salfit village	2	2.2 years	University degree
4	Male	46	Nablus	Nablus	5	2.5 years	University degree
5	Female	32	Nablus	Nablus	3	3 years	6 <sup>th</sup> grade
6	Female	35	Nablus	Nablus	4	2.7 years	University degree
7	Female	30	Nablus	Jamaeen village	3	3 years	MA degree
8	Male	62	Tamoon Village	Tamoon Village	10	1.5 years	University degree
9	Male	49	Nablus	Balata camp	5	1.10 years	University degree
10	Female	42	Nablus	Nablus	5	11 months	Diploma
11	Female	44	Nablus	Balata camp	6	5 years	6 <sup>th</sup> grade
12	Female	25	Nablus	Nablus	2	2.5 years	University degree

❖ Marital status of the participants: All were married.

From the interviews, four themes and 14 sub-themes emerged:

**1. Diagnosis** (Missed and Late diagnosis, Lack of evidence-based services, Satisfaction with Services).

**2. Stigma** (Social exclusion, and Negative labeling).

**3. Grief** (Denial and Isolation, Anger, Bargaining or Self-blaming, Depression, Acceptance).

**4. Family Challenges** (Physical burden, Family relationships, Awareness, Hope).

The themes and sub-themes are presented in Table (2).

**Table (2): Themes and sub-themes that emerged from the parents' interviews:**

<b>Themes</b>	<b>Sub-themes</b>
1. Diagnosis	1. Missed and Late-diagnosis 2. Lack of evidence-based services 3. Satisfaction with Services
2. Stigma	1. Social exclusion 2. Negative labeling
3. Grief	1. Denial and Isolation 2. Anger 3. Bargaining or Self-blaming 4. Depression 5. Acceptance
4. Family Challenges	1. Physical burden 2. Family relationships 3. Awareness about ASD 4. Hope

## **1. Diagnosis (The first theme):**

Diagnosis was the primary and the first common theme that most of the participants shared with different experiences for each because behind this word there is a journey full of challenges, difficulties, satisfaction, and dissatisfaction. This theme reveals so many important issues about the diagnosis and the rehabilitation services for children not only with autism, but also with other developmental disorders. This theme was a mirror which reflects the quality of the diagnosing services that are present in the West Bank.

Parents have expressed the sub- themes of diagnosis as follows:

### **1.1 Missed and Late Diagnosis**

Most of the participants of the study suffered from diagnosing errors, and a delay in diagnosis. This is due to a lack of medical knowledge, and lack of capacity to diagnose different types of ASD, all of which resulted in inadequate treatment options.

The following quotations reveal missed and late diagnosis clearly:

A mother reflected her experience through the diagnosis process for her child as follows:

*- "We noticed that he had dyslexia; as a result we took him to the doctor. He told us that he had a hearing problem, so we tested his hearing, finding nothing wrong with it". C3*

A mother expressed her experience as:

*- "When they checked his hearing, the doctor told us that he might be a retard because his hearing is ok". C5*

Another mother reflected her experience in the diagnosing process as:

*- "They didn't tell me that he has autism, instead they told me learning difficulties". C11*

While an educated mother talked about what they went through in the diagnosing process for her child:

*- "We took him to an impostor doctor in Hebron, who did a heart massage, telling us that he had Oxygen deficiency in the brain. In addition, he told us that he had autism and we had to stick to the massage in order to get better". C3*

## **1.2 Lack of evidence-based services**

The participants expressed indirectly their feelings towards the lack of well-researched interventions with clinical experience to deliver appropriate treatment and services. They felt they are alone as there were no practitioners to work with or to guide them to identify their problems. This approach (evidence-based services) has proved its effective outcomes. The following quotations demonstrate the participants' feelings towards this sub-theme.

A 31 year-old mother who was also a victim of miss diagnosis and the lack of professional diagnosing services reflected her experience as follows:

*"I took my son to that doctor every week to have his massage and give him medical herbs. We had to boil it with water ... I don't remember the name of the herb, can you imagine that? I had many doubts about him since then. Consequently, we didn't go back to him since it became apparent that he was a fraud". C3*

The same family went through other scenarios that represent the difficulties that the families go through in searching for evidence-based diagnostic services. The mother reflected this as follows:

*"We went to Jordan twice. There, the doctor gave him 13 types of medicine, which I actually bought. Thus, he gave him a hard diet depriving him from all the types of food. It was complementary portions, which I bought from Jordan because they were not available in the West Bank". C3*

An old mother expressed the lack of evidence-based services as:

*"In a neurologist's private clinic in Ramallah, who told us that he had autism? He also said that there were no tests to do in order to make sure that he had it or not". C7*

*"He checked him by weighing him without asking us for any tests or scans. He only asked for an iron test. When we did the test, it turned out that he had iron deficiency, so he gave us iron drops" C7.*



### 1.3 Satisfaction with ACI services

Some participants expressed satisfaction with the current provided services at the ACI, and they gave positive feedback about it, and they are summarized as follows:

An old mother reflected her satisfaction about the services as:

*- "But thank Allah, he has improved a lot since we took him to the ACI; they helped us a lot; he comes and tells us what he learned". C2*

A mother expressed her feelings as:

*- "In the ACI, they gave us hope telling me that my son was excellent and wonderful. The supervisor told me that he was making progress and responding to the treatment". C3*

While another mother spoke about her satisfaction with the services:

*- "Here in the ACI I can feel that there is an improvement. Imagine that we have sent him to another center for 3 years without any results. However, in a month the child got better and he started to do everything by himself ". C5*

In addition, a mother uttered her satisfaction as follows:

*- "If I can evaluate correctly, the boy has 80% improvement in the ACI. We lost all things that were causing quarrelling and screaming with my husband". C6.*

## 2. Stigma (The second theme):

Stigma is a Greek noun that is coming from roots which mean to make a point, although the word was not used in ancient Greece in relation to mental illnesses, but it was related to the sense of shame (Fink, 1992). It is a sign of disgrace that isolates and labels people by their illness, gender, skin color, education, nationality, ethnicity, beliefs, or religion. Such stereotypes create pre-judgment, which can cause negative actions and discrimination ([www.mentalhealth.wa.gov](http://www.mentalhealth.wa.gov)).

Stigma was the theme that most participants mentioned and showed annoyance of and refusal as they felt isolated during the diagnosing process and afterwards.

A 44 year-old mother expressed her feelings as follows:

*- "My wish was my son would be a good and intelligent student at school. My feeling was that like I was throwing myself from the tenth floor". C1*

Another one articulated her emotions as:

*- "My feelings were disappointment". C10*

While an old mother reflected her refusal of stigma, and the lack of awareness of others:

*- "I have a religious aunt who linked my son's sickness to my work. She thinks that when I used to sell cigarettes in the supermarket, my money was*

*illegal. She said, "I don't know why your son became like this. Glorify to God, you have done something wrong." C1*

One participant spoke about pre judgment that causes negative actions and labeling, as follows:

*- "As a result, people started pushing each other and said things about him asking me why I carry him." C3*

## **2.1 Social Exclusion**

The participants of the study suffered from social exclusion and discrimination as they felt isolated and deprived from their rights to access proper treatment and services.

The following quotations reflect their feelings regarding social exclusion:

A 46 year-old father spoke about how social exclusion and discrimination affected him deeply in a bad way; he expressed his feelings as the following:

*- "People made us feel that we didn't do our best for our son telling us to take him out as if there is a kind of treatment in another country and we don't want to cure him. It is strange that whoever doesn't experience it, doesn't feel it as well". C4*

An old mother expressed her refusal of labeling and social exclusion with tears in her eyes as:

*- "All of them say: "God help you. God heal him". I couldn't imagine myself every time explaining my child's situation to people". C1* Although these kinds of sentences in our Palestinian community may be considered as a part of the social support system, but the mothers in the study expressed their refusal and anger to such kind of sentences.

Another mother expressed social exclusion as follows:

*- "My mother told me to leave my son and get my social occasions done". C3*

An old father spoke about the lack of awareness and understanding of the people around them, which cause embarrassing situations for the family, as:

*- "When we took him to our relatives, they didn't accept the idea of yelling because the kid had a habit of yelling. We started to feel embarrassed". C4*

Another father expressed social exclusion with a sigh saying:

*- "We avoid talking about the boy". C9*

*- "When we go to some occasions we don't take him with us". C9*

In addition, a mother reflected her experience with her child when people try to socially exclude him, as:

*- "All schools refused to accept him". C1*

*- "When my husband takes our son to the market, the people say it's better to leave him home". C1*

## 2.2 Negative Labeling

Social exclusion eventually leads to negative labeling by using negative words and actions; the parents expressed their annoyance in the following quotations:

A mother spoke about how people label her child by his illness, as:

*“They said that their son was much better than mine repeatedly”. C3*

*“People hurt me by looking at my son in a bad way”. C3*

Another one expressed her feelings when people try to label her child in a negative way, as follows:

*-“Everybody, everybody tells me that I should be patient, this child is better than going to the pilgrimage, everybody says that he will be better”. C2*

In addition, a mother expressed how blaming and negative labeling affects her feelings:

*-“All people used to blame me when I leave him alone. They believe that when he is with me, he will be in best condition”. C1*

Also she showed tolerance and sympathy, as:

*-“I always feel sorry for people. Always when I see a boy with mental illness walking in the street, I feel pity for him and I like to give him some money. I always quarrel with those who mocking them. I want all people to feel pity for those kinds of people whom are disabled and with special needs. I wish I*

*had a lot of money in order to adopt an orphan. I became a kind-hearted woman who doesn't care about the decoration of the word". C1*

### **3. Grief (The third theme):**

Parents go through a lot of feelings during the diagnosing process; grief is one of the prominent feelings. According to the DABDA model (Kubler-Ross model in grieving; The-5-stages-of-loss-and-grief), grief is a personal process that is not limited in time. The following five stages which the parents showed are:

#### **3.1 Denial**

This stage is all about denying the reality of the situation, and it is a normal emotion and also a normal defense mechanism in dealing with shocks, and it is considered as a temporal phase (Axelrod, 2014 ).

An old mother reflected her experience with the denial stage through the diagnosing process of her child as follows:

*- "My husband thought that there must be a therapy, and when the child gets older in age he will recover and start talking". C1*

*- "I told myself that my son has no autism". C1*

*- "I say that it is better to see my son on a wheel chair instead of his mental disability". C1*

Another one reflected her denial and refusal of the fact that her child is diagnosed with ASD as:

*- "I did not believe until my oldest daughter argued with me asking why I don't believe. I refused to accept that and I said your brother is normal, she said that he is normal but he has a kind of autism. I refused to accept that and I asked them to never mention this again". C2*

While a father reflected his denial of his child's diagnosis as:

*- "We strongly believe that his disease is unforeseen and he would be better and mingle with the society normally". C4*

A mother, who is highly educated, expressed her feelings toward her child's diagnosis as:

*- "I wished that a miracle happened that I would open my eyes and see the child normal". C7*

Another one showed her denial as:

*- "I refused the fact that the boy has autism". C10*

### **3.2 Anger**

The intense emotions turned to anger and we can't blame anyone who is in this stage. This anger may be aimed at close friends, complete strangers, or even family members (Axelrod, 2014 ).

An old mother expressed her anger on the first time she heard of the diagnosis:

*- "When he told me that, it was a shock to me that I started crying". C1*

Another one reflected her anger and isolation as:

*- "The diagnosis affected me of course; my ambitions and dreams stopped, and my social relations were severely affected". C7*

One reflected her feelings as:

*- "I became nervous and didn't like to see people". C10*

In addition, a 25 year-old mother was disappointed and felt sorry for herself because she is young; she expressed her feelings as:

*- "It was very hard and it was a shock". C12*

While another one spoke about how diagnosing her child ended with neglecting herself:

*- "My weight increased and some people asked why I dressed like this". C1*

### **3.3 Bargaining or self-blaming**

This is the stage in which the person tries to find a way out of tragedy by 'being good', and trying to sacrifice specific things in hopes of gaining his/her way back into god's good grace. It is the stage of feeling helpless



and vulnerable, and these are normal reactions; it includes also self-blaming, and the need to control life again (Axelrod, 2014 ).

A mother expressed the bargaining stage through the diagnosing process for her child as:

*- "I sometimes tell myself that if my life hadn't been like this, I wouldn't leave him home". C1*

The same mother spoken about how she believed that having a child with ASD has something to do with her and she blamed herself for that all the time as:

*- "The kindergartens were bad and I sometimes brought him with me to the supermarket and tied him to a chair in order to talk to him and play with him. I feel guilty that I have been responsible for increasing his sickness". C1*

A mother expressed her feelings of helplessness as:

*- "I sat alone and I cried. I had never heard of autism". C2*

Another old mother showed how much she was disappointed after her child was diagnosed with ASD:

*- "I felt so bad that I said: "What luck"". C7.*

### 3.4 Depression

Depression has two types; the first type includes sadness and regret, while the second type is considered as the stage of preparation to separate, and leaving anyone and everything behind. Persons in this depression need kind words, a hug, helpful cooperation, reassurance, and simple clarification (Axelrod, 2014).

Participants showed depression on different levels, and they expressed their feelings as follows:

A mother reflected her feelings:

*- "I have depression. I don't visit anyone". C1*

Another one expressed it as:

*- "Any person who wants to ask about patience should go and see a mother who has a son with autism in order to see how she suffers". C6*

While one reflected her disappointing and helplessness as:

*- "His sickness has destroyed me because the time I heard his name, I cried for one hour". C1*

*- "My wish was my son would be a good and intelligent student at school. My feeling was that like I was throwing myself from the tenth floor". C1*

Another mother showed disappointing feelings as:

*- "My feelings were of disappointment". C10*

### **3.5 Acceptance**

If the person reaches this stage, then he is in the healing process because reaching this stage is considered a gift not offered to everyone. One must distinguish between this stage and the depression stage, as it is not a stage of happiness. Acceptance is marked with calm and withdrawal (Axelrod, 2014).

Most of the participants in the study have reached the acceptance stage as it is the first step in the healing process; they expressed their acceptance of the diagnosing of their child differently, as follows:

*- "I love him so much and I feel that he is very close to me. He is a very kind, cute and lovely child. He says lovely things. He laughs. I and my daughter love him very much and we usually laugh about his words". C1*

A mother who finished education until the sixth grade talked about what it is like to be a mother of an autistic child and how she accepted her son's situation; she answered with a smile and a lot of hope and love.

*- "This child was a gift from God, so we couldn't do anything but accept him". C5*

While a father expressed his way of caring, love and acceptance as:

*- "My feeling is that we are satisfied with our fate, the destiny that God wants". C8*

*- "Our son is like an angel, he is peaceful and he doesn't hurt anyone. We believe in our fate and what God wants". C8*

#### **4. Family challenges (The fourth theme):**

Family challenges include a common category of adjustment difficulty that leads people to seek psychological treatment. Family challenges can develop between parents when there is medical or psychological problems or illnesses in one of the children or parents.

The family challenges were expressed by the parents as follows:

##### **4.1 Physical burden**

Physical burden relates to the bodily difficulties that the parents experience through their journey in seeking the diagnosis. The participants showed how much they were tired and even exhausted because of the need to travel long trips in search for centers and doctors to provide them with the right diagnosis.

A mother spoke about the difficulties that she experienced when she daily deals with her autistic child as:

*- "I started to suffer in that he keeps bothering me by pulling my hair; I keep my head covered always because he keeps pulling my hair; he is my child, I don't know what to do with him". C2*

Another mother talked about the body difficulties that she suffered during the diagnosing process for her child due to the lack of local services as:

*- "I go and return everyday from Nablus to Jerusalem and then I used to take him to another center twice a week which was very exhausting ". C12*

## **4.2 Family relationships**

Family relationships are the main concern when it comes to family challenges, as they are affected either in a positive or a negative way. They also reflect the degree of the support that the family members can provide to each other. Participants of the study indicated that their relationships with their spouses, relatives, siblings, and family members are affected as follows:

A mother spoke about how having a child with ASD affects her relationship with her husband in a good way:

*- "My son has strengthened the relationship between me and my husband". C1*

While another one expressed how the relationship was affected in a bad way:

*- "My relation with my husband was affected a little bit because my husband was annoyed all the time". C5*

While a mother reflected how having an autistic child affects her relationship with her husband, and she also showed confusion about her concerns as a responsible mother and about living her own life as:

*- "My relationship with my husband has strengthened I became concerned about my family more and I want to live my life". C6*

Also a mother spoke about her feelings and the family support that they got as:

*- "My relation with my husband weakened because I would always be busy with the kid and his problem, which caused problems". C7*

*- "He gets upset. This is because I didn't want to visit his parents. He didn't know that I would be hurt from his parents or anywhere I felt uncomfortable". C7*

*- "My parents supported me the most because they always tell me to look for a cure even if it costs a lot. He also told me that he will pay if we cannot afford it, so their support is positive". C7*

### **4.3 Awareness about ASD**

The participants also revealed their willingness to seek knowledge and information to increase their awareness about the disease using different methods; they also highlighted different negative and positive aspects of the disease through their own personal experiences with their children as follows:

A mother spoke about the way she knew more about ASD as:

*- "They bring some media programs about autism, I started to follow them". C2*

Also a father spoke about seeking information regarding ASD as:

*- "We had enough information about the problem from our readings about it". C4*

*- "All the known information about this disease is a group of hypotheses and theories, and nothing is proven about the treatment and reasons. The researches didn't conclude anything about it due to disputes". C4*

#### **4.4 Hope**

It is worth mentioning that the process had some positive aspects that bring hope and optimism. The study reveals that despite the many negative attitudes that the parents went through, they have hope for a better future for their children, and strong determination to go all the way and fight for their children. The following quotations prove that.

A father reflected his feelings and ambition for his child as:

*- "Our ambition became to teach the kid the ABCs of life in order to get his things done well and contact with the world". C4*

Another father reflected his determination to fight for his child as:

*- "When we knew that this center was established, immediately we brought him ... I swear by Allah that we didn't miss any chance to improve the boy". C8*

Also a mother talked about how having an autistic child taught her tolerance and sympathy as:

*- "I learned patience, to love children; I never liked children, I did not want to give birth;, he taught me to petty him with my heart, I started to love all children, any child with disability, I love them and cry for them just as I do for my son ". C2*

In addition, another one uttered her feelings as:

*- "My son taught me determination, patience and that success is the end of each way". C6*



**Table (3): The analysis of the parents' interviews:**

Meaningful units	Formulate the meanings	Sub-themes	Themes
<p><i>- "We noticed that he had dyslexia; as a result we took him to the doctor. He told us that he had a hearing problem, so we tested his hearing finding nothing wrong with it". C3</i></p> <p><i>- "When they checked his hearing, the doctor told us that he might be a retard because his hearing is ok". C5</i></p> <p><i>- "They didn't tell me that he has autism, instead they told me learning difficulties". C11</i></p> <p><i>- "They told me your son has nothing. They gave him functional treatment". C11</i></p> <p><i>- "We took him to an impostor doctor in Hebron, who did a heart massage, telling us that he had Oxygen deficiency in the brain. In addition, he told us that he had autism and we had to stick to the massage in order to get better ". C3.</i></p> <p><i>- "Three neurologists indicated the disease. One of them said that the child has a mental disease, another said autism". C1</i></p> <p><i>- "The speech therapist diagnosed his case". C4</i></p> <p><i>- "Therapist in Hebron gave him sessions like the alternative medicine". C7</i></p>	dissatisfaction	Miss and Late diagnosis	Diagnosis
<p><i>- "I kept going to ..... center till the supervisor told me that I should go to another center in Jerusalem he would get better treatment. I went there for a week. I came back; he was moving all the time until I took him from that center, and he was two years old ". C2</i></p> <p><i>- "I took my son to that doctor every</i></p>	Feeling frustration	Lack of evidence based services	

*week to have his massage and give him medical herbs. We had to boil it with water ... I don't remember the name of the herb, can you imagine that? I had many doubts about him since then. Consequently, we didn't go back to him since it became apparent that he was a fraud". C3*

*-" We went to Jordan twice. There, the doctor gave him 13 types of medicine, which I actually bought. Thus, he gave him a hard diet depriving him from all the types of food. It was complementary portions, which I bought from Jordan because they were not available in the West Bank". C3*

*-" Then I emailed a Syrian women, who was a nutritionist. She gave me many natural remedies because her daughter had autism too".C3*

*-"My sister from Jordan came trying to interact with him. Then, she told me he might be autistic. It never crossed my mind because he always watches TV. When she told me that, I didn't buy her words. After that, he grew up, and I started to feel that there was something wrong. Besides, I went to psychological health care in Nablus when he was 3 years old. The specialist there told me that I shouldn't take my sister's words seriously because if he had had anything the symptoms would have appeared".C7*

*-"In a neurologist's private clinic in Ramallah, who told us that he had autism? He also said that there were no tests to do in order to make sure that he had it or not".C7*

*-" He checked him by weighing him without asking us for any tests or scans. He only asked for an iron test; When we did the test, it turned out that he had iron deficiency, so he gave us iron drops "C7.*

<p><i>"But thank Allah, he improved a lot since we took him to the ACI; they helped us a lot; he comes and tells us what he learned". C2</i></p> <p><i>-"In the ACI, they gave us hope telling me that my son was excellent and terrific. The supervisor told me that he was making progress and responding to the treatment".C3</i></p> <p><i>"Here in the ACI I can feel that there is an improvement. Imagine that we have sent him to another center for 3 years without any results. However, in a month the child got better so that he started to do everything by himself ".C5</i></p> <p><i>"If I can evaluate correctly, the boy has 80% improvement in the ACI. We lost all things that were causing quarrelling and screaming with my husband". C6</i></p> <p><i>"I have noticed that the ACI has excellent experience and the workers know how to deal with the child. The boy became better because of them". C10</i></p> <p><i>"I said thank to Allah. This program in the ACI has benefits".C11</i></p>	Positive feedback about the ACI center	Satisfaction of services	
<p><i>"They said that their son was much better than mine repeatedly".C3</i></p> <p><i>"People made us feel that we didn't do our best for our son telling us to take him out as if there is a kind of treatment in another country and we don't want to cure him. It is strange that whoever doesn't experience it, doesn't feel it well ".C4</i></p>	Blaming	Social exclusion	Stigma

<p><i>"I feel that my son is a piece from my body. I don't like this occasion, but we bring a cake and do the birthday party at home. Once my niece made a party for him. I hesitated to attend it. I don't like social occasions especially after his sickness".C1</i></p> <p><i>"All of them say:" God help you. God heal him." I couldn't imagine myself every time explaining my child's situation to people".C1</i></p> <p><i>"As a result, people started pushing each other and said things about him asking me why I carry him?"C3</i></p> <p><i>"People hurt me by looking at my son in a bad way".C3</i></p> <p><i>"My mother told me to leave him and get my social occasions done".C3</i></p> <p><i>"When we took him to our relatives, they didn't accept the idea of yelling because the kid had a habit of yelling. We started to feel embarrassed".C4</i></p> <p><i>"We avoid talking about the boy".C9</i></p> <p><i>"When we go to some occasions we don't take him with us".C9</i></p>	Embracement		
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<p><i>- "All schools refused to accept him". C1</i></p> <p><i>- "I have a religious aunt who linked my son's sickness to my work. She thinks that when I used to sell cigarettes in the supermarket, my money was illegal. She said, 'I don't know why your son became like this. Glorify to God, you have done something wrong.' C1</i></p> <p><i>- "When my husband takes our son to the market , the people say it's better to leave him home". C1</i></p> <p><i>- "There was a difference to deal with the educated people and the non, because explaining the situation to the educated people is way easier than doing the same to the non". C4</i></p> <p><i>- "When he will understand the interaction and the interaction will be friendly, Insha'Allah we will let him see the world". C9</i></p>	<p>Lack of awareness about ASD</p>		
<p><i>- " I take him with me when I visit a doctor, when going shopping and I walk in the street with him. It is not my problem that the people see my son who has autism". C1</i></p> <p><i>- "Everybody, everybody tells me that I should be patient, this child is better than going to pilgrimage, everybody says that he will be better". C2</i></p> <p><i>- "People sympathize with him. No one has bothered me and when the boy goes to the street; all people kiss him ". C8</i></p> <p><i>- "People are kind with him , they love him". C11</i></p> <p><i>- "All people used to blame me when I leave him alone. They believe that when he will be with me , he will be in best condition". C1</i></p>	<p>Feeling drained up</p>	<p>Negative labeling</p>	

<p><i>- "My husband thought that there must be a therapy, and when the child gets older in age he will recover and start talking".C1</i></p> <p><i>- "I told myself that my son has no autism".C1</i></p> <p><i>- "My husband feels happy when I tell him that autistic people can marry, although he knows that these kinds of people with autism don't marry".C1</i></p> <p><i>- "I say that it is better to see my son on a wheel chair instead of his mental disability".C1</i></p> <p><i>- "My husband denied the son's sickness".C1</i></p> <p><i>"I did not believe until my oldest daughter argued with me, asking why I don't believe. I refused to accept that and I said your brother is normal; she said that he is normal but he has a kind of autism. I refused to accept that and I asked them to never mention this again".C2</i></p> <p><i>- "Words annoyed me making me isolate myself from people".C3</i></p> <p><i>- "I haven't visited anyone for four months".C1</i></p> <p><i>- "We strongly believe that his disease is unforeseen and he would be better and mingle with the society normally".C4</i></p> <p><i>- "My feeling was denial and so was my husband's". C6</i></p> <p><i>- "I wished that a miracle happened that I would open my eyes and see the child normal". C7</i></p> <p><i>- "She doesn't like to talk about what her son has".C9</i></p> <p><i>- "I refused the fact that the boy has autism".C10</i></p> <p><i>- "I didn't believe the situation".C11</i></p>	Disappointment	Denial and isolation	Grief
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<p><i>"When he told me that, it was a shock to me that I started crying".C1</i></p> <p><i>"I sat alone and I cried. I had never heard of autism".C2</i></p> <p><i>"I was hurt and my heart burned because I saw him all the time".C5</i></p> <p><i>"The diagnosis affected me of course; my ambitions and dreams stopped, and my social relations were severely affected".C7</i></p> <p><i>"I became nervous and didn't like to see people". C10</i></p> <p><i>"I stopped interacting with the others because all my aim is the boy, all my life is the boy". C10</i></p> <p><i>"It was very hard and it was a shock".C12</i></p> <p><i>"My weight increased and some people asked why I dress like this".C1</i></p> <p><i>"I used to go to some occasions but now I don't go".C9</i></p>		Anger	
<p><i>"I sometimes say to myself that if my life hadn't been like this, I wouldn't leave him home".C1</i></p> <p><i>"I felt so bad that I said: "What luck"".C7</i></p> <p><i>"The kindergartens were bad and I sometimes, brought him with me to the supermarket and tied him to a chair in order to talk to him and play with him. I feel guilty that I have been responsible for increasing his sickness".C1</i></p>	self blaming	Bargaining	
<p><i>"I have depression. I don't visit anyone".C1</i></p> <p><i>" We sometimes should have faith, but we break and weaken so many times".C7</i></p> <p><i>"It crossed my mind a lot that medicine developed lot since people got</i></p>		Depression	

<p><i>to the moon. Despite all this development, no one could find a cure for autism even considering that it is spreading fast".C7</i></p>			
<p><i>- "Sometimes, my son would be with me in the street holding my hand, but, he suddenly lets go and runs away. I lost him many times, people get him back to me from down town as my brother did once. In another incidence, the police brought him back".C5</i></p> <p><i>- "Any person who wants to ask about patience should go and see a mother who has a son with autism in order to see how she suffers".C6</i></p> <p><i>- "They might say it as a joke, but everything is meant on the inside. For example, one night, they said: "Don't you want to sleep? Don't you get tired? Don't you like to relieve us?" This hurts".C7</i></p> <p><i>- "We are in severe pain because he doesn't communicate and complain".C9</i></p> <p><i>- "We accepted the idea but sometimes it affects our feelings".C9</i></p>	Suffering		
<p><i>- "My son's sickness has destroyed me because the time I heard his name, I cried for one hour".C1</i></p> <p><i>- "I wish that his father wasn't that man who is nervous who fills the house with stress. I wish he was calm".C6</i></p> <p><i>- "I have been annoyed by my husband when he beats him when he cries". C6</i></p> <p><i>- "It taught me patience and carelessness that I won't care about all the sabotage he does to the house. Everything became normal despite the things he breaks. I just close the door, and leave him to break whatever he wants".C7</i></p>	Giving up		



<p><i>- "I have sold the supermarket in order to keep looking after him". C1</i></p> <p><i>- "We left our city and came here for sake of our boy". C8</i></p>	Sacrifices		
<p><i>- "I love him very much and I feel that he is very close to me. He is a very kind, cute and lovely child. He says lovely things. He laughs. I and my daughter love him very much and we usually laugh about his words". C1</i></p> <p><i>- "I knew the situation from the beginning that my son has something wrong". C1</i></p> <p><i>- "I started to accept his condition". C2</i></p> <p><i>- "We accepted him willingly". C2</i></p> <p><i>- "This child was a gift from God, so we couldn't do anything but accept him". C5</i></p> <p><i>- "Because I'm educated and I have a degree in a specialization close to psychology, I started to accept his case". C6</i></p> <p><i>- "My feeling is that we are satisfied with our fate, the destiny that God wants". C8</i></p> <p><i>- "Our son is like an angel, he is peaceful and he doesn't hurt anyone. We believe in our fate and what God wants". C8</i></p> <p><i>- "We have to give him love and emotion. He still sleeps with me and hugs me at night". C8</i></p> <p><i>- "I believe that Allah gave him to me and I believe in Allah". C10</i></p> <p><i>- "I started accepting the situation slowly". C12</i></p>		Acceptance	

<p><i>"I started to suffer in that he keeps bothering me, pulling my hair; I keep my head covered always because he keeps pulling my hair; he is my child, I don't know what to do with him".C2</i></p> <p><i>"I was tired physically".C10</i></p> <p><i>"I go and return everyday from Nablus to Jerusalem and then I used to take him to another center twice a week, which was very exhausting".C12</i></p>		Physical burden	Family challenges
<p><i>"Because I had some problems with my husband, I used to run the supermarket. My husband couldn't shoulder any responsibility, so I had to leave my home to work from 7:00 pm until 12 midnight". C1</i></p> <p><i>"I have a strong feeling that the problems with my husband had influenced my son's sickness".C1</i></p> <p><i>"My son has strengthened the relationship between me and my husband".C1</i></p> <p><i>"My relation with my husband remained the same thanks to Allah".C2</i></p> <p><i>"My relationship with my husband remained as usual".C3</i></p> <p><i>"My relationship with my wife remained normal, and we cooperated on enhancing his condition".C4</i></p> <p><i>"My relation with my husband was affected a little bit because my husband was annoyed all the time".C5</i></p> <p><i>"My relationship with my husband has strengthened. I became concerned about my family more and I want to live my life".C6</i></p> <p><i>"My relation with my husband weakened because I would always be busy with the kid and his problem,</i></p>	Couples	Family relationships	

<p><i>which caused problems". C7</i></p> <p><i>-"He gets upset. This is because I didn't want to visit his parents. He didn't know that I would be hurt from his parents or anywhere I felt uncomfortable". C7</i></p> <p><i>-"She is nervous with me".C9</i></p> <p><i>-"We quarrel for a lot of things".C9</i></p> <p><i>-"My relationship with my husband has been strengthened".C10</i></p> <p><i>-"My relationship is strong with my husband. Nothing has affected it".C12</i></p>			
<p><i>-"My daughter also suffers a lot from this situation".C1</i></p> <p><i>-"She is nervous not only with him , but also with other her children".C9</i></p>	Siblings		
<p><i>-"My father and my brother usually help me with him".C1</i></p> <p><i>-"People are strange and harmful".C1</i></p> <p><i>-"My daughters help me".C2</i></p> <p><i>-"My husband helped me a lot taking me to the clinics".C3</i></p> <p><i>-"My parents and relatives always support me feeling what I feel".C3</i></p> <p><i>-"We stopped yelling at him, and his brothers and our relatives' cooperated with us. They understood his conditions and understood that he is sick".C4</i></p> <p><i>-"We supported each other in that we bring anything the child wishes". C5</i></p> <p><i>_ "My relationship with his brothers has strengthened and we became like a crew. We all help him". C6</i></p> <p><i>-"My parents supported me the most because they always tell me to look for cure even if it costs a lot. He also told</i></p>	Family support		

<p><i>me that he will pay if we cannot afford it, so their support is positive".C7</i></p> <p><i>- "My husband is not helpful. He doesn't help me".C11</i></p> <p><i>- "His father increased his help to me".C12</i></p>			
<p><i>- "They bring some media programs about autism, I started to follow them".C2</i></p> <p><i>- "It was necessary to defend my son without caring about people".C3</i></p> <p><i>- "We had enough information about the problem from our readings about it".C4</i></p> <p><i>- "All the known information about this disease is a group of hypotheses and theories, and nothing is proven about the treatment and reasons. The researches didn't conclude anything about it due to disputes ".C4</i></p> <p><i>- "My son taught me determination, patience and success is the end of each way".C6</i></p> <p><i>- "She diagnosed him as autistic. She searched on the internet, knew its symptoms and she told the physician".C9</i></p> <p><i>- "I have learned to be close to my son more and help him more".C10</i></p> <p><i>- "I have learned a lot and I can diagnose any child with autism".C12</i></p>		Awareness about ASD	
<p><i>- "Always I say to his father that I hope that our son grow up and marry".C1</i></p> <p><i>- "God would cure him once and for all, and until then, I hope that he will depend on himself without trusting in people. He will start defending himself against whoever beat or curse or mock him".C3</i></p> <p><i>- "He would get better if God</i></p>		Hope	

<p>wished".C3</p> <p>-<i>"Autism has a riddle and I must reach it because I'm 50% in solving this riddle. Insha'Allah when I reach it, I will declare it".C6</i></p> <p>-<i>"I hope that my son can depend on himself even at the lowest level".C9</i></p>			
<p>-<i>"It came to my thoughts that: could it be possible that this child would be healed? Or would he remain like this? I mean, if I could travel to America to treat him [I would do that]; the most important thing is to treat him, this thing comes to my mind".C2</i></p> <p>-<i>"My aim was only to cure my son to the extent that I didn't leave any doctors or religious men who could do anything for my son. Imagine that I took my son anywhere I hoped he would get better and get cured".C3</i></p> <p>-<i>"I told her that it was impossible to leave him alone since I had to be with him all the time to get used to people. This way, he would see the world instead of living in his world".C3</i></p> <p>-<i>"I learned that we should have a strong will to believe that nothing was impossible".C3</i></p> <p>-<i>"The most important thing was that my son be dignified. Now, I was not shy to shut up anyone who said a word about him and defend my son's right to defend himself".C3</i></p> <p>-<i>"Our ambition became to teach the kid the ABCs of life in order to get his things done well and contact with the world".C4</i></p> <p>-<i>"I learned to be patient, (she said it with a long sigh), and any human being has the right to live his childhood. Besides, it is my duty to make it happen with tolerance".C4</i></p>	<p>Determination to fight for the child</p>		

<p><i>- "They don't help me with the boy because I refuse ... It is right that the boy has the priority but also my husband and children. I don't want to finish my life and destroy my home because of one member. I control everything".C6</i></p> <p><i>- "When we knew that this center was established, immediately we brought him ... I swear by Allah that we didn't miss any chance to improve the boy".C8</i></p> <p><i>- "I will not miss any way for the treatment of our boy".C8</i></p> <p><i>- "Our concern is to put him on the road of life because he doesn't know to do that himself".C10</i></p>			
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## **Chapter Five**

### **5.1 Discussion**

This study gave the researcher the chance to have a better understanding of the experiences of the parents who have children with Autism Spectrum Disorder (ASD), and also to look deeper into the world of Autism which was and is still being considered as a world full of puzzles. This highlights the aim of the study which is to investigate and describe the experience of the parents going through the process of diagnosis of ASD in the West Bank. The specific objectives are: to describe how an autism diagnosis affected families, including the psychological effects on parents, the physical effect on parents, and the effect on couples' lives.

Through the study, parents of children with ASD expressed their struggle and frustration through the diagnostic process of ASD. Many of these realities are and will always remain to be extremely challenging for parents and children.

The study revealed these challenges, and they are summarized in four vital themes:

1. **Diagnosis:** Missed or late, lack of evidence-based services, and satisfaction with services.
2. **Stigma:** Parents had experienced embarrassing and frustrating situations where they suffered social exclusion and negative labeling.

3. Grief: All of the parent participants expressed grief on different levels for each of the following stages: denial, anger, bargaining, depression, and acceptance.

4. Family challenges: Most parents expressed how diagnosing ASD had affected their family relationships. They also talked about the positive impacts of the diagnosing process.

Parents gave us the permission to share their experiences in going through the diagnosing process of ASD with their children. They felt free to speak from their hearts because the interviews were their first chance to speak up and talk about their realities. They felt the responsibility to share with other parents what they had learned through the whole diagnosing journey. This study is unique because it allowed parents to speak about their own experiences, to connect with other parents of autistic children, and to help them take appropriate decisions when it comes to the diagnosing process.

Many researches like Sen & Yurtsever (2007), Papageorgiou & Kalyva (2010), Aziz (2014), and Desai, et al. (2012) have indicated that the burdens which the families of autistic children go through are present in different levels, including: cognitive, financial, psychological, and social support.

## **5.2 Discussion of the results**

1. **Diagnosis** (the first theme), and the sub-themes missed and late diagnosis, lack of evidence-based services, and the satisfaction with services.



The diagnosis is divided into three stages: pre-diagnostic stage, the diagnosis, and the post-diagnostic stage. Obtaining a specific diagnosis has benefits, such as: access to the suitable interventions, getting information regarding the challenges and how to cope with them, and also obtaining information regarding mental health and medical risks. Each family that goes through the diagnostic process of ASD considers the diagnosis itself as a potential stressor and it is rarely a positive experience. This has diverse impacts on families (Hodapp, 2011).

A lack of evidence-based services, a lack of diagnosing professionals, and missed and sometimes late diagnosis leave parents confused and unsatisfied. These results came parallel to other studies' findings like (Chamak, et al., 2011) which is a qualitative study on French parents resulted in "36% of parents of children with ASD and 93% of parents of adults with ASD were dissatisfied because of the long delays in obtaining the diagnosis". They also described the difficulties that they faced in obtaining the diagnosis as long, exhausting, no accurate diagnosis, changeable diagnosis, and diagnosis that had to be obtained abroad.

In addition, Crane, et al. (2015) conducted a survey of 1,000 parents in the UK and found that approximately half of the study participants were not satisfied with the process of diagnosis, indicating the length of the process, the accuracy of the diagnosis, the lack of information provided, the lack of professionalism of the person conducting the diagnosis, the stress

accompanying the process, and the lack of post-diagnostic support as reasons for this overall dissatisfaction.

Regarding the satisfaction results that are mentioned in detail above, parents showed satisfaction and talked about noticeable improvement with their children at the ACI. They were comfortable with the diagnosing, rehabilitation and intervention services that the ACI provides. They also contributed positive feedback about the services that are provided by the center. These services are based on ethical considerations of scientific research, which has made them more credible and acceptable.

2. **Stigma** (the second theme), and the sub-themes: social exclusion and negative labeling.

Stigma was one critical theme that most participants in my study mentioned. They expressed their feeling of isolation and rejection during the diagnosing process and afterwards.

In an Arabic Palestinian community, ASD is a stigmatized issue which most parents are being affected by at different levels. Some showed sympathy and tolerance, others are not aware enough about ASD as a disorder. They jumped into conclusions saying words that are hurtful and frustrating (either intentionally or not). Social exclusion was another practice where autistic children and their families were left out of various social events. One study with similar findings regarding stigma is that of Woodgate, et al. (2008). In their article, *Living in a World of Our Own: The Experience of Parents Who*

*Have a Child with Autism*, their findings highlighted the stigma very clearly, and the parents expressed their experiences as feeling a sense of disconnect from the family, finding that the social system was not supportive, feeling nostalgic about their previous, 'normal' way of living, and indicating that there was a lack of understanding in their communities.

Ludlow, et al. (2011) conducted a qualitative study of parents of children with ASD, who stated their challenges as coping with the judgment of others, and the unsupportive social system.

Another point of view that implies the stigma in a whole different way is that presented in a Heidary, Shahidi & Mohammadpuor (2015) study of 18 Iranian mothers of children with ASD who found that many mothers of autistic children thought of the diagnosis as punishment from God. This reflects the viewpoint of one of the participants of this study, who said: *"I have a religious aunt who linked my son's sickness to my work. She thinks that when I used to sell cigarettes in the supermarket, my money was illegal. She said, " I don't know why your son became like this. Glorify to God, , you have done something wrong."* This showed the lack of awareness that people have regarding this disorder and highlights the importance of raising the public awareness as mentioned in the recommendations below.

Furthermore, some of my study participants found that having a child with ASD is not only a duty but also a gift from God and a source of blessing.

Heidary, et al. (2015) also focused on the spiritual impacts and they found that some mothers who have a strong relationship with God and religious and spiritual beliefs can cope well with the challenges of having a child with ASD.

In addition, there are two studies that supported this study's theme of stigma (Aziz, 2014; Jeans, 2013). Both studies found that there is a huge need for people to understand the disorder. This is logical because we lack community awareness and media contribution to what ASD is. The importance of social inclusion of autistic children with their peers empowers them and has a positive social impact on the community (Aziz, 2014; Sen & Yurtsever, 2007; Kourkoutas, et al., 2012).

This study also focuses on the importance of providing social support for the families of the autistic children, which was found by numerous studies that found that the more social support provided to the families, the more they were able to cope with their autistic children (Sen & Yurtsever, 2007; Papageorgiou & Kalyva, 2010; Aziz, 2014; Kourkoutas, et al., 2012; Brobst, et al., 2009; Woodgate, et al., 2008; Ludlow, et al., 2011).

3. **Grief** (the third theme) and the sub-themes: Denial, Anger, Bargaining, Depression, and Acceptance.

Taking into consideration that all people grieve differently, some of them may mask their emotions or keep the grief internal, while others may exhibit their emotions in one way or another. We can state that all parents

of children with ASD experienced at least one of these emotional reactions as the participants in this study have expressed.

A number of studies have also dealt with the stages of grief among parents of children with ADS, finding that these parents feel sadness, frustration, anger, stress, depression, dysphoria, denial, and self-blaming (Abbott, et al., 2013; Sen & Yurtsever, 2007; Kourkoutas, et al., 2012; Dumas, et al., 2009; Hastings, et al., 2005; Ludlow, et al., 2011).

Brobst, et al. (2009) found that there were more issues with child behavior and parenting stress among parents of ASD children. In addition, another study measuring depression in mothers and fathers of children with ASD used both qualitative and quantitative methods, and found that the mothers of children with ASD have higher depression degree scores than mothers of children with intellectual disability without ASD (Olsson & Hwang, 2001).

**4. Family challenges** (the fourth theme), and the sub-themes: physical burden, family relationships, awareness, and hope. The challenges are considered the difficulties that the parents go through during the diagnosing process of ASD and afterwards, which lead parents to seek psychological help.

The participants in this study showed similar concerns to a study conducted by Desai, et al. (2012), which investigated the lived experience of 12 parents of children with ASD in Goa, India. The results showed that the parents have many concerns during the diagnosis process for their child,

such as new challenges, learning how to care for the child, specifically in addressing his/her basic needs, and supporting the child in finding his/her place in life.

#### 4.1 Physical burden

The participants showed how tired and even exhausted they were because of the need to travel long distances in search of centers and doctors to provide them with the right diagnosis. The results of this study are equivalent to other studies such as: Chamak, et al. (2011), Crane, et al. (2015), and Kourkoutas, et al. (2012).

#### **4.2 Family relationships**

Family relationships are reflected in the degree of support that couples and family members can provide to each other. Participants of my study indicated that their relationships with their partners, spouses, relatives, siblings, and family members were affected. Sen & Yurtsever (2007) had similar findings in that having a child with ASD in the family affects all family relationships.

In addition, Abbott, et al. (2013), Kourkoutas, et al. (2012), and Brobst, et al. (2009) showed parallel results to this study's results regarding how having a child with ASD affects couples' relationships in both positive or negative way.

### **4.3 Awareness**

The participants in this study suffered from the lack of information provided to them regarding the professional diagnosis, rehabilitation services and coping strategies in addition to the latest advances in ASD treatment interventions, which is similar to the findings of other studies (Sen & Yurtsever, 2007; Papageorgiou & Kalyva, 2010; Aziz, 2014; Woodgate, et al., 2008). In the same vein, Abbott, et al. (2013) talked about the importance of the clarity of the provided information to the parents of autistic children. Possible reasons behind these problems are: the weakness of the outreach programs which are directed at families of children with ASD, the absence of local media tackling the issue, and the lack of effective NGOs and other governmental institutions. If these agencies were able to play an more effective role in the community, families would be educated about the future of their child's education, rehabilitation, training, and medical interventions.

The participants also revealed their willingness to seek knowledge and information to increase their awareness about the disorder using different methods (as mentioned in their quotations), similarly to Mackintosh, et al. (2005) who aimed to discover the source of information that the parents use to obtain information about the diagnosis for their child. This study used an online survey for parents of children with ASD. The results indicated that the most-used source of information for families were as follows in order of prevalence: other parents of children with ASD, ASD specialists, doctors

and teachers, family members, friends, spouses, web pages, ASD support groups, newsletters, books, conferences, and workshops.

#### **4.4 Hope**

The participants in this study showed that they have hope for a better future for their children, and strong determination to go all the way and fight for their children. This finding is similar to Oprea & Stan (2012) and Ogston, et al. (2011) as the latter resulted in that hope is a protective factor against psychological distress. They also found a relationship between hope and education of the mother; mothers who are educated or have higher education levels have less worries and have higher hope levels. This is contrary to my finding that women who are not educated or have less education levels showed that they have higher hope levels than the educated ones.

- **The Financial burden**

There are some studies which considered financial burden or the family income as a challenge for the families of autistic children (Sen & Yurtsever, 2007; Aziz, 2014; Mackintosh, et al., 2005; Hsiao, 2013; Sharpe & Baker, 2007). Our study, on the other hand, did not find that the financial burden was important and that even if a family has many children, they still put aside a specific amount of their money for the treatment of their autistic child. It is also possible that a family with a lot of children will not specify



anything for their autistic child because they give up on his recovery and decide to save their money to spend on the non-autistic children.

In addition, because of the nature of my study sample that includes families with their autistic child enrolled in the ACI, which is a private institution that means that the financial burden is not considered important for them.

## **Chapter Six**

### **6.1 Conclusion**

The study revealed 4 core themes and 14 sub-themes representing the vital challenging elements of the participant parents' experiences: diagnosis, stigma, grief, and family challenges.

Studying the experiences of parents of children with ASD was an exceptional and interesting endeavor, as it is one of the first times that we listen to the parents of the autistic children and the first time that they actually speak out freely about their feelings through the whole diagnosing process.

ASD is still under a big stigma shadow in our Arabic Palestinian culture. Our society is not ready to accept and deal with disabilities yet. Parents go through a lot of feelings such as grief, anger, denial, depression, isolation, guilt, and self-blaming. They are stressed and ashamed as they feel lonely when their child is diagnosed with ASD. This study aims at minimizing the stigma in the community by emphasizing the role of early intervention, rehabilitation, and inclusion services.

This experience was rich in adding information about ASD on how to accurately diagnose it and empower parents and families in order to help the children and provide them with ample resources.

Moreover, the study provided deeper insight into parents' feelings during the diagnosing process and afterwards, and shed light on many different aspects, either positive or negative, regarding the parents' experiences.

This study also highlights the needs of the parents and their children in order to let the community and the policy makers be aware of this vulnerable group of people as the Palestinian community remains with a true lack of professionals, facilities, training, and support surrounding the topic of ASD.

We personally believe that we can be part of the change, and this point is clearly reflected in our recommendations and suggestions.

## **6.2 Recommendations**

This study is unique in being a pioneer in the field of ASD. It highlights the needs of children and their families throughout the process of diagnosis and afterwards. It provides information on how to accurately diagnose and empower parents and families in order to help the children and provide them with ample resources. It also aims at minimizing the stigma in the community by emphasizing the role of early intervention, rehabilitation, and inclusion. We need to advocate for a broader understanding of the needs of the parents, children, and young people with autism. In addition, there is a need to establish special centers and educational support along with rehabilitation programs in Palestine.

Recommendations are grouped in these strategic categories, and they will be discussed in more details.

## **1. Recommendations for the media (campaigns and information approaches) and for minimizing the Stigma (behavioral change and social approach):**

- Broad campaign:

Media can play a powerful role in educating the public. Community-wide campaigns on a large-scale, multi component campaigns that deliver messages and information about ASD by using different ways is needed. Once we work on increasing people's awareness and knowledge regarding this issue, stigma, discrimination and social exclusion will be minimized.

- Media stories about families of children with ASD can be newsworthy and important to be covered.
- Schools can play an important role in socially exclusion and inclusion for the child, as they can minimize victimization, discrimination, and bullying.
- Community inclusion should be encouraged. Parents should also participate in the community activities and celebrations.

## **2. Recommendations for the future research:**

- There is a need for qualitative research types and models in order to get more insight into the challenges encountered by the families of the ASD children.

- There is a need for conducting further research that includes siblings and other members of the extended family, with the use of other methodologies.
- There is a need for more research that investigates the relationship between ASD and behavior problems in children.
- There is a need for research that focuses on the marital relationships of the parents of ASD children.
- Data and studies are needed about the diagnostic systems that are being used in other cities in Palestine in order to make comparisons.
- There is a need for research that examines the procedure of the diagnosis of ASD, including the extent to which families are provided with adequate support, knowledge, treatment strategies, and options.
- Studies that particularly address the father's experiences are needed in order to see if gender is a significant variable or not.

### **3. Recommendations for building a policy and supportive environment (societal change approach):**

- The health sector should allocate a budget for the autistic children in the governmental insurance system, in order to help families with treatment expenses.
- Establish special centers and educational support along with rehabilitation programs in Palestine.

- Establish family-centered services that teach parenting and coping skills, and provide sufficient support that the families of children with ASD need in dealing with stressful emotions and challenges.
- There is a lack of human resources such as specialized trained professionals that can provide a structured, caring environment and sufficient coaching for the families.
- Regular specialized and professional training for nurses, doctors, pharmacists, psychologists, pediatricians, and speech and language therapists is needed.
- Formulate a policy that aims to include autistic children in mainstream schools. And Schools should cooperate with professionals, and the parents of the children with ASD.
- Formulate policies that will enhance the school environment in order to be safe and free from the means of any harm for autistic children.
- The importance of directing NGOs (non-governmental organizations) to help providing effective services that are child- parent oriented.

#### **4. Recommendations for intervention activities:**

- The importance of developing two-way communication that is based on trust and privacy during the diagnosis and assessment process between the parents and the clinicians.
- Establish, implement and evaluate programs that are based on multi-dimensional strategies of primary and early prevention. It is proven that early intervention does positively affect the progress of the condition and lessens associated complications. The areas of intervention therapy involve

multiple intervention strategies based on individual needs, for example: Educational interventions, ABA, TEEACH, and others, such as: speech and language therapy, occupational therapy, physical therapy, dietary interventions (Gluten-free and Casein-free diets) and pharmacological interventions.

❖ **More Suggestions:**

- Autism is a stigmatized issue. When it comes to our Arabic Palestinian society, we can find that our society in general, has not learned how to accept disabilities yet. Parents go through a lot of feelings, such as grief, anger, denial, depression, isolation, guilt, and self-f blaming. They are stressed and ashamed when their child is diagnosed with autism. We need to increase the society awareness regarding ASD, for better understanding of the parents' reaction in dealing with their emotional, social, and financial stress.
- Throughout this study, I learned that parents need help to accept the fact that their child has autism. Here are some helpful hints that need to be acknowledged:
  - Learn about autism. The more you know about autism spectrum disorders, the better equipped you'll be to make informed decisions for your child.
  - Educate yourself about the treatment options.
  - Ask questions.
  - Participate in all treatment decisions.

- Become an expert on your child. Figure out what triggers disruptive behaviors and what causes a positive response.
- Find out what your autistic child finds stressful, calming, uncomfortable, and enjoyable. This will help you deal with the child more easily.
- Accept your child rather than focusing on how your autistic child is different from other children and what he or she is “missing.”
- Enjoy your child’s special days, celebrate small successes.
- Stop comparing your child to others.
- Love your child no matter what. Feeling loved and accepted will help your child more than anything else
- Have faith and be patient. Do not give up. Your child will grow up, learn, develop, and show improvement.

### **6.3 Limitation of the study**

- The study has some limitations, and the main one may be considered the limited participation of fathers, which might be attributed to the dynamics of the typical Arab family, where mothers are mostly responsible for their child's education and upbringing.

Also, the translation of the data (the interviews) from auditory to written language in Arabic and then to English might contribute to loss of meaning, but this limitation was taken seriously and minimized by translation and back-translation of the texts by the researcher.



## **6.4 Strengths of the study**

- The meaning of the experiences came directly from the parents themselves, and it is the first time that those parents freely spoke up with open hearts about their experiences, and this is what makes the findings of this study interesting and important.
- The study is important because it highlights the lives of parents with ASD children. It also sheds some light on the parenting experience of children with ASD. This will give professionals a deeper insight into the actual experience, which will allow them to provide more specialized and comprehensive care.
- A lack of evaluation studies and research in Palestine regarding ASD, either qualitative or quantitative, makes this study a pioneer in this field.
- In comparison to what could happen if focus groups were chosen, semi-structured interviews do not include tough emotional dynamics, which might stimulate parents to over dramatize the negative effects of their experiences.
- The crucial points which parents reflected in their experiences might be used to formulate future policy programs regarding providing support for them.
- All of the literature review of this study has been chosen carefully and recently (from the year 2000 and more recent).
- The ACI is a pioneer center in implementing the international standards for testing and diagnosing children with autism. It seeks to add another piece to the Autism puzzle in Palestine. The ACI provides professional

diagnosing and rehabilitation services for the children with ASD. The professionals provide the appropriate environment for the children through individual and group therapy. It is also unique in providing psychological and emotional support for families through the presence of a clinical psychologist, speech and language therapists, nurses, and Montessori teachers. They all provide intervention programs, educational plans, and rehabilitation services for the children and their parents. All the participants in my study were recruited from the ACI; this makes the results of assessments and diagnosis more reliable and accurate.

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**Annexes**

Annex 1: The Participant's Information Sheet English and Arabic.

Annex 2: The Consent Form English and Arabic.

Annex 3: The Interview Guidance Questions English and Arabic.

Annex 4: Certificate of completion.

Annex 5: IRB Approval Letter.

## **Annex 1**

### **Participant's information sheet**

**Title of the study:** Parents' Experience during the diagnostic process of Autism Spectrum Disorder in the West Bank. A Descriptive phenomenological Study

#### **Introduction:**

I'm Nagham Taslaq; a student in the public health master program at Al-Najah National University, the third term, my supervisor is Dr Sabrina Russo.

You are being asked to be a volunteer in a research study. Below you will find information about the purpose of this study and a description of what you can expect if you agree to participate. You will also find information about potential risks and benefits of being a part of this study and how your privacy will be handled (confidentiality). Please be sure to read all information carefully. If you have any questions, please contact either me or my research advisor, Dr. Sabrina Russo.

#### **The purpose of this study:**

The purpose of this study is to investigate and describe the experience of the parents going through the process of diagnosis of autism spectrum disorder in the West Bank.

#### **Eligibility:**

In order to participate in this study:

1. You must be parents who have at least one child diagnosed with ASD.
2. You must have your child diagnosed in Al-Najah Child Institute (ACI); Participants will be recruited from it.

**What are you expected to do:**

You as parents who have a child diagnosed with ASD, and for the purpose of this study are chosen to participate, and your participation means that I will conduct an interview with you , taking into consideration that the interview will be recorded (for the study purposes ) , and it is expected to last between 30-60 min . All the interviews will be implemented in the ACI.

**Privacy:**

All data is recorded only for the study purpose, and will remain stored in a locked cabinet during the study, and destroyed after the study is complete. No real names will be mentioned in this study and the informant will be identified by codes.

**Participant Rights:**

Your participation in this study is voluntary. You have the right to leave the study at any time without giving any reason, and without penalty.

**Benefits:**

Research has shown that talking about painful or difficult experiences can be helpful. For instance, after talking or writing about a difficult life experience, people in general can experience a sense of emotional release, a greater sense of understanding, and in some circumstances, can even experience health benefits. An indirect benefit (i.e., one that will not be experienced directly by you) may be that some of the information shared by you may be used to more effectively understand how the parents feel through the whole diagnosing process. The results of this study will help set basis for understanding

parents' reactions to diagnosis and suggest individual and family support. It will also help future studies in this field.

**Harms:**

The risks of participating in this research study are expected to be small. Participating in this study and speaking about the parent experiences through the diagnosing process, if you do experience discomfort as a result of the interview, you may tell me at any point during/after the interview. You may stop the interview at any time, with or without telling me why.

Finally, you can discuss any issues that may come up due to your participation in the study with your primary therapist, if you have one.

If you don't have a therapist the Clinical psychologists of the ACI will be available for debriefing and psychological support.

Your safety is the highest concern; therefore I will take all the necessary steps to keep this commitment. **(Transparency is very important to achieve productive results).**

And after the interviews if you still have something to convey, we are ready for more clarifications. Should you not hesitate contact us at the following telephone number

Dr. Sabrina Russo

0598-353-210

Nagham Taslaq

0599-107-226



## معلومات حول الدراسة للمشاركين

### عنوان الدراسة:

دراسة حول تجارب الاهالي خلال عملية تشخيص مرض التوحد عند الاطفال في الضفة الغربية ، دراسة نوعية ذات اسلوب وصفي.

### مقدمة:

انا الطالبه نغم روجي تصلق طالبة ماجستير صحة عامة في جامعة النجاح الوطنية ، اقوم بتحضير رسالة ماجستير حول موضوع تجارب اهالي الاطفال الذين يعانون من مرض التوحد، باشراف الكتورة سابرينا روسو.

نطلب منك المشاركة الطوعية في هذا البحث ، و في ما يلي ستجد معلومات عن اهداف الدراسة ، ووصف لما تتوقعه اذا وافقت على المشاركة. ستجد كذلك معلومات تتعلق بالمخاطر الممكنة والفوائد من جراء موافقتك ان تكون جزء من هذه الدراسة . و كذلك معلومات عن سرية المعلومات .

نرجو ان تقرا جميع المعلومات و ان كانت لديك اية اسئلة لا تردد بان تسالني او تسال المشرفه على هذه الدراسة دكتورة سابرينا روسو.

### هدف الدراسة :

وصف خبرات اباء الاطفال الذين يعانون من مرض التوحد .

### دورك في الدراسة:

لقد تم اختياركم للمشاركة في هذه الدراسة لان لديكم طفلا يعاني من التوحد ، و بناء عليه سيتم اجراء مقابلة معكم . لافتين انتباههم الى ان المقابلة سيتم تسجيلها لاهداف الدراسه فقط،و ستكون مدتها ما بين 30-60 دقيقه و جميع المقابلات ستتم بمعهد النجاح للطفوله.

سوف تكون جميع المعلومات لاستخدام الدراسة فقط، و جميع المستندات و التسجيلات سوف تحفظ في مكان امن و محكن الاغلاق ، و جميع التسجيلات سوف تتلف بعد الدراسة، ولن يكون هناك ذكر للاسماء الحقيقيه للمشاركين.

#### حق الرفض بالمشاركة في الدراسة او الانسحاب:

مشاركتك في الدراسه هي دراسه طوعيه ، لكم الحق في الرفض او الانسحاب من الدراسة في اي وقت من غير تقديم اسباب و لن يكون هناك اي ضرر عليكم .

#### الفوائد المتوقعه من الدراسة:

قد تعود المشاركة في الدراسة ببعض الفوائد على المشتركين ،فقد اثبتت العديد من الابحاث ان الحديث عن التجارب المؤلمة و الصدمات التي نمر بها قد تكون مفيدة قد تكون مفيدة في التخلص من اثارها و فهمها بصورة اكثر عمقا و بالتالي اعتبارها فرصة للنمو و التعلم.

اما الفوائد غير المباشرة هي ان المعلومات المقدمة منكم سوف تسهم بشكل اكبر بفهم مرض التوحد و خاصة ان هذا المرض اصبح اكثر انتشارا .

#### الاضرار المتوقعه من الدراسة:

يتوقع ان تكون المخاطر من المشاركة في الدراسة صغيرة و ان تمر بشكل سريع.

يتوقع ان الحديث عن التجارب التي مررت بها قد تعيد الى ذاكرتك المشاعر المؤلمة التي مررت بها ، و في حال الشعور بالاجهاد او عدم المقدرة على الاستمرار او عدم الرغبة بالحديث بامكانكم ترك المقابلة دون ابداء اي سبب في اي لحظة خلال او بعد المقابلة.

بامكانكم ان رغبتم طلب حضور معالجتك النفسية ان وجدت .

وان لم يوجد ، المركز يحوي اخصائيين نفسيين و بامكانه تقديم المساعدة لمن يحتاج.

ان سلامتكم هي الاهتمام الاكبر و الرئيسي، لذا سنتخذ كل الاجراءات اللازمة للوقايه من اي اثار سلبية قد تعود عليكم من مشاركتكم بالدراسة.

**معلومات للاتصال:**

ان كان لديكم بعد المقابلة اي استفسار او سؤال او في حال رغبتكم بمعرفة النتائج و الاطلاع عليها ، بإمكانكم

الاتصال علينا وفق الارقام الموجودة هنا:

دكتورة سايرينا روسو

0598-353-210

نغم روجي تصلق

0599-107-226

**Annex 2****Consent Form**

The undersigned....., (Name), Male / Female ..... Age  
 ..... born in ..... Confirms to have read / been explained  
 requests to participate in research project on "Parents' Experience going through the  
 process of diagnosing Autism Spectrum Disorder".

I have been given a copy of your request / project orientation and are willing to  
 participate in the project. I have received both verbal and written information about the  
 study, and I'm aware that my participation is voluntary. I am informed that at any time,  
 without having to explain it might withdraw from study if I wish. If needed I can be  
 contacted for a new interview or clarification of unclear relationship.

Address.....Telephone number .....

Email .....Academic level .....

The undersigned confirms that he / she provided information about the project and has  
 handed over the above copy of the request/ project orientation and consent to participate.

Date.....

Signature of informant .....

Signature of the project leader .....

نموذج موافقه على المشاركة في الدراسة:

الاسم..... الجنس..... العمر..... مكان الولادة

..... المستوى التعليمي.....

لقد تلقيت المعلومات المكتوبة و الكلامية حول الدراسة و التي ستكون حول تجارب اباء الاطفال الذين يعانون من مرض التوحد، و اوافق على المشاركة بالدراسة بشكل طوعي و قد تم اخباري انه بإمكانني الانسحاب باي وقت من الدراسة دون اعطاء اي اسباب.

العنوان ..... رقم الهاتف..... ايميل.....

..... التاريخ.....

..... التوقيع.....

**Annex 3****Interview Guidance Questions**

1. How did you<sup>i</sup> feel when you first noticed that your child is behaving differently?
2. What did you do when you notice that the child was behaving differently?
3. Where did you get the ASD diagnosis?
4. When did you get the diagnosis?
5. How did they make the diagnosis?
6. What were your feelings through the diagnosing journey?
7. Did the diagnosis of ASD change anything in your life and inside your family?
8. What support do you have from outside or in the family?
9. What did you learn about Autism?

اسئلة ارشادية للمقابلات:

1. كيف كان شعوركم عندما اكتشفتم و للمرة الاولى ان طفلكم يتصرف بشكل مختلف؟

2. ماذا فعلتم عندما اكتشفتم ان طفلكم يتصرف بشكل مختلف؟

3. اين حصلتم على التشخيص؟

4 متى حصلتم على التشخيص؟

5 كيف قامو بالتشخيص ؟

كيف كانت مشاعركم خلال مرحلة تشخيص المرض؟6

7. هل غير تشخيص مرض التوحد اي شئ في حياتكم و الحياة الزوجية؟

8. ما نوع التأييد الذي حصلتم عليه من الخارج او من داخل الاسرة؟

9. ماذا تعلمتم عن مرض التوحد؟

**Annex 4****Certificate of Completion**

The National Institutes of Health (NIH) Office of Extramural Research certifies that Nagham Taslaq successfully completed the NIH Web-based training course “Protecting Human Research Participants.”

Date of completion: 01/15/2015

Certification Number: 1650183



**Annex 5****IRB Approval Letter**

On Sunday, February 1, 2015 2:32 PM, I received an email from [irb@najah.edu](mailto:irb@najah.edu) telling me Congratulations you have got the IRB Approval for your proposal

جامعة النجاح الوطنية  
كلية الدراسات العليا

## تجربة الـاهل خلال عملية تشخيص اضطراب التوحد في الضفة الغربية دراسة نوعية الاسلوب الوصفي

إعداد  
نعم تصلق

إشراف  
د. سابرينا روسو

قدمت هذه الأطروحة استكمالاً لمتطلبات الحصول على درجة الماجستير في الصحة العامة  
بكلية الدراسات العليا في جامعة النجاح الوطنية في نابلس- فلسطين.

2016

ب

تجربة الاهل خلال عملية تشخيص اضطراب التوحد في الضفة الغربية

دراسة نوعية الاسلوب الوصفي

إعداد

نغم تصلق

إشراف

د. سابرينا روسو

### الملخص

يعتبر اضطراب التوحد أحد المواضيع المهمة في مجال الصحة العقلية باعتباره اضطراباً عالمياً سريع الانتشار. تهدف الدراسة إلى كشف ووصف خبرات الآباء الذين يمرون بمراحل تشخيص ووصف اضطراب التوحد في الضفة الغربية. باختصار أهدافي الخاصة تتلخص في اثر تشخيص التوحد على العائلات الأثر النفسي والعاطفي على الآباء العباء الجسدي الذي يرافق التوحد. قامت الدراسة كذلك ببحث آثار تشخيص التوحد على حياة الأزواج وديناميكية العائلة، وآثار الصورة النمطية المجتمعية. من أجل تحقيق هدف الدراسة استخدم منهج جوري وكانت الدراسة نوعية استخدمت الاسلوب الوصفي. شملت الدراسة اثني عشرة من آباء الأطفال المصابين بالتوحد في الضفة الغربية. صممت كذلك مقابلات وجهاً لوجه معدة جزئياً من أجل استخلاص خبرات الآباء. عند تحليل المعلومات تم استنتاج أربعة مواضيع رئيسية وأربعة عشر فرعية. تمثلت عوامل التحديات الأساسية لخبرات الآباء في: 1. التشخيص 2. الصورة النمطية المجتمعية 3. الحزن والمرارة 4. التحديات العائلية. الدراسة فريدة من نوعها لكونها رائدة في مجال مرض التوحد في الضفة الغربية إذ قامت بإلقاء الضوء على حاجات الاطفال وعائلاتهم خلال عملية التشخيص وبعدها. باختصار هذه الدراسة تملأ فراغاً في الابحاث الحالية عن مرض التوحد.

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