

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

Naghah Taslaq^{1*} Sabrina Russo²

1.School of Medicine and Health Sciences, Pharmacy, AL-Najah National University of Nablus/Palestine.
PO.box 707, Old Campus, Najah Street, Nablus, Palestine

2.School of Medicine and Health Sciences, Clinical Director of a Najah Child Institute, a Najah National University, Nablus/Palestine. PO.box 707, Old Campus, Najah Street, Nablus, Palestine

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.

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

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, Strömland & 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).

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.

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.

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.

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?

6. 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 22 selected using purposive sampling, and they were adult parents of children diagnosed with ASD located in the West Bank.

6.1 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.

6.2 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).

6.3 Study Population

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

6.4 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.

6.5 Sample size

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

6.6 Inclusion criteria

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

6.7 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.

6.8 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.

7. 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.

7.1 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 th 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 th 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 th 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 labelling).
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:

Themes	Sub-themes
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

8. 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 labelling.

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 a 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.

9. 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.

10. 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.

1. Recommendations for the media (campaigns and information approaches) and for minimizing the Stigma (behavioural change and social approach).
2. Recommendations for the future research.
3. Recommendations for building a policy and supportive environment (societal change approach).
4. Recommendations for intervention activities.

References

- Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of Autism Spectrum Disorder-a qualitative study of parents' experiences. *Clinical child psychology and psychiatry*. , 18(3), 370-382.
- American Psychiatric Association/Highlights of Changes from DSM-IV-TR to DSM-5. (2013). Retrieved from www.dsm5.org.
- Aziz, O. F. (2014). The Needs of Families of Autism Spectrum Disorder (ASD) and Their Relation to Certain Variables.
- Baio, J. (2012). Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States. *CDC*, Volume 61, Number 3.
- Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting Children with Autism Spectrum Disorders,

the Couple's Relationship. Focus on Autism and Other Developmental Disabilities. SAGE journals, 24(1), 38-49.

- Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *Jama*, 285(24), 3093-3099.
- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *SAGE journals*, <http://aut.sagepub.com/content/15/1/83>, 15(1), 83-97.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2015). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. 1362361315573636.
- Croen, L.A., Grether, J.K., Yoshida, C.K., Odouli, R., Hendrick, V. (2011). Antidepressant use during pregnancy and childhood autism spectrum disorders. *Archives of General Psychiatry*, Ar68(11), 1104-1112.
- Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). the discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural psychiatry*, 49(3-4), 613-637.
- Diagnosis Overview. (2014). Retrieved from http://readingroom.mindspec.org:http://readingroom.mindspec.org/?page_id=3190
- Doja, A., Roberts, W. (2006). Immunizations and autism: a review of the literature. *The Canadian Journal of Neurological Sciences*, 33(4), 341-346.
- Dresden, S. (2013). 12 famous people with autism. Retrieved from www.babble.com/entertainment.
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (2009). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *A Special Education Journal*, 2(2), 97-110.
- Englander, M. (2012). The-Interview-Data-Collection-in-Descriptive-Phenomenological-Human-Scientific-Research. *Journal of Phenomenological Psychology*, 43(1), 13-35. Fink, P. J. (1992). Stigma and mental illness. *American Psychiatric Pub*.
- Folstein, S. E., & Rosen-Sheidley, B. (2001). Genetics of autism: complex aetiology for a heterogeneous disorder. *Nature Reviews Genetics*, 2(12), 943-955.
- Fombonne, E. (2005). Epidemiology of autistic disorder and other pervasive developmental disorders. *The Journal of clinical psychiatry*, 66, 3-8.
- Giorgi, A. P., & Giorgi, B. M. (2003). The descriptive phenomenological psychological method. *American Psychological Association*.
- Giorgi, A. ((1985b)). Sketch of a psychological phenomenological method. Pittsburgh, PA, Duquesne University Press, 1, 23-85.
- Giorgi, A. ((1997)). Theory, practice and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28(60), 235.
- Grandin, T., & Panek, R. (2014). *The Autistic Brain: Thinking Across the Spectrum* | Dr. Temple Grandin. New York: www.amazon.com.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18(1), 59-82.
- Hallmayer, J. I., Cleveland, S., Torres, A., Phillips, J., Cohen, B., Torigoe, T., Miller, J., Fedele, A., Collins, J., Smith, K., Lotspeich, L., Croen, L.A., Ozonoff, S., Lajonchere, C., Grether, J.K., Risch, N. (2011). Genetic heritability and shared environmental factors among twin pairs with autism. *Arch Gen Psychiatry*, 68 (11), 68(11):1095-1102. doi:10.1001/archgenpsychiatry.2011.76.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). *HastinSystems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. Journal of autism and developmental disorders*, 35(5), 635-644.
- Heidary, A., Shahidi, L. H., & Mohammadpuor, A. (2015). Spiritual Journey in Mothers' Lived Experiences of Caring for Children With Autism Spectrum Disorders. *Global Journal of Health Science*, p79.
- Hodapp, R. M. (2011). *International Review of Research in Developmental Disabilities*. Academic Press.
- Hornig, M., Briese, T., Buie, T., Bauman, M. L., Lauwers, G., Siemetzki, U., & Lipkin, W. I. (2008). Lack of association between measles virus vaccine and autism with enteropathy: a case-control study. *PLoS One*, 3(9), e3140.
- Hsiao, Y. J. (2013). Parental Stress, Family-Professional Partnerships, and Family Quality of Life: Families of Children with Autism Spectrum Disorder.
- Hughes, V. (2011). Researchers track down autism rates across the globe. SFARI Simons foundation autism research initiative.
- James, S.J., Cutler, P., Melnyk, S., Jernigan, S., Janak, L., Gaylor, D.W., & N. (2004). Metabolic biomarkers of increased oxidative stress and impaired methylation capacity in children with autism. *The American journal of clinical nutrition*, 80(6), 1611-1617.
- Jeans, L. (2013). Family empowerment: the use of online parent discussion groups following diagnosis of

ASD in young children. Doctoral dissertation, University of Illinois at Urbana-Champaign.

- King, M., & Bearman, P. (2009). Diagnostic change and the increased prevalence of autism. *International journal of epidemiology*, 38, 38(5), 1224–1234.
- Kourkoutas, E., Langher, V., Caldin, R., & Fountoulaki, E. (2012). Experiences of parents of children with autism: Parenting, schooling, and social inclusion of autistic children. *Selected Papers from the Third International Congress on Interpersonal Acceptance and Rejection, Held in Padua, Italy*.
- Landgren, M., Svensson, L., Strömland, K., & Grönlund, M. A. (2010). Prenatal alcohol exposure and neurodevelopmental disorders in children adopted from Eastern Europe. *Pediatrics*, 125(5), e1178-e1185.
- Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of health psychology*, 1359105311422955.
- Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, 12(1), 41-51.
- Malterud, K. (2002). Qualitative methods in medical research--preconditions, potentials and limitations. *Tidsskrift for den Norske laegeforening: tidsskrift for praktisk medicin, NY raekke*, 122 (25), 2468-2472.
- Mertenz, D.M., and McLaughlin, J.A. (2004). *Research and evaluation methods in special education*. Thousand Oaks, Calif: Corwin Press.
- Molina Jr, R. M. (2014). "I Wouldn't Change Anything": The Everyday Realities of Living with Autism from a Parent's Perspective.
- Mostafa, G. A., & Al-Ayadhi, L. Y. (2012). Reduced serum concentrations of 25-hydroxy vitamin D in children with autism: relation to autoimmunity. *J Neuroinflammation*, 9(1), 201.
- Mutter, J., Naumann, J., Schneider, R., Walach, H. & Haley, B. (2005). Mercury and autism: accelerating evidence? *Neuro Endocrinol Lett*, 26 (5), 439-46.
- Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders*, 5(4), 1378-1384.
- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45(6), 535-543.
- Oprea, C., & Stan, A. (2012). Mothers of autistic children. How do they feel? *Procedia-Social and Behavioral Sciences*, 46, 4191-4194.
- Panerai, S., Ferrante, L. & Zingale, M. (2002). Benefits of the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme as compared with a non-specific approach. *J Intellect Disabil Res*, 46 (4), 318-27.
- Papageorgiou, V., & Kalyva, E. (2010). Selfreported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders*, 4, 653-660.
- Plotkin, S., Gerber, J. S., & Offit, P. A. (2009). Vaccines and Autism: A Tale of Shifting Hypotheses. *Clinical Infectious Diseases*, 48 (4), 48(4), 456-461.
- Robson, C. (2002). *Real World Research. A Resource for Social Scientists and Practitioner-Researchers (Second Edition)*. Oxford: Blackwel.
- Rogers, S. J., Wehner, E. A., & Hagerman, R. (2001). The Behavioral Phenotype in Fragile X: Symptoms of Autism in Very Young Children with Fragile X Syndrome, Idiopathic Autism, and other Developmental Disorders. *Journal of developmental & behavioral pediatrics*, 22(6), 409-417.
- Sen, E., & Yurtsever, S. (2007). Difficulties experienced by families with disabled children. *Journal for Specialists in Pediatric Nursing*, 12(4), 238-252.
- Sharpe, D. L., & Baker, D. L. (2007). Financial issues associated with having a child with autism. *Journal of Family and Economic Issues*, 28(2), 247-264.
- Smith, J. A., & Osborn, M. (2003). *Interpretative phenomenological analysis. A Practical Guide to Research Methods*. Sage.
- *The Diagnostic and Statistical Manual of Mental Disorders: DSM 5*. (2013). US: American Psychiatric Association.
- The-5-stages-of-loss-and-grief. (n.d.). Retrieved from <http://psychcentral.com/lib/>.
- Treatment Interventions. (n.d.). Retrieved from Autismcenter.org.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative health research*, 18(8), 1075-1083.
- Abdel Hamid, A., Samir, Q., Eyad, E.L. (2004, November). Mental Health Needs in Palestine. Gaza Community Mental Health Program, p. Issue 28.
- Autism History. (2013, May 12). Retrieved 2013, from www.webmd.com:

[www.webmd.com/brain/autism/history of autism neurodiversity.com](http://www.webmd.com/brain/autism/history-of-autism-neurodiversity.com)

- Autism-medication. (2014, Jan 29). Retrieved from [www.child-autism-parent-cafe.com: http://www.child-autism-parent-cafe.com/autism-medication.html](http://www.child-autism-parent-cafe.com/autism-medication.html)
- Axelrod, J. (2014, April 15). The 5 stages of loss and grief. Retrieved from psychcentral: <http://psychcentral.com/lib/the-5-stages-of-loss-and-grief/000617>
- Facts about ASD. (2014, November 12). Retrieved from [http://www.cdc.gov: http://www.cdc.gov/ncbddd/autism/facts.html](http://www.cdc.gov/ncbddd/autism/facts.html).
- (n.d.). Retrieved from www.mentalhealth.wa.gov.