

# **Improving Quality Of Life Among Children with Autism Spectrum Disorder**

*Thesis*

*Submitted for Partial Fulfillment of the Requirements of the  
Doctorate Degree in*

*Nursing Science*

*Community Health Nursing*

*By*

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# **Improving Quality of Life among children with Autism Spectrum Disorder**

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*Abeer Husein*

# List of Contents

<b>List of Contents</b> .....	I
<b>List of Abbreviations</b> .....	II
<b>List of Tables</b> .....	III
<b>List of Figures</b> .....	VI
<b>Abstract</b> .....	VIII
<b>Introduction</b> .....	- 1 -
<b>Aim of the study</b> .....	- 6 -
 <b>Review of Literature</b>	
➤ <b>Definitions of Autism</b> .....	- 7 -
➤ <b>Quality of life</b> .....	- 57 -
➤ <b>The Role of the Nurse in caring for children with Autism Spectrum Disorder</b> .....	- 80 -
<b>Subjects &amp; methods</b> .....	- 97 -
<b>Results</b> .....	- 113 -
<b>Discussion</b> .....	- 172 -
<b>Conclusion</b> .....	- 201 -
<b>Recommendations</b> .....	- 202 -
<b>Summary</b> .....	- 204 -
<b>References</b> .....	- 211 -
<b>Appendix 1</b> .....	- 243 -
<b>Appendix 11</b> .....	- 257 -
<b>Appendix 111</b> .....	- 264 -
<b>Appendix IV</b> .....	- 269 -

## List of Abbreviations

<b>ABA</b>	: Applied Behavior Analysis (ABA)—a treatment approach that utilizes principles of learning theory to bring about meaningful and positive change in behavior.
<b>ADHD</b>	: Attention Deficit Hyperactivity Disorder
<b>ADL</b>	: Activities of Daily Living
<b>ADOS</b>	: Autism Diagnosis Observation Schedule
<b>AIT</b>	: Auditory Integration Training
<b>ASD</b>	: Autism Spectrum Disorders
<b>CDC</b>	: Centers for Disease Control
<b>DLT</b>	: Daily Life Therapy
<b>DSM-5</b>	: Diagnostic and Statistical Manual of Mental Disorders 5 <sup>th</sup> edition.
<b>FC</b>	: Facilitated Communication
<b>GT</b>	: Gentle Teaching
<b>HT</b>	: Holding Therapy
<b>PDD-NOS</b>	: Pervasive Developmental Disorder –Not Otherwise Specified.
<b>PDS</b>	: Pervasive Developmental Disorders
<b>PE</b>	: Physical Exercise
<b>PECS</b>	: Picture Exchange Communication System
<b>PHCC</b>	: Palestinian Happy Child Center
<b>QOL</b>	: Quality of Life
<b>SIT</b>	: Sensory Integration Therapy
<b>SST</b>	: Social Skills Training
<b>TEACCH</b>	: Treatment and Education of Autistic and Communication related Handicapped Children
<b>WHO</b>	: World Health Organization

## List of Tables

Table No.	Title	Page No.
Table(1):	Distribution of parents according to their socio-demographic characteristics (N=60).....	120 -
Table(2):	Distribution of mothers according to their residence, family type, number of family members and monthly income.(N=60) .....	123 -
Table(3):	Distribution of children according to their demographic data (N=60).....	126 -
Table (4):	Distribution of mothers according to their first recognition of child disorder.(N=60) .....	130 -
Table (5):	Distribution of mothers according to their opinion regarding consanguinity (N=60) .....	131 -
Table (6):	Distribution of mothers' knowledge regarding complications of ASD (N=60) .....	132 -
Table (7):	Percentage Distribution of mothers according to their satisfactory knowledge regarding ASD, post program (N=60) .....	132 -
Table (8):	Percentage distribution of mothers total satisfactory knowledge regarding ASD pre and post nursing intervention program (N=60) .....	133 -
Table (9):	Percentage Distribution of mothers according to their satisfactory reported practices regarding sleep post intervention program(N=60).....	134 -
Table (10):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Toilet Training and personal hygiene(N=60).....	135 -
Table (11):	Percentage Distribution of mothers according to their reported satisfactory practices regarding movement(N=60) -	137 -
Table (12):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Safe environment(N=60).....	138 -
Table (13):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Breathing(N=60) -	139 -
Table (14):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Dressing and undressing(N=60) .....	140 -

## List of Tables

Table No.	Title	Page No.
Table (15):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Fear from others(N=60) .....	141 -
Table (16):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Cooperation(N=60) .....	142 -
Table (17):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Aggressiveness(N=60) .....	143 -
Table (18):	Percentage Distribution of mothers according to their reported satisfactory practices Social withdrawal and play(N=60) .....	144 -
Table (19):	Percentage Distribution of mothers according to their reported satisfactory practices regarding child Sex recognition(N=60).....	146 -
Table (20):	Percentage Distribution of mothers according to their reported satisfactory practices regarding Attention and Hyperactivity(N=60) .....	147 -
Table (21):	Percentage Distribution of mothers according to their reported satisfactory practices regarding communication(N=60) .....	148 -
Table (22):	Percentage Distribution of mothers according to their satisfactory reported practices regarding ADL,attention and communication and social skills pre,post program (N=60) .....	149 -
Table (23):	Percentage distribution of mothers total satisfactory practices regarding ASD pre and post nursing intervention program (N=60) .....	150 -
Table (24):	Distribution of children according to their problems regarding ADL. ....	151 -
Table (25):	Distribution of mothers according to their needs for child care .....	152 -
Table (26):	Distribution of children according to other health problems besides ASD,investigations,treatment and complications .....	153 -

## List of Tables

Table No.	Title	Page No.
Table (27):	Percentage Distribution of children according to effect of ASD on their quality of life post intervention program (N=60) .....	156 -
Table (28):	Percentage Distribution of children according to effect of ASD on their quality of life pre intervention program (N=60) .....	157 -
Table (29):	Distribution of childrens' pre and post mean and standard deviation regarding their quality of life (N=60) If Mean is between( 2.5-3)Average, less than 2.5=Bad QOL, If Mean is more than 3=Good QOL.....	158 -
Table (30):	Distribution of children pre and after mean and standard deviation regarding effect of nursing intervention program on their quality of life (N=60).....	160 -
Table (31):	Relation between mothers' total satisfactory practices and children quality of life post intervention program (N=60) ...	161 -
Table (32):	Relation between mothers' total satisfactory knowledge and children quality of life (N=60).....	162 -
Table (33):	Relation between mothers' total knowledge and practice (N=60).....	162 -
Table (34):	Relation between child diagnosis and quality of life (N=60).....	163 -
Table (35):	Relation between total satisfactory knowledge and practice with mother demographic data(N=60).....	165 -
Table (36):	Relation between QoL and mother demographic data (N=60).....	166 -
Table (37):	Relation between QoL and child demographic data (N=60) -	170 -



## List of Figures for Review

Figure No.	Title	Page No.
Figure (1):	Types of Autism Spectrum Disorders .....	11 -
Figure (2):	Factors explaining increase in ASD prevalence. ....	16 -
Figure (3):	Possible relationships between seizure, epilepsy and Autism .....	16 -
Figure (4):	Developing zebrafish models of autism spectrum disorder (ASD) .....	22 -
Figure (5):	Current Opinion in Genetics & Development.....	24 -
Figure (6):	Further evidence for links with stress and autism.....	34 -
Figure (7):	Further evidence for links with stress and autism.....	34 -
Figure (8):	Autism and other causes .....	38 -
Figure (9):	Model of interrelationship between health, quality of life and health-related quality of life. ....	59 -
Figure (10):	Auditory integration training .....	75 -

## List of Figures for Results

Figure No.	Title	Page No.
Figure (1):	Distribution of mothers according to their socio-demographic data (N=60) .....	122 -
Figure (2):	Distribution of Fathers according to their socio-demographic data ( N=60) .....	122 -
Figure (3):	Distribution of mothers according to consanguinity between parents( N=60) .....	123 -
Figure (4):	Distribution of mothers according to their residence, family type, number of family members and monthly income.(N=60) .....	125 -
Figure (5):	Distribution of mothers according to monthly family income(n=60) .....	125 -
Figure (6):	Distribution of children according to their socio-demographic data (N=60). .....	128 -
Figure (7):	Distribution of children according to kind of disease among children as expressed by their mothers (N=60).....	128 -
Figure (8):	Distribution of children according to presence of other children with ASD in the family(N=60) .....	129 -
Figure (9):	Distribution of children according to presence of disease other than ASD in the family (N=60) .....	129 -
Figure (10):	Distribution of Mothers according to their opinion regarding consanguinity .....	131 -
Figure (11):	Percentage distribution of mothers total satisfactory knowledge regarding ASD pre and post nursing intervention program (N=60) .....	133 -
Figure (12):	Percentage Distribution of mothers according to their satisfactory reported practices regarding ADL, pre,post program (N=60) .....	150 -
Figure (13):	Distribution of children according to presence of other health problems ,investigations,treatment and complications (N=60) .....	155 -
Figure (14):	Distribution of children according to kind of complications (N=60) .....	155 -
Figure (15):	Distribution of children according to effect of ASD on quality of life pre and post intervention program .N=(60)....	159 -
Figure (16):	Relation between child diagnosis and quality of life N=(60) .....	164 -

# Abstract

## Improving quality of life among children with Autism Spectrum Disorders

By

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**Aim** of the study is to Improve quality of life among children with Autism spectrum Disorders. **Research design:** A quasi experimental design was utilized. **Settings:** The study was conducted at The Palestinian Happy Child Center, Al Yasmin Charitable Society, and Al-Awda Children and Youth Rehabilitation Center in Ramallah and Tulkarm Governorates in Palestine. **Subjects:** A purposive sample composed of sixty mothers of children diagnosed with ASD. **Tools** of data collection: First tool: Structured interviewing questionnaire, it was developed to assess mothers knowledge and practices, It was composed of 4 parts, part one: socio-demographic data, part two: Assess mothers knowledge regarding ASD .Part three: Assess mothers practices adopted from *Hewalla,(2004)*. part four: Assess needs and problems of mothers. Second tool: Child medical record to assess child diagnosis, investigations, treatments and complications. Third tool: Quality of life questionnaire .Adopted and adapted from *Varni et al., (2006)*, WHOQOL-100.**Results:** Revealed a statistical significant relation between children quality of life and knowledge and practices of mothers regarding ASD. **Conclusion:** This study concluded that, the intervention of a nursing health education program had a significant statistical relationship with improved quality of life of children with Autism Spectrum Disorder. **Recommendations:** The study recommended that adequate education for family about the effect of the disorder on the quality of life on their children having ASD must be provided.

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**Key words:** Autism Spectrum Disorder, quality of life, Nursing intervention program.

# Introduction

Autism is known as a complex developmental disability. Experts believe that Autism presents itself during the first three years of a person's life. The condition is the result of a neurological disorder that has an effect on normal brain function, affecting development of the person's communication and social interaction skills (*Medicalnewstoday, 2015*)

Autism or (ASD) is a wide-spectrum disorder. This means that no two people with autism will have exactly the same symptoms. As well as experiencing varying combinations of symptoms, some people will have mild symptoms while others will have severe ones. Below is a list of the most commonly found characteristics identified among people with an ASD (*Eapen, 2011*)

The diagnosis usually takes place between the ages of two to three years old. Often parents seek medical attention when they feel that their child is not developing properly. A red flag is delayed speech, a common symptom of autism. In some cases, autistic children develop speaking skills early but suddenly regress, losing what they learned, which is devastating for their parents (*Fathi, 2016*)

Children with autism are special children with special needs as they have their own ways of perceiving the various stimuli,

whether sensory, motoric, vestibular, or proprioceptive, and therefore, they respond differently and act uniquely within our world through different manners of communication (*Sheikhany, 2013*)

Early signs of ASD are usually present before 18 months of age, and parents usually know that there is something wrong with their kid. Family members and healthcare providers should value parents' instincts and concerns expressed in relation to their child's development ( *Sheikhany, 2013*)

Genomic research is beginning to discover that people with autism spectrum disorders probably share genetic traits with individuals with ADHD (attention-deficit hyperactivity disorder), bipolar disorder, schizophrenia, or clinical depression (*Medicalnewstoday, 2015*)

QOL is the perceived quality of an individual's daily life that is, an assessment of their well-being or lack. Therefore, this includes all emotional, social, and physical aspects of the individual's life (*CDC, 2011*)

QOL domains such as social activity, family burden, family activities, schooling, independence and parental concerns about their children's quality of life should be considered when determining the impact of autism rather than examining symptoms alone. It has been suggested that an improved understanding of

how QOL is affected by autism may lead to better recognition of the needs of young people with autism and their families and the necessary services and supports can be put into place (*Brereton, 2013*)

Treatment should begin as early as possible using validated screening tools and should be tailored for every child to meet his/her needs. Early intervention and an educational approach may help in improving the quality of life of an autistic child and the family members ( *Sheikhany, 2013*)

Children with an Autism Spectrum Disorder (ASD) who received early intervention tend to have better brain function, communication skills and overall social behavior compared to ASD children with no early intervention (*Medicalnewstoday, 2015*)

Healthcare workers need to understand quality of life for clients/persons. It is particularly significant in the vulnerable population of autistic children and their caregivers. Children are being stolen from their loved ones by autism at a rate of one in every 30 minutes (*Eapen, 2014*)

Healthcare providers should be aware of the fine line between typical and atypical development and be able to identify the red flags that indicate that a child should be evaluated and screened. (*Sheikhany, 2013*)

## **Significance of the study:**

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.

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 currently there are no statistics available (*Taslaq, 2016*)

Very little data is currently available on disability in Palestine. The most comprehensive data is from a 1996 Palestinian Central Bureau of Statistics health survey that found that 1.7% of children aged 0-14 have some form of disability. No data was available specifically on autism (*Odeh , 2011*).

More than 3.5 million Americans are estimated to have autism, while in the U.K., more than 604,000 have the disorder (*Boucher, 2014*)

To date, Egypt does not have specific statistics on how prevalent the disorder is in the country (*Fathi, 2016*) .The common statistic used by researchers to estimate the prevalence of ASD globally is approximately 1 percent of the population worldwide (*Malcolm-Smith et al.; Wallace et al., 2013*).