Parent's Adjustment of Children with Autism Spectrum Disorders

Thesis

Submitted for the Master Degree in Nursing Science
(Community Health Nursing)

By

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List of Abbreviations

Abbr.	Full-term
ABA	Applied Behavior Analysis
ADHD	Attention-Deficit Hyperactivity Disorder
ADLs	Activities of Daily Living
APA	Americian Psychiatric Association
AS	Asperger's Syndrome
ASD	Autism Spectrum Disorder
BFB	Bio-Feed Back
CDC	Center for Disease Control
CDD	Childhood Disintegrative Disorder
CHN	Community Health Nurse
DNA	Deoxyribonucleic Acid
EEG	Electro-Encephalo-Gram
ERVs	Endogenous Retro-Viruses
FAAR	Family Adjustment and Adaptation Response
FDA	Food and Drug Administration
GERD	Gastro-Esophageal Reflux Disease
GI	Gastro-Intestinal
HERVs	Human Endogenous Retro-Viruses
HIV	Human Immunodeficiency Virus
HPA	Hypothalamic-Pituitary-Adrenal

IQ	Intelligence Quotient
M-CHAT-R	Modified Checklist for Autism in Toddlers- Revised
MDD	Major Depressive Disorder
NFB	Neuro-Feed Back
NGOs	Non-Governmental Organizations
PDD	Pervasive developmental disorders
PDD-NOS	Pervasive Developmental Disorder– Not Otherwise Specified
PDDST-II	Pervasive Development Disorders Screening Test-II
SCQ	Social Communication Questionnaire
SDT	Self-Determination Theory
NN	United Nations
UNICEF	United Nations International Children's Emergency Fund
US	United States
WHO	World Health Organization

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Abstract

Autism was a very complex neurobiological developmental disorder. Parents with autistic children face many challenges, affecting not only the autistic child and development but also parents functioning and quality of life. **Aim:** Assess parent's adjustment of children with autism spectrum disorders. **Research design:** A descriptive analytical design was used. **Setting:** The study was conducted at Pediatric Outpatient Clinic at El-Abbasia Governmental Hospital for Mental Health. **Sample:** Convenient sample of one hundred and forty-five of all parents accompanying their children who have been diagnosed with autism spectrum disorders. **Tools for data collection:** Data were collected through two tools include, first tool: Interviewing questionnaire to assess demographic characteristics, knowledge, practice, and obstacles of the study sample, in addition to needs and problems of autistic children, second tool: Parent's Adjustment Scale to measure parent functioning and adjustment pattern of challenges. **Results:** The study revealed that 51.7% of parents had unsatisfactory level of total knowledge about autism, and there were 79.3% of parents had un acceptable level of practice with their autistic children. Furthermore, there were 85.5%, 82.1% & 80.7% of parents had high financial stressors, physical stressors, and psychological stressors. While 75.8% of parents had high educational and rehabilitation stressors. In relation to parents' pattern of adjustment there were 64.1% of them had low-level of total adjustment with their autistic children. **Conclusions:** there was positive correlation between total knowledge and practice of parents about autism spectrum disorder and their adjustment with their autistic children. There was negative correlation between total knowledge and practice of parents about autism spectrum disorder and their obstacles with their autistic children. **Recommendation:** Counseling programs for parents to help them better understand the disorder and assist them with adjustment processes on daily problems that arise when dealing with their autistic children.

Keywords: autism, parent's adjustment, knowledge & practice, autistic children,

Introduction

Childhood ordinarily spans from the end of infancy to the start of adolescence. It is often divided into early, middle and late childhood. The early childhood is the period of eruption of milk teeth, which spans the period between one to 6 years, is the most important determinant of health and well-being across life course. The middle and late childhood spans the ages between early childhood and continues up to the time of puberty. Childhood is a time of significant growth and development ***(MacLeod, & Betker, 2017; & Lally, & Valentine-French, 2019).***

Autism Spectrum Disorders (ASD); also known simply as autism, is a lifelong disability that affects not only the children but the family as well. However previously thought to be one of the groups of pervasive developmental disorders, but it is now considered a complex neurological disorder that affects brain function, which causes impairment in multiple areas of development including social interaction, communication, and behavior. Typically, it appears within the first 3 years of life and tends to persist into adulthood ***(Omar et al., 2017).***

According to World Health Organization, the last estimate that worldwide 1 in 160 children have an ASD. The prevalence of ASD in many low- and middle-income countries is so far unknown ***(World Health Organization***

(WHO), 2019). In addition to this, Centers for Disease Control and Prevention has estimated identified that in Europe, Asia and North America the rate is between 1% to 2% ***(Centers for Disease Control (CDC), 2018).***

Many children with autism are a whole-body disorder; its frequent co-morbidities include seizures, gastrointestinal disorders, sleep disturbances, feeding challenges, attention deficit and hyperactivity disorder, anxiety, schizophrenia and bipolar disorder. These issues can extend across the life span; they also contribute to an alarming rate of premature death among those with autism ***(Croen et al., 2015; Guan, & Li, 2017)***.

Early diagnosis is important due to the high success rate of early intervention programs. It is diagnosed behaviorally through a series of observations criteria rather than through a medical examination ***(Videbeck, & Miller, 2017).*** Parenting knowledge and practices are shaped not only by each other but also by a number of factors; including children's characteristics, parents' own experiences, and expectations learned from others, cultural systems, as well as the supports available and opportunities within the larger community provided by institutions and community services ***(Navot et al., 2016)***.

Raising a child with autism spectrum disorder (ASD) can be overwhelming for parents and families in several ways, including increased parental stress, higher levels of mental health concerns, increase in problems within marital relationships, feelings of anxiety and depression, feel isolated and locked at home, as they fear taking their child out in public, and decreased quality of life for the family ***(Chu et al., 2018).***

Parent's adjustment enhances the accomplishment of other general adaptive tasks, such as: preserving a satisfactory self-image, keeping the family together, and preparing for an uncertain future, as well as the accomplishment of illness-related tasks ***(Mostafa et al., 2015).***

The community health nurse plays a significant role in the care of the child with autism in each of the three specific areas of concern: the child with autism, the parent who experiences stress related illness, and the family support network. Therefore, should be actively involved in the process of early diagnosis of autism and intervention, directing the family to behavioral services, specialists in autism, and therapists who are well versed in ASD, as well as informed parents about interventions of therapy and treatment programs that are available for their child ***(Omar et al., 2017).***