

**Expressed Emotion among Family
Caregivers of Children
with Autism**

Thesis

Submitted for Partial Fulfillment of Master Degree
In Psychiatric/Mental Health Nursing

By

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**Faculty of Nursing
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List of Abbreviations

5-HT	Serotonin
ADHD	Attention-Deficit/Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CC	Critical Comment
CNS	Central Nervous System
EE	Expressed Emotion
EEG	Electroencephalogram
EOI	Emotional Over Involvement
FP	Family psychoeducation
H	Hostility
PDD-NOS	Pervasive Developmental Disorder- Not Otherwise Specified
WHO	World Health Organization

Abstract

Background: Parenting a child with autism spectrum disorder represents extraordinary challenge to family caregivers, thus, they continue to have high level of stress and burden which consequently affect their expressed emotion and attitude toward their children.

Aim: This study aimed at assessing levels of expressed emotions among family caregivers of children with autism. **Design:** A descriptive explanatory research design was utilized in this study.

Setting: This study was carried out in the outpatient clinic of the Institute of Psychiatry affiliated to Ain Shams University. **Subjects:**

this study was conducted on 100 family caregivers of children with autism spectrum disorder. **Sample type:** Purposive sample was recruited for the study. **Data collection tools:** Data were obtained through three tools; 1) Interviewing Questionnaire, 2) The expressed emotions scale and 3) The family attitude scale. **Results:** The majority of the studied caregivers had high levels of expressed emotions, less than one fifth of them had low levels of expressed emotions and nearly three quarters of them had negative attitude toward their children with autism. **Conclusions:** this study concluded that the majority of studied caregivers of children with autism had high levels of expressed emotions and nearly three quarters of them had negative attitude toward their children with autism. Also, this study concluded that there is a highly statistical correlation between attitude of the studied caregivers of children with autism and their total expressed emotions levels. **Recommendations:** Utilization of our study results in designing and implementing counseling program for family caregivers of children with autism to management and control of their expressed emotions.

Keywords: Autism spectrum disorder, Expressed emotions, Family caregivers.

INTRODUCTION

Autism Spectrum Disorder is a complex developmental disorder with a neurobiological character, characterized by problems of communication and relating to others as well as interests, activities and behaviors that are restricted, repetitive and stereotypical (**Hsiao, 2018**).

Raising a child with an autism spectrum disorder (ASD) can be an overwhelming experience for parents and families. Family is the first natural context that is a child exposed for and it is the first social environment that surrounds the child. In other hand, the parent may be exposed to problems or sudden situations that can't be resolved at all, so they find themselves obligated to deal with and sometimes to adapt with over their whole life; thereby this mean that there is a change in roles and expectations among parents, especially if a child diagnosed with autism spectrum disorders (ASD), which is an emotionally challenging event for the parent (**Predescu & Şipoş, 2017**).

Parents of children with ASD tend to experience more mental health issues, depression, anger and stress than other parents who have children with other developmental disabilities (**Alquraini & Mahoney, 2015**).

The stress experienced due to the complexity of the ASD symptoms. It could also stem from the caregivers having to readjust their family life to accommodate to one

individual's needs; and also being burdened with the responsibilities of seeking out assistance from health, education and social care. Furthermore, caregivers may also have to deal with negative and judgmental views from others especially while being in public (**Pande & Sharma, 2018**).

Autism spectrum disorder (ASD) is a disease that may result in "caregiver syndrome" or "caregiver stress", (a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill and dependent child). This, in turn, can contribute to high expressed emotion (EE), with caregivers making critical comments to, and being hostile, emotionally over-involved and over-protective toward the child with autism (**Han & Lam, 2018**).

The term "expressed emotion (EE)" refers to the emotional climate within a family. Specifically, "high EE" refers to critical, hostile, or overinvolved attitudes expressed by a family member toward their ill child (**Izon, Berry, Law, & French, 2018**).

Hence, it's important to examine EE because negative dimensions of EE have been associated with the behavior problems of children with ASD, and expressions of warmth were associated with reductions in behavior

problems and increase social interaction and communication over time (**Romero-Gonzalez, Chandler & Simonoff, 2018**).

Thus, nursing interventions should provide illness-related knowledge and assess family responses in the context of the child's behavior and life situation and help families develop more effectual coping strategies which, in turn, contribute to lower level of expressed emotions (**Hodgetts, Zwaigenbaum & Nicholas, 2015**).

Also, Nurses can play a valuable role in directing the family to behavioral services, specialists in autism and therapists who are well versed in ASD. Nurses should listen and act upon parents' concerns about their child's communication limitation, play, and behavior problems by completing additional testing that could be provide early diagnosis of autism. Nurses should be informed parents about treatment programs that are available for their child (**Alqahtani, 2016**).

Significance of the study

Autism Spectrum Disorder (ASD) has become increasingly prevalent over the past 15 years, which has baffled researchers and frustrated parents. In mid-November 2015, The National Health Statistics Report revealed an increase of ASD prevalence, suggesting that 1 in 45 children, ages 3 through 17, have ASD (**SooHoo, 2019**).

Autism diagnosis does not only change the life of the children, but also their family members. Family of children with ASD have been known to experience higher levels of stress, anxiety and depression than parents of children with any other condition and parents report that ASD affected each area of their lives and contribute to high expressed emotions.

Examining expressed emotion is important because EE global response to the parents' stress toward child illness. Also, the child with high EE family may have maladaptive behavior, impaired interaction, and ineffective communication. So this study aims at Assess level of expressed emotions among family caregivers of children with autism

AIM OF THE STUDY

The aim of the study is to: -

- Assess level of expressed emotions among family caregivers of children with autism.

Research Question: -

This study is based on answering the following question:

- What are the levels of expressed emotions by family caregivers of children with autism?
- What are the attitudes of family caregivers toward their children with autism?
- What is the relationship between family attitude and level of expressed emotions among family caregivers of children with autism?

AUTISM SPECTRUM DISORDERS (ASD)

Overview about neurodevelopmental disorders:

Neurodevelopment disorders are disabilities associated primarily with the functioning of the neurological system and brain. Examples of neurodevelopmental disorders in children include attention-deficit/hyperactivity disorder (ADHD), autism, learning disabilities, intellectual disability (also known as mental retardation), conduct disorders, cerebral palsy, and impairments in vision and hearing. Children with neurodevelopmental disorders can experience difficulties with language and speech, motor skills, behavior, memory, learning, or other neurological functions. While the symptoms and behaviors of neurodevelopmental disabilities often change or evolve as a child grows older, some disabilities are permanent (Ahn, 2016).

Definition of autism spectrum disorder:

ASD is one of the most common neurodevelopmental disorders. The term consists of two Greek syllables: (*aut*) *a means of* self-regarding, and (*ism*) means the situation or orientation, that the word means all self-orientation, or state reliance (Blatt, 2019). The term

“spectrum” refers to the wide range of symptoms, skills and levels of impairment or disability that children with ASD have. Some people are mildly impaired by their symptoms, while others are severely disabled (**National Alliance on Mental Illness, 2015**).

Autism is a neuropsychiatric disorder characterized by severe and sustained impairment in social interaction, deviance in communication, and patterns of behavior and interest that are restricted, stereotyped, or both (**Ghaneshirazi & Moghimi, 2018**).

Children with Autism Spectrum Disorders (ASD) are not physically ill or disabled the same as someone with brain injury. ASD are mostly characterized by some or all of the followings: Difficulties interacting with others or socializing with other people, Communication challenges and Repetitive behavior (**National institute of Mental Health, 2017**), and also Autism spectrum disorder (ASD) is a developmental disorder that affects a person’s ability to socialize and communicate with others. And can also result in restricted, repetitive patterns of behavior, interests or activities (**National Alliance on Mental Illness, 2015**).

The World Health Organization has described Autism Spectrum Disorder (ASD) as group of complex disorders of brain development that include impaired social interaction