

Counseling Intervention for Parents Caring for Children with Autism

Thesis
***Submitted For Partial Fulfillment of the
Requirements of Doctorate Degree in
Psychiatric Nursing***

By
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2012

Acknowledgment

Sincere gratitude should be should be submitted for **Allah** who always helps and care for me, not only through work but also through my whole life.

*It is a great hour for me to take opportunity to express my most profound & deepest respect to **Prof. Dr. Zeinab Abdel Hamid Loutfi** Professor of psychiatric / mental health nursing department, faculty of Nursing, Ain Shams University for her sincere guidance, constructive criticism and valuable help in revising this work. Wards can not convey my sincere thanks and appreciation to **Prof. Dr. Sorayia Ramadan** Professor of psychiatric / mental health nursing department, faculty of Nursing, Ain Shams University for her continuous encouragement, unlimited support and close supervision that paved my way and encouraged the accomplishment of this work. I would like to express my hearted thanks to **Dr. Mona Reda** Assistant Professor of Psychiatric Medicine, Medical children studies department Institute of post graduate childhood studies- Ain Shams University for her continuous encouragement, guidance, and cooperation in all stages of this work wish also to express my great thanks and respect to **Dr. Mona Hasan** Lecturer of psychiatric / mental health nursing department Faculty of Nursing - Ain Shams University for her valuable assistance and constant supervision. She gives me a lot of her time, patience, care and advice in every stages of this work. Finally, I wish to extend my appreciation to all parents and person who provide care for children suffering from autism and helping me throughout this work.*

✍ Eman Elsayed Bauomey

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Introduction

Autism is a complex developmental disability; it is a neurological based developmental disorder. It is characterized by varying degrees of impairment in communication skills, social interactions and the presence of repetitive and stereotyped behaviors (*Wallace, 2010*). Onset occurs before the child reaches the age of 36 months that affects normal functioning of brain, it affects boys four times more than girls (*Makrygianni, & Reed 2010*). Parents usually notice signs in the first two years of their child's life. The signs usually develop gradually, but some autistic children first develop more normally and then regress (*Probst et al., 2010*).

Caring for a child with autism may be very difficult for parents. When the symptoms of autism get clear the parents have confusion because of the uncertainty about their children. The parents may have feeling of fear, rejection, or shock after the diagnosis is made by the professional following the assessment of the child (*Johnston, et al., 2010*).

The nature of parent stress has been shown to several aspects of parents' life such as daily care demands, emotional distress (e.g., maternal depression), interpersonal difficulties (e.g., parental discord), financial problems and adverse social

consequences (*Singer & Powers , 2010*). Studies have found them to be at a higher risk for marital discord and social isolation (*McCubbin & Patterson, 2009*). In addition, families are also concerned with communication, education and related services, relationships with professionals and the independence of the child and his/her future concerns (*Wallace, 2010*).

Caring for the child requires a great deal of time, routine, energy, and money. Provide parents with the most up-to-date information on autism. Clear explanations of recommended treatment plans and parental involvement in decision making are essential to help the child achieve long-term goals (*Johnston, at al., 2010*).

Parents of children with autism play a critical role in supporting their children's learning. Consequently; parents require emotional support, advice, and training in working with their children. They also require access to up to date and accurate information about available treatment options and support services (*Harris et al., 2007*).

Parents are engaged in process of child development, So they need resources and support for caring of their children with appropriate assessment, education programs, awareness and support for parents helpful them to provide these children with the skills necessary for successful integration, and become

active and contributing members of their communities, additionally early counseling intervention can improve long-term function and help the families (*Ghanizadeh, et al, 2009*).

Counseling parents about autism can help parents, in modifying their children's behavior, which contains some activities for developing some social skills, self care skills (*Kirby, 2006*). The training of the parents of children with autism improves their positive behavioral transactions with their children, increases satisfaction with their parenting, increases social interactions with their children, and decreases parenting stress and aggression (*Singh et al., 2007*).

Psychiatric mental health nurse play important role to assess the parents and families level of understanding about autism, their coping abilities, and their access to support groups or services, as well as their willingness to avail themselves of these services (*Mohr 2009*), in addition to that , nurses can provide parents anticipatory guidance to prepare child adequately for increasing independence, also instruct families to keep channels of communication opened with child and the system (*Hassan , 2008*). So this study aims to assess the effect of counseling intervention for parents caring for children with autism to help parents to provide these children with the skills necessary for successful caring, enhance parents practice and coping pattern.

Significance of the study

The incidence of autism is on the rise. The number of children born with, or who develop autistic disorder, is estimated to be 1 in 166 births. It is the third most prevalent developmental disorder. It is four times more likely to occur in males than females for unknown reasons, (*Neeb, 2006*). The World Health Organization states that 1 in every 500 children is autistic. Therefore, according to the latest demographic studies, it means that there are more than 140,000 children in Egypt who suffer from autism (*Haffiz, 2007*). This indicates that a considerable number of parents are directly involved in caring of the children with autism. Furthermore, autism is a lifelong disorder that most of the families have to live and care their children on their own forever (*Ghanizadeh, et al., 2009*). The nurse plays an important role regarding to the children and their families' condition, through counseling. The nurse can help people to discuss their problems honestly and openly, deal with issues that are preventing them from achieving their goals and ambitions, and have a more positive outlook on life (*Wallace, 2010*).

Nurse act as advisors to introduce new idea and methods to provide stimulation and use technique to developing skills. Provide parents anticipatory guidance to prepare child.

Aim of the Study

This study aims to assess the effect of counseling intervention for parents caring for children with autism to help parents to provide these children with the skills necessary for successful caring, enhance parents practice and coping patterns.

This aim will be achieved through:

Phase 1: Assessing the pattern of care (daily living activity, attention, communication and social skills) as provide by parents caring for child with autism.

Phase 2: Assessing coping pattern of parents caring for child with autism.

Based on the found result the researcher develop

Phase 3: Implementing counseling intervention to enhance parents practice and coping pattern.

Phase 4: Evaluating the effect of this counseling intervention on parents' pattern of care providing to these children and their coping patterns.

LITERATURE REVIEW

Definitions of autism:

The English term consists of two Greeks are; aut a means of self regarding, and ism means the situation or orientation, that the word means all self- orientation, or state – reliance (*Al Shakhs, 2007*). Autism is a complicated neuro developmental disorder that impairs social interaction and communications and causes repetitive and stereotypical behavior patterns (*Heather, 2008*).

Autism is a severe neurodevelopment disorder characterized by impaired language, communication and social skills as well as by repetitive and stereotypic pattern of behavior. All in all autism is complex neuro developmental problems distinguished by defect social interaction and communication, as well as represented of repetitive behaviors (*Lauren et al., 2010*).

In the absence of a specific biological marker (e.g. blood test) for autistic disorder is defined by behavioral criteria. These criteria have evolved over the almost 60 years since Kanner and Asperger first introduced the term autism for childhood disorders of social interaction. In response to research findings, there has been a progressive widening of

diagnostic criteria, *Wing & Gould, (2008)* identified that the two key features of autism, social isolation and insistence on added impairment in language development.

Prevalence rates:

One of the biggest problems in Egypt today is that autism is very often under- diagnosed or more commonly, misdiagnosed. The World Health Organization states that 1 in every 500 children is autistic. Therefore, according to the latest demographic studies, it means that there are more than 140,000 children in Egypt who suffer from autism (*Haffiz, 2007*).

It is estimated that 105 million children in the U.S.A. and one over ten of millions worldwide are affected by autism. The prevalence rate of autism is increasing 10 – 17 percent annually, studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently *Salama (2009)* .

Clinical manifestation of autism

Signs and symptoms of Children with autism exhibit a wide array of signs and behaviors that can range from mild to severe. This disorder usually presents in the first year of life and almost always by age three. Autism is characterized by

absent or abnormal of social interaction, speech and language problems, repetitive and ritualistic behaviors, and lack of intellectual performance. The typical social interaction could include withdrawn behavior in which the child prefers to be alone, not interacting with peers, not making eye contact, and not wishing to be touched,(*Ehlers, et al.,2008*).

The child may be unable to understand or interpret social cues such as smiles, facial expressions, and tone of voice. Speech and language problems can include delayed or absent speech, communicating only with gestures instead of words, repeating specific words or phrases, not comprehending the actual meaning of some words, and having a short attention span as mentioned by *Tadevosyan, et al. (2009)* mentioned .

Whereas severe social skills deficits and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities are core features of all autistic child disorder, significant. *Wallace (2010)* mentioned that one of the most challenging aspects in recognizing autism is the wide heterogeneity of features in individual children. There is no pathognomonic feature; however, a few of the early social deficits (eg, delayed or absent joint attention) seem to be fairly reliable red flags for autism. The autism spectrum encompasses an extremely heterogeneous phenotype with indistinct end