

Stress and Burdens among Parents of Children with Autism

Thesis

Submitted for Partial Fulfillment of Requirements of the Master

Degree

In

Psychiatric Mental Health Nursing

By

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Summary

Autism is a cluster of lifelong neurodevelopmental disorders. Autism impacts children in a variety of ways. There is no single behavior that is always typical of autism and no behavior that would automatically exclude an individual child from a diagnosis of autism, even though there are strong commonalities, especially in social deficits. In general terms, children within the autism display a highly unusual pattern of deficits and skills. Individuals with autism are impaired in the areas of social interaction and communication, and they exhibit restricted stereotyped and repetitive behaviors, interests, and activities **(ANH, 2015)**.

Early screening of autism is important because early intervention may be more effective for children with autism than for children with other developmental disabilities **(Matson, et al, 2008)**. Additionally, early identification can provide access to appropriate interventions, which lead to better prognosis. Even with the importance of early identification, autism is often not diagnosed until children are 3-4 years old. Current diagnostic techniques can diagnose it as early as 2 years old, and most diagnoses are stable from this age on. Autistic infants were much less likely to orient when their name was called and less likely to look at another person while smiling **(Volkmar & Chawaska, 2009)**.

Researcher found that caregivers of children with autism tend to experience more mental health issues, depression, anger and stress than other caregivers who have children with other developmental disabilities. Additionally, caregivers of children with autism reported increased burden and psychological distress, decreased marital satisfaction, lower self-confidence, increased helplessness and increased negative emotions

including fear, anger and resentment. In part, these negative outcomes were related to the challenging nature of the problem behaviors and symptoms associated with autism (**ANH, 2015**).

According literature review, many factors related to burden of caregivers with autistic children. Numerous studies indicated that higher burden subscale scores were variously associated with caregiver lower level of education, child female gender and younger age, as well as child lower subjective quality of life and needs for medical care, and educational services, deficits in communication and language skills ,social skills, and repetitive behaviors were the greatest determinant of global rating of burden. However, child self-care ability, duration of care and social support has been documented that has highly important (**Chuang et al., 2014**).

Parents of children with developmental disabilities face challenges that place them at high risk for distress and negative psychological outcomes. Parenting a child with autism involves additional stressors related to the child's challenges in communication, unpredictable and aggressive behaviors, social isolation, limitations in self-care, and lack of respite owing to an inability to find suitable substitute caregivers. Several studies have reported increased psychological distress, including depression and anxiety, and indicators of stress, such as decreased family cohesion and increased somatic complaints and burnout in parents of children with autism and related disorders compared with parents of typically developing children (**Mao, 2012**).

Aim of the Study

This study was aimed to explore stress and burden among parents of children with autism through:

- 1- Assess parent stress of children with autism.
- 2- Assess burden facing parents of children with autism.
- 3- Assess the relationship between stress and burden among the parents of children with autism?

Research question:

The current study answered the following question:

- 1-What is the stress facing the parents of children with autism?
- 2-What is the burden facing the parents of children with autism?
- 3- Is there a relationship between stress and burden among the parents of children with autism?

Research design: A descriptive research design was used in the study.

Research Setting:

The study was conducted at Autism Day Care Unit- Beat El Shams- Child psychiatry clinic in El- Abbasia Psychiatric Mental Health Hospital.

Subjects:

Purposive sample of (100) from the parent of children with autism who attended to Child Psychiatry Clinic in El- Abbasia Psychiatric Mental Health Hospital.

Tools for data collection:

Tool – Socio-demographic sheet: developed by the researcher this includes:

A-Socio-demographic data about parents of children with autism: parent's age, level of education, occupation, family mental history.

B- Socio-demographic data about children with autism: child's age, gender, degree of autism, child's birth order, comorbid mental disorders in child and presence of autism in the family.

Tool II - Parenting stress index (PSI): This is an adopted self-report questionnaire developed by (Elbeblawy, 2002) consists of 101 questions (Arabic version), which assess parental stress, PSI measured child, parent and situational characteristics that lead to parenting stress.

Tool III - Burden interview questionnaire: measures the extent to which parent emotional and physical health, social life and financial status are affected by caring for their child with autism; it is formed of 29 statements (Zarit et al, 1980).

Results

The results of the study showed that:

- More than half (58%) of studied parents aged between 30:40 years old with a mean age 35.77 ± 6.37 . Also it revealed that majority of them (90%) were mothers.

- More than half (56%) of studied parents had primary education. In addition, more than two third of mothers doesn't work, but majority of fathers work.
- Majority (89%) of studied parents doesn't have family mental history.
- Majority (71%) of children was males and (29%) were females. And aged between 6:9 years old with mean age 7.78 ± 2.27 .
- More than half (59%) of children had moderate degree of autism, and nearly half of them had mild to severe degree of autism. Nearly half of them were the first child in the family.
- Majority (79) of children comorbid with Attention Deficit Hyperactivity Disorder (ADHD).
- The study revealed that parenting stress related to Child's Domains (65%) is slightly higher than parenting stress related to Parent Domains (55%).
- More than half (61%) of the studied parent suffering from severe level of stress, and (29%) had mild level of stress, (10%) had moderate level of stress with range 233-393.
- The study revealed that more than half (54%) of studied parents had severe level of burden and nearly half of them had mild to moderate level of burden.
- More than two third (67%) of studied parents suffering from severe physical burden, more than one third (40%) of them

had severe psychological burden, nearly half (45%) of them had social burden and (44%) had financial burden.

- There was no statistically significant relation between stress and socio-demographics data of the parent except with parental age when p- value 0.003* and high statistically significant relation with mother occupation when p-value <0.001*.
- There was no statistically significant relation between parent stress and socio-demographics data of the child except with degree of autism in the child with p-value 0.006*.
- There was no statistically significant relation between burden and socio-demographic characteristics of parent except with parental education with p-value 0.006*.
- There was statistically significant relation between burden level and degree of autism in the child, child's birth order and with comorbid mental disorders in the child with p-value <0.001**.
- There was a high statistically significant relation between burden and stress (p-value was <0.001** and X^2 19.265).
- There was highly positive significant correlation between stress and burden with p- value was <0.001** and R was 0.478.

Conclusion

In the light of the present study findings, it can be concluded that:

Parents of children of autism had severe level of stress and the parenting stress related to child characteristics is more than parenting stress related to parent characteristics. The studied parents had severe level of burden, and suffering from severe level of different types of burden (physical, social, psychological and financial). There was a highly statistically significant relation between burden and stress, and highly positive significant correlation between burden level and parent stress. The finding of the study answered the research question.

Recommendations

Based on the finding of the present study, the following suggestions are recommended:

- 1) Providing program to reduce parent burden and dealing with stress associated with caring of the children with autism.
- 2) Appropriate and enough information regarding ASD are needed and very necessary to provide among parent of ASD children to rectify their perception and dealing with autistic children
- 3) Counseling units can be established in the primary care centers for coordinating their services to the autistic child and their family.
- 4) Psychiatric nurses in the child's outpatient's clinics can play important role through follow up with the family caregivers their children's progress, providing information and guidelines of daily care.

Further studies:-

-Recommended program to reduce the family burden of autistic children and further comprehensive study to explore their burden and stress and proper program should be applied to help them managing their burden and stress.