
Mini Review

Helping Families for Caring Children with Autistic Spectrum Disorders

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Many families are directly involved in caring of their children with the lifelong autistic spectrum disorders. Sometimes, they are the victims of their children's behaviors.

The family, including siblings, may have to explain the children's behaviors to others. Their mothers have poorer mental health with difficulties in family adaptability and cohesion.

Its burden is not just limited to psychologic aspects but on the quality of life, economic aspects, and parent-child relationship.

This is a narrative review of some of the aspects that families of children with autistic spectrum disorders are facing.

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Introduction

There is a dramatic increase in the incidence of autism from 1970s through 2008. This incidence increased from one in 10,000 before the 1970s to one in 150 in the last year.¹ This indicates that a considerable number of parents are directly involved in caring of the children with autism.² Furthermore, autistic spectrum disorders (ASD) are lifelong disorders that most of the families have to live and care their children on their own forever. In recent years, it is emphasized that these children should not be separated from their own families. Children with ASD are less adaptable.³ Sometimes, the families have to explicate the reason or justify the behaviors of the children to others that it is not easy at all. A large amount of energy must be spent to make a balance between their needs and those of their children. This is not also an easy task. Authoritative parenting is weaker.⁴ The parents are

usually really tired and depressed, showing their reactions among family and even in professional life.⁵ They have to spend a lot of time with the child; so, they have less social contacts with the family members, relatives, and community. On occasion, the family is the victim of physical aggression of the children. Many of performance and behavior problems of children with ASD are preserved even with receiving proper health services.⁶ Moreover, community understanding from the behavioral characteristics of children with ASD is limited or they do not understand it.⁷

The parents are worried more than control groups for their children's learning problems and being bullied by others.⁸ There is an emphasis that the parents should be equipped to engage, communicate with, and teach their own children.⁹ Also, counseling and helping such a family to regulate their deficits in different areas of the problem are recommended.¹⁰

Siblings

Since siblings may provide opportunities for social interactions, the siblings of children with autism may also have an important role in this regards. The presence of a child with autism may have some unfavorable effects on the siblings.¹¹ Other kids in the family have stressful life

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conditions.¹⁰ Temperament profile including lower positive affect and higher negative affect differentiates children with ASD from non-ASD siblings and the control group.¹² ASD children with less behavioral problems have more positive affect and share activities with their brothers and sisters.¹³ The siblings of these children may have more social and behavioral adjustment problems that last long for older ages.¹⁴ The siblings of the children are facing precocious responsibility, feeling sorry, observing, and involving in scary behaviors. Even, their relationships with their friends are affected.¹⁰ Also, the risk of developing internalizing behavior problems is higher in them.¹⁵ They have less intimacy and nurturance than the control group.¹⁶

Higher parental support predicts higher positive affect in sibling relationships.¹³ Sibling dissatisfaction from different parental care may compromise sibling relationship.¹⁷ Training such parents can improve positive and decrease negative social interactions with the siblings.¹⁸ Also, managing parenting stress improves the effectiveness of teaching interventions for the children.¹⁹ So, these relationships should be strengthened and the family counseling of siblings is recommended.¹⁰

Mothers

The mothers of children with ASD have poorer mental health than the general population.²⁰ The mothers have negative feelings²¹ and the burnout effect of having such a child with ASD for the mothers is even stronger than the fathers.²²

Less severe maladaptive behaviors and less social impairments of the child with ASD and also lower level of pessimism in the mothers predict more positive mother-child relationship.²³ The greater positive affect and warmth of mother-child relationship is associated with greater caregiving gains.²³ Meanwhile, the feeling of the mothers is related to the quality of their lives.²⁴ Those who have difficulties in family adaptability and cohesion²⁵ have higher levels of depressive symptoms and anxiety.²⁵

Coping

Couples with children suffering from ASD have more conflicts²⁶ and the family's quality of life should be improved.⁷ The parents of children with ASD have somewhat lower marital happiness and family cohesion. In addition, their family adaptability is less than normal groups.⁷ Moreover,

lower level of coping mechanism of family is related with higher level of stress and tension.²² Parental coping does not differ with the age of the child with autism.²⁷ However, the coping strategies of the parents change over the time.²⁸ Aging of parents is associated with less coping through reliance on service providers, family support, social withdrawal, and individualism. They usually cope by their religious beliefs and some other emotion-focused strategies.²⁸ Acquiring social support is a coping strategy which is frequently used by the families and should be encouraged.²⁹ Coping style can moderate parental stress and it decreases the rate of negative outcomes such as depression, social isolation, and spousal relationship problems.³⁰ The parents of children with autism should be aware whether or not they are using healthy coping mechanisms. They need a social network support to be able to adjust themselves for their long and difficult journey of caring for the children.³¹ Avoidance should be reduced and the use of positive coping strategies should be increased.²⁷

Sleep

Children with autism usually have sleep problems, mostly insomnia. Screening and management of their sleep problems improve family functioning.³² The parents of children with autism suffer from greater sleep problems than those of typically developing children.³³ Sleep quality of the parents is poorer and their sleep quantity is lower than the parents of children without ASD.³⁴ Level of symptoms of these children is not related to the parents' sleep problems. However, children's sleep problems are in association with parents' sleep problems.³³

Feeding problems

Feeding problems and gastrointestinal disturbances are more common in these children and many of the parents might be worried about such problems.³⁵ Being a picky eater and resistance for trying new foods are more common in children with autism.³⁶ The parents should be trained about the management of these behaviors to decrease family stress.

Sensory problems

Sensory impairments such as taste, smell, visual, and auditory processing problems are another features of some children with ASD.^{37,38} Sometimes these impairments are not detected by

clinicians but they are reported by the parents.^{39,40} For example, they are defensive to tactile or auditory stimulation.⁴¹ The deficits of sensory motor gating might be associated with restrictive and repetitive behaviors.^{40,42} Unfortunately, there are not enough empirical supports for effective treatments for some of these problems.⁴¹ Implications for the presence of sensory problems in the children should be considered in parents' and families' counseling and management.⁴³

Quality of life

Quality of life of families with ASD children is seriously less than the other families.⁸ In developed countries, the quality of life rather than a financial burden affects family members.⁴⁴ A study reported that the health-related quality of life of the mothers "but not the fathers" of children with high-functioning Asperger syndrome is impaired.⁴⁵

Economic aspect

The families of children with ASD usually have a lower level of income. They have to spend a part of their income on the child with ASD.⁴⁶ Their families more likely have financial problems and they need additional income for the costs of child's medical care. The families usually decrease work hours or stop it to care for the children. It is reported that the family have to spend many hours to receive care.⁴⁷ It should be noticed that the facilities and cares might not be available in some regions or cities, or all of the affected children might not have access to the mental health services. Most of the families who need for participation for psycho-educational early intervention program do not participate for the reasons such as a long waiting time.⁴⁸ The parents have to spend about 1000 hours each year for caring and supporting of the child with ASD.⁴⁴ Meanwhile, there is a discrepancy between different regions regarding policies and practices for the screening and care of the children.⁴⁹

Mental healthcare system

The burden of ASD is not just limited to the families but it also affects the society. Autism is associated with a higher rate of using childcare services that it seriously affects the employment of the parents.⁴⁶ Many of them will be unemployed.⁵⁰ The growing healthcare expenditures of children with ASD put a burden on mental health services. It threatens access of these children to the proper care.⁵¹ Autism burden for lifetime per capita in the

USA is \$3.2 million, which is increasing.⁵² This burden is even higher than the other disabled children groups.⁵³ Their annual mean number of total clinic visits, hospitalization, and the using of different medications such as psychotherapeutic medications are higher.^{54,55} The cost for caring the children with ASD is more than twice of the children without ASD.⁵⁴ Therefore, "supported employment programs" and lifelong financial help should be planned not only for the children but also for the families and service providers.⁵⁰

Parent-child relationship

Higher quality of mother-child relationship such as maternal warmth and praise decreases internalizing and proceeds externalizing problems. It also diminishes impairments in social reciprocity and repetitive behaviors of the children.⁵⁶ The training of the parents of children with ASD 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.¹⁸ Mothers who accepted the diagnosis of autism and resolved their emotion have a higher cognitive engagement and supportive engagement in play interactions with the children. In other words, their verbal and nonverbal communications with the children are enhanced and stabilize a greater reciprocity.⁵⁷

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