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Original Research Article

A Prospective Observational Study to Examine the Roles of Parenting Stress and Parenting Self-Efficacy as Mediators between Child Behavior Problems and Parental Anxiety/Depression

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Conflict of interest: Nil

Abstract

Aim: The current study sought to examine the roles of parenting stress and parenting self-efficacy as mediators between child behavior problems and parental anxiety/depression.

Methods: This was a cross-sectional descriptive study investigating depression and burden among caregivers of ASD patients. Participants were all caregivers who brought ASD patients to the outpatient at Department of Psychiatry ,Jawaharlal Nehru Medical College and Hospital, Bhagalpur, Bihar, India. Participants included 50 caregivers, of whom the majority was mothers of ASD patients.

Results: In the present study, there were 70% females and 30% were males. 70% were mothers as caregivers with the child. 60% were married in the study. Only 34% patients were giving care to the child. Most of the caregivers were doing full time job. As for the ASD patients, 88% were boys. The mean age of the patients was 6.4 (SD 3.4). Most of them (92%) were classified into the moderate and high function group. Significant correlations were also observed between the caregiver burden and months after diagnosed, the number of patient's problems and the number of hours that the caregiver spent with patient.

Conclusion: The prevalence of depression in and severe burden on caregivers of autistic children from the present study was low. Factors related to the burden were months after diagnosed, the number of patient's problems, the number of hours that caregiver spent with patient, patient's communication problems and inappropriate or odd repetitive behaviors.

Keywords: Autism, Mental health, Mental Wellbeing, Caregiver, Daily Living Skills, Emotional And Behavioural Difficulties.

Introduction

Autistic spectrum disorder (ASD) is a lifelong developmental disorder characterized by significant impairment in social interaction, communication and the presence of restricted and repetitive behaviors or interests. [1] Autism spectrum disorders (ASDs) are lifelong neurodevelopmental disabilities that begin in infancy and impair communication and social behaviors. With the incidence of ASD on the rise, it becomes important to understand how these disorders affect the parent-child relationship, including reciprocal associations between parent emotions and child behavior.

Several factors have been shown to work in concert to increase stress in parents of children with ASD. First and foremost, the realization that there is no cure for the disorder may serve to increase parenting stress. [2] Aspects of the child's behavior, specifically socially inappropriate and aggressive behaviors typically associated with ASD, have been found to be associated with increases in parenting stress [3,4], as well as being confronted by antipathy for their child's behaviors [5] due to a lack of understanding of ASD. [6] Additionally, raising a child with ASD typically involves allocating extra time to meet the needs of the child. [7] These findings suggest that multiple changes occur in the parental role to accommodate the challenges of raising a child with ASD. While examining such changes is helpful in increasing our understanding of parenting stressors, examining the interplay of both parental and child factors as they contribute to the parent-child relationship (in terms of parental emotions and child behavior problems) will provide a greater understanding of the types of support and potential interventions needed by families of children with ASD.

In fact, the lifetime prevalence of major depressive disorder may be higher in the parents of children with autism than parents of children with Down syndrome. [8] Mothers of youth with ASD also report experiencing excessive anxiety. [9] In another study, nearly half of the parents of youth with ASD were found to be severely anxious, and nearly two-thirds were found to be clinically depressed. [10]

Child behavioral problems in particular, and not the severity of the disorder, have been found to contribute to maternal depressive symptoms; additionally, a child's lack of prosocial behaviors contributes to maternal stress. [11] Other studies indicate that behavior problems in youth with ASD also predict the level of maternal anxiety and stress experienced [12,13], as well as maternal mood disorders and depression. [14-17] These findings suggest that the child's behavioral problems produce negative effects on the parents' psychological well-being. While the relationship between child behavior problems and negative parental psychological well-being has been established within the current literature, studies examining the mechanisms underlying this relationship are scarce.

Materials and Methods

This was a cross-sectional descriptive study investigating depression and burden among caregivers of ASD patients. Participants were all caregivers who brought ASD patients to the outpatient at Department of Psychiatry, Jawaharlal Nehru Medical College and Hospital, Bhagalpur, Bihar, India. Participants included 50 caregivers, of whom the majority was mothers of ASD patients.

The individuals with ASD were children younger than 15 years old and diagnosed as having autistic spectrum disorder by child psychiatrists or developmental pediatricians according to the Diagnostic and Statistical Manual IV (DSM-IV) criteria. The caregivers who were ineligible to read and write were excluded from the study. Information sheets regarding the present study were presented to the participants recruited. After they had consented to participate, they were given the questionnaires, which were collected on the same day.

Measurement

Measures included general information about the caregivers and the ASD patients, caregiver depression and caregiver burden. Instrument used in this study was self-administered questionnaires. Patients' diagnoses and functions were obtained from child psychiatrists and pediatricians who were responsible for the patients. Caregivers rated how they had felt over the past week on 20 items; each of which had

4-point scale, ranging from 0 (rarely) to 3 (most of the time). Scores ranged from 0-60. CES-D is a widely used depression-screening tool, which has been reported to be reliable and valid. The internal consistency reliability of CES-D in Thai version was 0.82, and the mean score in normal population studied was 20.4 (SD 5.8).

This questionnaire was developed for assessing burden in caregivers of patients with chronic illness. The caregivers rated the frequency of described statements, which comprised 22 items; each of which had 5-point scale, ranging from 0 (never) to 4 (always). Score ranged from 0-88, with four levels: little or no burden (0-21), mild to moderate burden (21-40), moderate to severe burden (41-60) and severe burden (61-88). The internal consistency reliability of the burden interview in Thai was 0.92.

Data analysis

SPSS version 20.0 was used to analyze the information in the present study. Descriptive statistics were conducted to describe demographic data, caregiver depression and caregiver burden. T-test, Pearson's correlation, Spearman's correlation and one-way ANOVA were conducted to examine factors related to caregiver burden by setting statistical significance at $p<0.05$.

Results

Table 1: Demographic characteristics of caregivers of children with ASD

Variables	N%
Gender	
Male	15 (30)
Female	35 (70)
Caregiver's age (year; mean + SD)	39.7+9.5
Relationship with patients	
Mother	35 (70)
Father	10 (20)
Relative	5 (10)
Marital status	
Married	30 (60)
Single	17 (34)
Divorced/widowed	3 (6)
Caregiver's level of education	
Elementary school	15 (30)
High school or equivalent	16 (32)
Bachelor's degree or higher degree	19 (38)
Employment status	
Full-time 27 (52.9%)	26 (52)
Part-time	5 (10)
Unemployed	19 (38)
Number of hours spent with patients	12.4+8.4
Had someone help taking care of patients	
No (only one caregiver)	17 (34)
Yes	33 (66)

In the present study, there were 70% females and 30% were males. 70% were mothers as caregivers with the child. 60% were married in the study. Only 34% patients were giving care to the child. Most of the caregivers were doing full time job.

Table 2: Demographic characteristic of children with ASD

Variables	**N%**
Gender	
Male	44 (88)
Female	6 (12)
Patient's age (year; mean + SD)	6.4+3.4
Patient's problems (can be more than 1 problem)	
Delayed speech/communication problems	32 (64)
Hyperactive and aggressive behaviors	29 (58)
Poor social skills	26 (52)
Inability to perform age-appropriate activities of daily living (ADLs)	24 (48%)
Difficulties in eating/sleeping/excretion	17 (34)
Learning problems	17 (34)
Inappropriate/odd repetitive behaviors	14 (28)
Months after having been	19.9+20.1
Function	
Low	4 (8)
Moderate	26 (52)
High	20 (40)

As for the ASD patients, 88% were boys. The mean age of the patients was 6.4 (SD 3.4). Most of them (92%) were classified into the moderate and high function group.

Table 3: Pearson's correlation between demographic data

Variable	**Correlation (r)**	**p-value**
Patient's age	0.045	0.740
Household income	0.059	0.720
Caregiver's age	0.266	0.065
Months after having been diagnosed	0.305	0.040
Hours spent with patient per day	0.322	0.022
Number of patient's problems	0.484	<0.001

Significant correlations were also observed between the caregiver burden and months after diagnosed, the number of patient's problems and the number of hours that the caregiver spent with patient.

Discussion

The caregivers participating in the study mainly were mothers with diversity as regards their work status. The number of those working full-time was similar to the number of those working part-time and unemployed. With respect to their educational background, the caregivers' highest education ranged from primary to college education. The household incomes varied widely (37,829.2+31,028.7), and more than half of the caregivers had assistance in the patient care. Most of the autistic patients, whose caregivers participated in the study, were male (84% vs. 16% female), similarly to the autism morbidity being higher in male than in female at an approximate ratio of 4- 5:1.[18] Most of the patients were in kindergartens or primary schools, and more than 90% of the patients were in the moderate to high function group. The caregivers were found to pay attention to problems of communication, hyperactive behaviors and sociability. The present study has, therefore, revealed that the hyperactive and aggressive behaviors are another focus of the caregivers in addition to the social and communication problems, which are major points in the disease diagnosis criteria. Treating teams should also take this into consideration as the patients may have attention deficit hyperactivity disorder (ADHD) as co-morbidity. In fact, ADHD is found in up to 28.2% of ASD patients. [19]

The present study found depression in 6% of all the participating caregivers of autistic patients. This is close to the depression morbidity between 2- 7% in the general population [18], but less than that from the study by Lin Y et al on caregivers of autistic patients. [20] The 5.9% in the present study may be explained by the fact that more than 90% of the autistic child patients participating in the study were in the moderate to high function group. Past studies [21,22] additionally discovered that parents who perceived their children as being a burden and hard to handle were more associated with poor mental health than parents who felt that their children were easy to handle. The present investigation found no caregivers who reported that their children were a heavy burden, and, in turn, found a low depression rate in the caregivers. At the same time, 66% of the caregivers reported having help in taking care of the children and not being alone. The family and social support is a factor that prevents caregivers from the problem of depression. [22,23]

Most of the caregivers felt that the children were a small to moderate burden, which is different from the results of Stuart M [24] and Mugno D [25] studies, in which families reported that the care of autistic children was a high-level burden. Nevertheless, the present study results, which demonstrated the correlation between the perception of burden and the time duration spent taking care of each child daily, the total number of each child's problems, the problems of communication, the behaviors that were inappropriate or differed from norms, and the length of period after the diagnosis, are consistent with the above studies by Stuart M and Mugno D. The increased time duration spent taking care of the children has direct effects on the caregivers in that they have less personal time to take care of themselves, hence the feeling of burden. Indirectly, it may affect their marriage as well as cause financial problems from the time taken off work. All these may also result in the feeling of burden. As for children with many problems, more problems mean that the caregivers have to simultaneously manage problems in more aspects, rendering them to feel incapable of handling the problems, that the problems are too big[26] and eventually more heavily burdened. At the same time, the fact that the children's problems of communication and their deviant or inappropriate behaviors were involved with directly increased feeling of burden may reflect that the caregivers see these problems as important and hard to control as well. [26]

An additional observation was that the depression score was correlated with the increased caregiver burden. This is in line with the studies by Lin Y [20] and Oyebode J. [23] Caregiver burden20,26 corresponds with depression psychosocial factors [22], being the changes in life that cause stress and the person's view that problems are a burden that is so heavy that cannot be helped or overcome. The scores of depressions and burden are, therefore, related. [27]

Conclusion

The prevalence of depression in and severe burden on caregivers of autistic children from the present study was low. Factors related to the burden were months after diagnosed, the number of patient's problems, the number of hours that caregiver spent with patient, patient's communication problems and inappropriate or odd repetitive behaviors.

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