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ORIGINAL PAPER

An Examination of the Relations Between Symptom Distributions in Children Diagnosed with Autism and Caregiver Burden, Anxiety and Depression Levels

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Abstract
High stress levels and impairment of physical/mental health in parents can delay early and effective intervention in autism. The purpose of this study was to examine relations between the clinical characteristics of children diagnosed with autism spectrum disorder (ASD) and caregiver burden, and anxiety and depression levels. Seventy cases under monitoring at the Namık Kemal University Medical Faculty Child and Adolescent Psychiatric Polyclinic with a diagnosis of ASD, and their principal caregivers, were included in the study. The Autism Behavior Checklist (ABC), Beck Depression Inventory (BDI), Beck Anxiety Inventory, and the Zarit Caregiver Burden Scale were completed. At multiple regression analysis, autism symptom severity and caregiver depressive symptom levels emerged as significant predictors of total caregiver burden scores. Only the ABC language subscale score had a determining effect on caregiver burden ($r=0.51$, $r^2=0.26$, $p=0.04$). ABC body and object use subscale scores were identified as the symptom cluster affecting depression and anxiety scores ($r=0.25$, $r^2=0.06$, $p=0.03$ and $r=0.28$, $r^2=0.08$, $p=0.01$). Our findings show that ASD symptom severity and depressive symptoms in the caregiver are the most important factors giving rise to the caregiver burden, and that the main ASD symptom cluster affecting the caregiver burden was problems associated with language development. Better understanding of variables impacting on the caregiver burden will increase the quality of psychosocial services for caregivers.

Keywords ASD · Caregiver burden · Anxiety · Depression

Introduction

Autistic spectrum disorder (ASD) is a neurodevelopmental disorder characterized by varying levels of impairment of social communication and interaction, and restricted repetitive patterns of behavior, interest and activity from the early period of life (APA 2013). Autistic spectrum disorder (ASD) is one of the most common of all developmental disorders, and is estimated to affect 6.6 out of every 1000 children (Hill et al. 2014).

The parents of children diagnosed with ASD have an increased risk of psychosocial problems. The arrival of a new member of the family is an important period of transition requiring a restructuring of members' roles. Changes in routine are required, such as alterations in time devoted to social and occupational activities and sleep patterns. Interruption of the child's developmental process can make adaptation to this restructuring problematic. Recent years have seen an increase in studies assessing psychological effects and protective factors in members of families of children with developmental delay. Research has emphasized that caregivers of children diagnosed with ASD have higher depression and stress levels than caregivers of children with normal development and of children with other developmental impairments (Carter et al. 2009; Baker et al. 2002). The mothers of children diagnosed with

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autism are at particular risk in terms of high stress levels, anxiety, and depressive symptoms (Taylor and Warren 2012; Kousha et al. 2016; Green et al. 2010). The principal factors that exacerbate parental stress levels are becoming aware of deficiencies in the social skills and communication of children in the developmental process, observing stereotypic behaviors, social stigmatization, therapeutic options being restricted, and uncertainty regarding their children's futures (Green et al. 2010; Rezendes and Scarpa 2011). High stress levels and impaired physical/mental health in a parent can restrict opportunities for early and effective intervention. Understanding the variables associated with disorder affecting caregiver mental health, identifying high-risk groups, and increasing parental functionality by establishing support programs for these parents can therefore accelerate access to effective therapeutic options (Warren et al. 2011).

Living with an autistic child affects all members of the family, and primary caregivers are thought to be at greater psychosocial risk. The purpose of this study was to examine the relations between clinical characteristics of children and adolescents under monitoring with a diagnosis of ASD, sociodemographic variables and the caregiver burden.

Method

Sampling

The study population consisted of 70 children and adolescents aged 3–15 assessed at the Namık Kemal University Medical Faculty Child and Adolescent Mental Health Clinic, Turkey, diagnosed with ASD based on DSM-V diagnostic criteria, and still undergoing monitoring and treatment, together with their primary caregivers. Subjects were administered an evaluation form prepared by the authors, and sociodemographic and clinical data were obtained. Diagnosis of ASD at patient assessment was based on DSM-V diagnostic criteria. The Autism Behavior Checklist (ABC) was completed by a clinician, and subscale scores and severity of autism-related symptoms were determined. Comorbid psychiatric disorders in children and adolescents were determined using the semi-structured Schedule for Affective Disorders and Schizophrenia for School-Age Children-Preent and Lifetime Version (K-SADS-PL). Inclusion criteria for caregivers consisted of living with the patient, primary responsibility for patients' attending hospital follow-up and maintenance of such processes as special education support and drug therapy, and willingness to take part in the study. Caregivers completed the Beck Depression Inventory (BDI), the Beck Anxiety Inventory (BAI), and the Zarit Caregiver Burden Scale.

Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version

This semi-structured interview form was developed by Kaufman et al. in 1997 for the purpose of determining past and present psychopathologies in children and adolescents based on DSM-III-R and DSM-IV diagnostic criteria. The validity and reliability of the Turkish-language version of the K-SADS-PL were established by Gökler et al. (2004) (Kaufman et al. 1997; Gökler et al. 2004).

The Autism Behavior Checklist (ABC)

Developed by Krug et al. (1980). The reliability and validity of the Turkish-language version were confirmed by Irmak et al. (2007). This evaluation tool consists of 57 items in five subscales—sensory behavior (9 items), social relating (12 items), body and object use (13 items), language and communication skills (13 items), and social and adaptive skills (11 items).

Beck Depression Inventory (BDI)

The BDI was developed by Beck AT (1961) for the purpose of determining an individual's risk of depression ad measuring depressive symptom levels and severity changes (Beck 1961). The reliability and validity of the Turkish-language version was investigated by Hisli et al. (1989). It consists of 21 self-evaluation sentences on a four-point Likert-type measurement scale. Total scores range between 0 and 63. A cut-off point of 17 was determined in the paper on the validity of the Turkish-language version.

Beck Anxiety Inventory (BAI)

This was developed by Beck et al. (1988) and was translated into Turkish by Ulusoy et al. before entering into use (Beck et al. 1988; Ulusoy et al. 1998). The BAI is a self-report scale used to determine the frequency of anxiety symptoms experienced by an individual. It is a Likert-type scale consisting of 21 items scored from 0 to 3 with response options consisting of 'never', 'mild', 'moderate', and 'severe'. Possible scores range between 0 and 63, with higher total scores indicating a higher severity of anxiety.

Zarit Caregiver Burden Scale (ZCBS)

Confirmation of the reliability and validity of the Turkish-language version of this scale was performed with the caregivers of schizophrenia patients (Zarit et al. 1980; Özlü et al. 2009). The original version of the ZCBS consists of 22 items, but three were removed during confirmation of the reliability and validity of the Turkish-language version.

The scale can be completed by caregivers or by researchers. It consists of 19 statements determining the effect of caregiving on the life of the individual concerned. This five-point Likert-type scale contains response options of 'never', 'rarely', 'sometimes', 'frequently' and 'almost always.' The internal consistency of the Turkish-language version has been validated (Cronbach alpha = 0.83). Five subdimensions are described in the structural validity—psychological tension and impaired private life, irritability and restrictedness, impaired social relations, economic burden and dependence.

Statistical Analysis

Pearson correlation analysis was used to determine the type and power of correlations between patients' symptom degrees (ABC) and the caregiver burden (ZCBS), caregiver anxiety (BAI) and caregiver depressive symptom levels (BDI). Relation coefficients greater than $r = 0.250$ were regarded as indicating presence of correlation. Multiple regression analysis was used to identify predictive factors for caregiver burden. A significance limit of 0.95 was adopted ($p < 0.05$). Study data were analyzed on SPSS 17.0 software.

Results

Sociodemographic Characteristics of Children and Adolescents with ASD and Their Caregivers, and Scale Score Information

Patients' sociodemographic characteristics, disease-related information and ABC subscale and total scores are given in Table 1.

Table 1 Patients' sociodemographic and disease characteristics and ABC scores

	Mean ± SD/% (n = 70)
Age	7.11 ± 3.64
Sex	Male 74.7%
Patients receiving special education	68%
Hours of special education per week	3.35 ± 2.32
Age at diagnosis	2.74 ± 0.84
Time since diagnosis	4.41 ± 3.63
ABC subscale and total scores	
Sensory behavior	9.58 ± 5.35
Social relating	19.71 ± 8.32
Body and object use	16.17 ± 8.81
Language and communication skills	13.51 ± 7.06
Social and adaptive skills	11.72 ± 5.81
Total	70.84 ± 25.89

ABC Autism Behavior Checklist

Of the patients in the study, 89.3% lived with their families, 4% with other blood relatives, and 6.7% in institutions. At least one comorbid psychiatric disease was present in 56% (n = 42). Additional diagnosis of obsessive compulsive disorder was present in 16% (n = 12), attention deficit hyperactivity disorder and/or behavioral problems in 50.7% (n = 38), bipolar affective disorder in 5.3% (n = 4), psychotic disorder in 1.3% (n = 1), and depressive disorder in 2.7% (n = 2). Additionally, 42.7% (n = 32) exhibited normal mental development, while intellectual disability was present in 50.6% (n = 38).

Correlations Between Severity of Symptoms and Symptom Subtypes of patients with ASD and Caregiver Burden

Investigation of correlation between ABC total and subscale scores and caregiver burden revealed no significant correlation between ABC social relations skills and total caregiver burden score ($r = 0.23$, $p > 0.05$), while sensory behavior ($r = 0.38$, $p < 0.01$), social relating ($r = 0.35$, $p < 0.01$), body and object use ($r = 0.34$, $p < 0.01$), and language and communication skills ($r = 0.41$, $p < 0.01$) were significantly correlated with caregiver burden (Table 2).

Correlations Between Symptom Severity and Subtypes in Children with ASD and Caregiver Anxiety and Depression Scores

Correlation analysis of caregiver BAI and BDI scores and ABC total and subscale scores revealed threshold correlation between BAI score and ABC sensory behavior ($r = 0.25$, $p = 0.03$) score, and significant correlation between BAI score and ABC body and object use ($r = 0.28$, $p = 0.01$) subscale score and ABC total score ($r = 0.28$, $p = 0.01$). Threshold significant correlation was determined between BDI score and ABC body and object use ($r = 0.25$, $p = 0.03$) and ABC total score ($r = 0.25$, $p = 0.03$). However, no significant

Table 2 Pearson correlation coefficient between patients' symptom scores and ZCBS total scores and BAI and BDI scores

	BAI	BDI	ZBCS-total
ABC-sensory behavior	0.25*	0.18	0.38**
ABC-social relating	0.18	0.19	0.35**
ABC-body and object used	0.28*	0.25*	0.34**
ABC- language and communication skills	0.11	0.17	0.41**
ABC-social and adaptive skills	0.15	0.11	0.23
ABC-total	0.28	0.25	0.48**

ZBCS Zarit Caregiver Burden Scale, *BAI* Beck Anxiety Inventory, *BDI* Beck Depression Inventory

*$p < 0.05$, **$p < 0.001$

correlation was determined between BAI score and ABC social relating, language and communication skills, or social and adaptive skills. No significant correlation was also determined between BDI and ABC sensory behavior, social relating, language and communication skills, or social and adaptive skills.

Multiple Regression Analysis of predictors Constituting a Risk for Caregiver Burden

Potential risk factors for the independent variable caregiver burden were examined using multiple regression analysis, and two models were obtained. We think that model 2 provided a better explanation of our findings. In model 2, severity of autism symptoms and caregiver depressive symptom levels emerged as predictors affecting total caregiver burden scores (Table 3). Caregiver anxiety level, duration of disease, presence of attention deficit-hyperactivity disorder and destructive behavior, caregiver age, and length of education were not identified as predictors of caregiver burden.

We also analyzed the correlation between ABC subscales and total ZCBS score, and sought to determine the autism symptom group with the greatest effect on caregiver burden by applying multiple regression analysis. The analysis results revealed that only the ABC language and communication skills subscale had a determining effect on caregiver burden ($r=0.51$, $r^2=0.26$, $p=0.04$, Beta = 0.24, Durbin–Watson = 2.16). Similarly, at investigation of the autism group affecting the severity of caregiver depression and anxiety symptoms, the ABC body and object use subscale emerged as a common symptom group in caregiver depression and anxiety levels ($r=0.25$, $r^2=0.06$, $p=0.03$, Beta = 0.25, Durbin–Watson = 1.86 and $r=0.28$, $r^2=0.08$, $p=0.01$, Beta = 0.28, Durbin–Watson = 2.46).

Discussion

Our study shows that ABC symptom severity and caregiver depressive symptoms are the principal factors constituting the caregiver burden, and that problems with language development are the principal ABC symptom group affecting that burden.

Previous studies examining anxiety and depression levels in the mothers of children diagnosed with autistic disorder have showed that these mothers have high anxiety and depression levels, and that high anxiety and depression levels are associated with low quality of life (Kousha et. 2016). Some of these studies have shown that severity of autistic symptoms and presence of comorbid disease are predictive factors for severity of depression in mothers (Kousha et al. 2016; Zablotsky et al. 2013; Benson 2006). In addition, studies concerning caregiver burden have concluded that depressive mood emerges as a result of the caregiving process, and causes cognitive worsening and an increase in mortality by lowering caregiver quality of life (Stommel et al. 1994). Emotional and physical burdens cause caregivers to experience greater anxiety and depression, to have impaired health, to visit physicians more frequently, and to make greater use of psychotropic drugs (Schulz and Beach 1999). In agreement with previous studies, we observed that caregiver depressive mood state affected caregiver burden. In contrast to other studies, we determined no correlation between caregiver burden and parental anxiety scores. This is probably due to anxious parents behaving in a more protective manner when completing the caregiver burden scale. In addition, it must be remembered that mild anxiety may be a source of motivation in caregiver responsibility. Future studies will more clearly reveal the effects of both anxiety disorders at the clinical level and severity of anxiety on the care of individuals with ASD.

Table 3 Multiple regression analysis results of independent variable predictors of caregiver burden

Variable	B	SEB (ß)	t	p	95% confidence interval	
1. ABC-total	0.22	0.34	3.58	0.001**	0.10	0.35
2. BDI	0.60	0.43	4.23	< 0.001**	0.32	0.89
3. BAI	0.27	0.18	1.76	0.08	0.03	0.57
4. Caregiver age	0.33	0.11	1.20	0.23	− 0.22	0.89
5. Caregiver length of education	1.11	0.07	0.84	0.40	− 1.53	1.75
6. Time spent with the disease	0.22	− 0.04	− 0.48	0.62	− 1.13	0.69
7. Presence of ADHD/behavioral disorder	− 2.58	0.07	0.83	0.40	8.79	3.62
Constant	11.14		0.86	0.39	− 14.60	36.89

ZBCS Zarit Caregiver Burden Scale, *BAI* Beck Anxiety Inventory, *BDI* Beck Depression Inventory, *ADHD* Attention Deficit-Hyperactivity Disorder

Multiple R = 0.72 Multiple $R^2=0.51$, Durbin–Watson = 2.48 ($p=0.000$)

The severity of ASD symptoms was one of the most important factors affecting the caregiver burden in our study. Our scan of the literature revealed no previous studies investigating caregiver burden and ASD symptom severity. However, studies investigating caregiver burden in such childhood neurodevelopmental diseases as underdeveloped intelligence (Sarı 2007), attention deficit-hyperactivity disorder (Matza et al. 2005), and Tourette syndrome (Cooper et al. 2003) have reported that caregiver burden increases with symptom severity and in the presence of comorbid diseases. In their study from 2006, Allik et al. reported that the families of children with high functioning autism had a higher quality of life than those of children without high functioning autism (Allik et al. 2006). In the light of these studies, our finding that severity of ASD symptoms predicts caregiver burden is not surprising.

Several previous studies have revealed that additional diagnoses occurring in psychiatric diseases reduce the quality of life of both the patient and family, and increase the caregiver burden (Kring et al. 2008; Kim et al. 2000; Lecavalier et al. 2006). In our study, attention deficit-hyperactivity disorder and destructive behavior comorbidity were not identified as predictors of total caregiver burden scores. Although these data may appear inconsistent with those of previous research, another study published in 2012 compared the parents of children with attention deficit-hyperactivity disorder and ASD in terms of caregiver burden and reported similar levels of burden in both diseases, and that this was the same as the burden in the families of children with cerebral palsy (Cadman et al. 2012) On the basis of the findings of this study, we think that ASD, a chronic condition, causes a severe caregiver burden even by itself, and that difficulties created by additional diseases may not be capable of differentiation by parents. In addition, since a large part of our patient group were using pharmacological therapies, the probable effect on caregiver burden of the presence of attention deficit-hyperactivity disorder destructive behavior may not have been identified objectively. Caregiver exhaustion may increase in the presence of comorbid psychiatric diseases. Studies with larger participant numbers examining the effect of additional diseases on family burden may reveal the difference in caregiver burdens between groups with and without comorbidity. Another important finding from our study is that language and communication problems constitute the ASD symptom group with the greatest impact on caregiver burden. We encountered no previous study in which the autism symptoms affecting caregiver burden have been evaluated separately. However, delayed language development in ASD has been described as a poor prognostic factor (Gillberg and Steffenburg 1987). Poor language development may also cause the caregiver to feel a greater burden by affecting the course of the disease. Our study findings show that the main autism symptoms affecting the caregiver burden are clustered within the ABC language subscale.

We determined no relation between duration of disease and caregiver burden. Although duration of disease might be expected to be a factor affecting that burden, previous studies have reported inconsistent findings. One study from 2015 reported that learning of a diagnosis of ASD at an early age and prolonged duration of disease were correlated with a low quality of life associated with maternal depression and health (Kousha et al. 2016). In contrast, one study from the USA reported clinical anxiety symptoms in 6% and depression in 33% of mothers of 54 children newly diagnosed with ASD and concluded that the early phase of diagnosis was more associated with caregiver stress and depression levels (Davis and Carter 2008). Another study of children with cancer reported that mothers' psychosocial adaptation increased and their anxieties decreased in line with time elapsed since diagnosis (Han 2003). The average time since diagnosis in our study was 4.41 years. Parents learning of the disease and completing the adaptation process during this time frame may have been exposed to less caregiver burden. In addition, the inconsistent findings reports may also derive from differences in access to social support systems between countries.

We also observed no relation between parental education levels and caregiver burden. While some authors have reported that caregivers with a relatively lower socioeconomic level experience a greater burden and poorer health (Montgomery et al. 1985), others have reported no association between socioeconomic characteristics and caregiver burden (Biegel et al. 1994). Our study findings show that ASD, a chronic condition, creates similar effects at all socioeconomic levels in Turkish society.

The research findings show the need for clinicians to adopt a holistic approach when assessing children diagnosed with ASD and to include caregivers in the evaluation process. Some ASD symptoms may indicate an increased risk group in terms of the caregiver burden, and it will be useful for at-risk groups to be referred to mental health professionals in the early period. Caregivers must be able to make active use of social support systems, to maintain their own day-to-day social activities, and to benefit from psychopharmacological and/or psychotherapy techniques in the event of an existing psychiatric diagnosis. This will result in a decrease in the caregiver burden increase the quality of life of the caregiver and the child with ASD, and probably increase the level of benefit from education support on the part of children with ASD while reducing destructive behavior. Further comparative research is now needed to assess these parameters.

One of the principal limitations of our study is that due to its cross-sectional nature, we were unable to evaluate whether or not changes in patients' symptom levels also modified the caregiver burden. Another limitation is that

economic and social support, which also probably affect caregiver burden, were not fully evaluated. In addition, parents' existing physical diseases and their severity, if applicable, were not analyzed. The burden experienced by the mother within the family is generally greater (Angold et al. 1998). Our study did not investigate sex distribution among caregivers and its effect on caregiver burden. Our research did not investigate whether gender in individuals diagnosed with ASD had any effect on caregiver burden. Another limitation of our study is that the caregiver burden was assessed through self-reports. Additionally, since no control group was enrolled, we were unable to compare the caregiver burden in ASD with that in other chronic diseases.

In conclusion, to the best of our knowledge, ours is the first study to evaluate subdimensions of the caregiver burden in patients diagnosed with ASD and to examine the relation between symptom distribution and caregiver burden subdimensions. Future studies with greater numbers and parameters will examine the burdens of parents of children with chronic psychiatric disease in economic, social, and psychological terms, and investigate their quality of life in greater detail. This will permit the production of more effective solutions for social support to be provided for caregivers.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval This study was performed with the approval of the Namık Kemal University Medical Faculty local ethical committee (No. 2016/85/06/02). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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