

Original Research Paper

# Factors contributing to higher caregiving burden in Turkish mothers of children with autism spectrum disorders

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**Objectives:** The aim of this study was to explore the caregiver burden and related factors such as expressed emotion (EE), social support, life satisfaction, dyadic adjustment, post-traumatic growth, and socio-demographic characteristics of mothers with autism spectrum disorder (ASD) children.

**Methods:** Sixty-two mothers of children with autism spectrum disorder and 60 mothers of typically developing children completed the Zarit Burden Scale, the Multidimensional Scale of Perceived Social Support, the Satisfaction with Life Scale, the Dyadic Adjustment Scale, the Expressed Emotion Scale, and the Post-Traumatic Growth Inventory. The Autism Behavior Checklist was used to examine the severity of autistic behaviors. A socio-demographic data form was applied to the subjects. Participants were recruited in Autistic Children Education Center, homes, and workplaces. Correlation analysis, independent-samples *t*-tests, *post hoc* Mann–Whitney *U*, and SEM tests were conducted for statistical analyses.

**Results:** Higher maternal caregiving burden was associated with lower life satisfaction and higher level of disability in Turkish children with ASD. Also, higher life satisfaction of mothers with ASD children was related to higher social support and dyadic adjustment, and lower EE. According to the SEM analysis, disability percentages, autism-related behaviors in children, and poor dyadic adjustment were significant predictors of caregiving burden in these mothers which in turn resulted with higher EE and poor life satisfaction.

**Conclusions:** There are several studies that have investigated the distress in parents of children with developmental disabilities in general, but caregiving burden in ASD was not evaluated elsewhere in detail. These mothers need professional guidance and psychosocial support during the parenting process. Further studies that aim to investigate the whole family, including the father and the siblings, are also necessary.

**Keywords** ASD, caregiving burden, satisfaction with life, dyadic adjustment, expressed emotion

## 1. Objectives

Autism spectrum disorder (ASD), which is characterized by communication disabilities as well as behavioral problems, is a debilitating disorder and these children need sustained assistance from their parents due to the life-long nature of the disorder. According to the American Center for Disease Control and Prevention (Christensen *et al.* 2016), ASD is seen in every 1 of 68 live births and is thought to be approximately 1% of the world population. It is estimated that the number of children with ASD is 450,000–500,000 in Turkey (Öztürk 2012).

Caregiving to children with ASD is a stressful process and the parents occasionally need professional support. Mothers are much more involved with their children and gain much of the responsibility. Previous research reported higher maternal stress, less well-being as well as more

psychiatric morbidity, like depression and anxiety among these caregivers compared to typically developing children (TDC) (Blacher and McIntyre 2006; Eisenhower *et al.* 2005; Hayes and Watson, 2013; Hoffman *et al.* 2009; Singer 2006). Several psychological or disease-related factors that are associated with caregiving burden/distress in parents of children with ASD were studied. Most of these studies highlighted an association among maternal/parental stress, maladaptive behavior and low social support (Boyd 2002; Blacher and McIntyre 2006; Bromley *et al.* 2004; Estes *et al.* 2013; Gabriels *et al.* 2005; Lecavalier *et al.* 2006).

Furthermore, higher caregiving burden/maternal distress was associated with high parental expressed emotion (EE) (Hastings *et al.* 2006; Orsmond *et al.* 2006). The construct of EE refers to the affective attitudes and behaviors of a relative toward a psychiatric patient (Barrowclough and Hooley 2003; Butzlaff and Hooley 1998). The EE has

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two main dimensions; criticism/hostility (C/H) and emotional over-involvement (EOI). C/H includes critical comments made about the patient. EOI reflects an exaggerated emotional response, marked concern reflected in unusually self-sacrificing or clearly overprotective behaviors.

Previous research has also highlighted lower relationship satisfaction between couples with an ASD child (Brobst *et al.* 2009). Gau *et al.* (2012) compared parents of children with ASD ( $n = 151$ ) and TDC ( $n = 113$ ) in Taiwan and found less dyadic consensus and more psychopathology in the ASD group. Mothers of the ASD group had less marital satisfaction, affection expression, family adaptability, and cohesion.

Moreover, having a child with ASD may also have positive impacts on the parents, such as the post-traumatic growth (PTG) that implies ‘a positive psychological change experienced as a result of the struggle with highly challenging life circumstances’ (Tedeschi and Calhaun 2004). This phenomenon was studied in parents of ASD children who experience a kind of traumatic loss that is having a child with a major disability. Although such studies have revealed different results, they highlighted the significant PTG in these parents (Phelps McCammon *et al.* 2009; Zhang *et al.* 2013).

Burn-out, grief reaction to a diagnosis of ASD, anxiety, and depression levels of Turkish mothers with ASD children were investigated in previous studies. In general, higher levels of burn-out, grief, distress, depression, and anxiety were reported. Some of these studies highlighted the effect of some socio-demographic factors like age and education on the psychological outcome in the mothers (Çengelci 2009; Karpat and Girli 2012). Several studies investigated the relation between the level of hopelessness and social support perceived by the mothers of children with ASD. They concluded that the levels of hopelessness decreased as the social support perceived by the mothers increased (Akmanis 2010; Unluer 2009). However, caregiving burden of parents of children with ASD, which is a frequent phenomenon, has not been investigated in Turkey before. Caregiving burden is known as a negative reaction to the impact of providing care on caregivers’ social, occupational, and personal roles (Given *et al.* 2001). Caregiving burden was studied by Lin (2011) in Taiwanese mothers of adolescents with ASD, and functional independence, severe maladaptive behaviors, and severity of autism were found as predictive factors.

The present study aimed to evaluate the caregiving burden and contributing factors in mothers with ASD children. Generally, mothers are the primary caregivers of the children in Turkish society; therefore, only mothers were evaluated. The first hypothesis of the study was the higher levels of caregiving burden in mothers of children with ASD compared to mothers with TDC. Secondly, we aimed to investigate the association between caregiving burden of the mothers and some psychological factors such as perceived social support, dyadic adjustment, satisfaction

with life, PTG, EE as well as disease-related factors like ASD symptom severity and disability percentages of the children. We hypothesized a model indicating that lack of perceived social support, poor dyadic adjustment, low levels of PTG, severe behavioral symptoms, and high disability percentages predicted higher caregiving burden and higher caregiving burden resulted with high levels of EE and poor life satisfaction in the mothers with ASD children.

## 2. Methods

### 2.1. Participants

The participants of the study were 62 mothers of children with ASD and 60 mothers of TDC. 31.6% ( $n = 12$ ) of the children with ASD had also a diagnosis of intellectual disability. The mean duration of the ASD diagnosis was  $8.02 \pm 4.82$  years. The mean disability percentage of the children with ASD was  $78.53 \pm 17.28$ . Disability percentages of the children with ASD refers to the rate of loss of functionality (atypical ASD gets 40%, typical ASD gets 80%, and any comorbidity such as linguistic, neurological or movement disorder takes additional disability percentage) which is determined by a medical committee according to a national disability report (Council of Europe 2002, p. 86; Republic of Turkey Ministry Family and Social Policies 2013).

### 2.2. Measures

Autism Behavior Checklist (ABC) was used to examine the severity of autistic behaviors of the children with ASD. The mothers’ caregiving burden was evaluated by the Zarit Burden Scale (ZBS), perceived social support was assessed by the Multidimensional Scale of Perceived Social Support (MSPSS), and life satisfaction of the mothers was evaluated by the Satisfaction with Life Scale (SWLS). The Dyadic Adjustment Scale (DAS) was used for the evaluation of marital/dyadic adjustment of the parents, and the Expressed Emotion Scale (EES) was used to assess the EE of the mothers toward their children. Also, the Post-Traumatic Growth Inventory (PTGI) was used for the evaluation of post-traumatic development. A socio-demographic form including the socio-demographic data as well as the familial environment and clinical information regarding psychiatric and other medical issues was applied to the mothers. The ABC scores of the children with ASD was  $60.69 \pm 3.22$ . The details about the measures are given below.

#### 2.2.1. Autism Behavior Checklist

The Autism Behavior Checklist (ABC) was developed by Krug *et al.* (1978). The revised version of the checklist (1993), which is comprised of 5 subscales and 57 items, was used in the study. The subscales are sensory behavior (9 items), social relating (12 items), body and object use (12 items), language and communication skills (13 items), and social and adaptive skills (11 items). The total points to be obtained from the scale range from 0 to 159. The

Turkish validity and reliability study of the scale was carried out by Yılmaz Irmak *et al.* (2007). The cut-off point of the scale was 39; children who score more than 39 on the scale are considered as having a risk of ASD.

### 2.2.2. Zarit Burden Scale

The Zarit Burden Scale (ZBS) was developed to assess difficulties experienced by the caregivers by Zarit *et al.* (1980). The scale has a Likert-type rating ranging from 1 to 5 (never, rarely, sometimes, quite frequently or nearly always). Higher scores reflect more severe burden (Zarit *et al.* 1980). Two different Turkish adaptation studies exist. The first was performed by Inci and Erdem (2008) and involved 220 caregivers of elderly people. Internal consistency correlations for the scale were reported as 0.95 and inter-item correlation values were moderate, strong and very strong (between 0.43 and 0.85). The test-retest consistency coefficient was 0.90. Factor analysis yielded only one factor, which explained 53.6% of the total variance (Inci and Erdem 2008). The latter study involved 100 caregivers of patients with schizophrenia and was carried out by Ozlu *et al.* (2009). In this study, factor analysis yielded five factors, explaining 61% of the total variance. These factors were ‘mental irritability and subjective deterioration of living’ (items: 2, 3, 10, 11, 12, 17, 19), ‘nervousness and feeling restricted’ (items: 5, 9, 22), ‘deterioration in social relationships’ (items: 6, 13, 18), ‘economic burden’ (items: 15, 20, 21, 7) and ‘dependency’ (items 8, 14). Items 1, 4 and 16 were not included in any factor because of their low factor loadings (Ozlu *et al.* 2009). In this study, the ZBS total score was used to assess the caregiving burden.

### 2.2.3. Dyadic Adjustment Scale

The Dyadic Adjustment Scale (DAS) was developed by Spanier (1976) and consists of 32 items. The scale is designed as both yes-no questions and Likert type items. The scale has four subscales that are ‘dyadic cohesion’ (5 items), ‘dyadic consensus’ (13 items), ‘dyadic satisfaction’ (10 items), and ‘affective expression’ (4 items). 30 items of the scale consist of 7 Likert style questions, with options ranging from ‘always’ to ‘never.’ The lowest score of the scale is 0 and the highest score is 151. The increase in the total score shows the pair harmony in the marriage. A score lower than 98 indicates marital incompatibility. In the validity and reliability study of the Turkish form that was performed by Fıfılođlu and Demir (2000), the internal consistency value was found to be 0.92. The other two questions are scored as 0 or 1, with the ‘yes’ or ‘no’ response.

### 2.2.4. Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) was developed by Zimet *et al.* (1988). The scale with 12 items contains three different supports: family

(4 items), friends (4 items), and the significant other (4 items). The scores of subscales can be summed up to determine the total score of the scale. The Likert type scale scored from 1 to 7, the subscale scores ranged from 4 to 28, and the whole scale score ranged from 12 to 84. The high score indicates high perceived social support. Turkish adaptation, reliability and validity study of the scale was performed by Eker *et al.* (2001). Factor analysis in this study revealed the original three factors.

### 2.2.5. Expressed Emotions Scale

The Expressed Emotions Scale (EES) that consists of 41 items was developed by Berksun (1992). The level of EE increases as the scores on the scale rated as 0–1 and answered as true / false increase. It consists of two subscales that are C/H and EOI. One of the strengths of the scale is that the Turkish society and its cultural characteristics are taken into consideration during the development of the scale.

### 2.2.6. Satisfaction with Life Scale

The Satisfaction with Life Scale (SWLS) consisting of 5 items is a measure designed by Diener *et al.* (1985). The Likert type scale has 1 to 7 options (1 = ‘Not at all appropriate,’ 7 = ‘very appropriate’). The adaptation study of the scale to the Turkish was carried out by Köker (1991).

### 2.2.7. Post-Traumatic Growth Inventory (PTGI)

The scale that was developed by Tedeschi and Calhoun (1996) to evaluate the positive changes in individuals consists of 21 items. The psychometric properties of the Turkish version of the PTGI were performed in patients with rheumatoid arthritis by Dirik (2006). In the factor analysis conducted within the scope of the reliability-validity studies, 3 sub-dimensions were identified; they were ‘changes in self-perception,’ ‘changes in interpersonal relationships,’ and ‘changed philosophy of life.’ As a result of the reliability analyzes, it was found that the reliability coefficients of the subscales were changed between 0.81 and 0.95.

## 2.3. Procedures

Following relevant approvals from the ethics committee of Near East University of Northern Cyprus, individuals were recruited in Bursa province (consisting of both urban and rural areas). The ASD sample was gathered from the Autistic Children Education Center and mothers with TDC were gathered by visiting their homes and workplaces at the same area. Informed consents were taken from all the participants. After providing consent, all the measures mentioned above were self-rating scales except the ABC that was filled out by a psychologist (GÇ) in an interview with the mothers.

## 2.4. Analysis

Two groups were compared in terms of the socio-demographic and the clinical variables. Chi Square test was used for categorical variables; for continuous variables, either

**Table 1** The socio-demographic characteristics of the participants

		TDC group (n = 60)	ASD group (n = 60)	Statistical significance
Age of mothers		37.83 ± 7.54	38.11 ± 6.51	$t = .22$ $p = 0.83$
Education of mothers (years)		12.77 ± 3.24	8.13 ± 3.47	$t = -7.62$ $p < 0.001$
Marital status	Married	55 (91.7%)	59 (95.2%)	$\chi^2 = 0.61$ $p = 0.49^a$
	Divorced/widowed	5 (8.3%)	3 (4.8%)	
Number of children	1 child	29(48.3%)	14 (22.6%)	$\chi^2 = 8.86$ $p < 0.01$
	>2 children	31(51.7%)	48 (77.4%)	
Employment status	No	3 (5%)	58 (93.5%)	$\chi^2 = 95.63$ $p < 0.001$
	Yes	57 (95%)	4 (6.5%)	
Presence of any chronic physical disease	No	60 (100%)	58 (93.5%)	$\chi^2 = 4.00$ $p < 0.05^a$
	Yes	0 (0%)	4 (6.5%)	
Presence of any psychiatric disorder	No	60 (100%)	53 (85.5%)	$\chi^2 = 9.00$ $p < 0.01^a$
	Yes	0 (0%)	9 (14.5%)	
Psychotropic medication usage	No	60 (100%)	55 (88.7%)	$\chi^2 = 7.19$ $p < 0.01^a$
	Yes	0 (0%)	7 (11.3%)	
Any other disabled family member	No	60 (100%)	60 (96.8%)	$\chi^2 = 1.97$ $p = 0.16^a$
	Yes	0 (0%)	2 (3.2%)	
Sex of the child	Male	23 (38.3%)	52 (83.9%)	$\chi^2 = 26.7$ $p < 0.001$
	Female	37(61.7%)	10 (16.1%)	
Age of the child		10.58 ± 6.5	11.53 ± 5.14	$t = 0.90$ $p = 0.37$

Note:  $t$  = Independent samples  $t$  test.

<sup>a</sup>Fisher's exact test.

**Table 2** Mean and standard deviations of scores obtained from the scales

Scales	TDC group (n = 60)	ASD group (n = 62)	Statistical comparison
ZBS total score	37.15 ± 8.80	56.02 ± 15.75	$t = -8.13, p < 0.001$
DAS total score	106.10 ± 25.84	105.05 ± 24.82	$t = 0.23, p = 0.82$
DAS-Dyadic Satisfaction	36.07 ± 9.53	34.92 ± 8.46	$Z = -1.21, p = 0.23$
DAS-Dyadic Cohesion	13.28 ± 5.43	12.19 ± 5.63	$t = 1.09, p = 0.28$
DAS-Dyadic Consensus	47.83 ± 10.75	46.66 ± 11.92	$t = -0.89, p = 0.38$
DAS-Affective Expression	8.92 ± 2.63	8.27 ± 3.19	$t = 1.21, p = 0.23$
MSPSS total score	67.60 ± 11.58	49.55 ± 20.17	$t = -6.04, p < 0.01$
MSPSS-Significant Other	20.50 ± 6.73	13.00 ± 8.36	$t = 5.44, p < 0.05$
MSPSS-Family	23.32 ± 5.23	19.11 ± 7.81	$t = 3.48, p < .001$
MSPSS-Friends	23.78 ± 4.04	17.44 ± 8.26	$t = 5.37, p < .001$
EES total score	13.33 ± 3.23	18.55 ± 3.78	$t = -8.18, p < 0.001$
EES-Criticism/Hostility	6.40 ± 2.31	8.82 ± 3.15	$t = -4.83, p < 0.05$
EES-Emotional Over-Involvement	6.93 ± 2.35	9.73 ± 1.53	$t = -7.80, p < 0.001$
SWLS total score	23.15 ± 6.39	19.71 ± 6.86	$t = -2.86, p < 0.01$
PTGS total score	76.02 ± 19.18	77.13 ± 18.35	$t = -0.33, p = 0.83$
PTGS-Changes in Interpersonal Relationships	25.20 ± 6.66	23.34 ± 7.33	$t = 1.47, p = 0.20$
PTGS-Changed Philosophy of Life	16.45 ± 5.04	17.26 ± 5.19	$t = -0.87, p = 0.68$
PTGS-Changes in Self-Perception	34.37 ± 8.73	36.53 ± 8.56	$t = -1.38, p = 0.87$

Notes: MSPSS = Multidimensional Scale of Perceived Social Support; EES = Expressed Emotion Scale; PTGI = Posttraumatic Growth Inventory; SWLS = Satisfaction with Life Scale; ZBI = Zarit Burden Inventory; DAS = Dyadic Adjustment Scale.

$t$ : Independent samples  $t$ -test.

$Z$ : Mann-Whitney  $U$  test.

independent sample  $t$ -test or Mann-Whitney  $U$  test was performed according to the distribution of the data. A correlation analysis was carried out to analyze the relationship between the caregiving burden and other variables in the ASD group. Finally, a model for defining the predictors of caregiving burden in mothers with ASD was generated and tested by using Structural Equation Modeling (SEM). The SEM analysis was carried out by the AMOS.

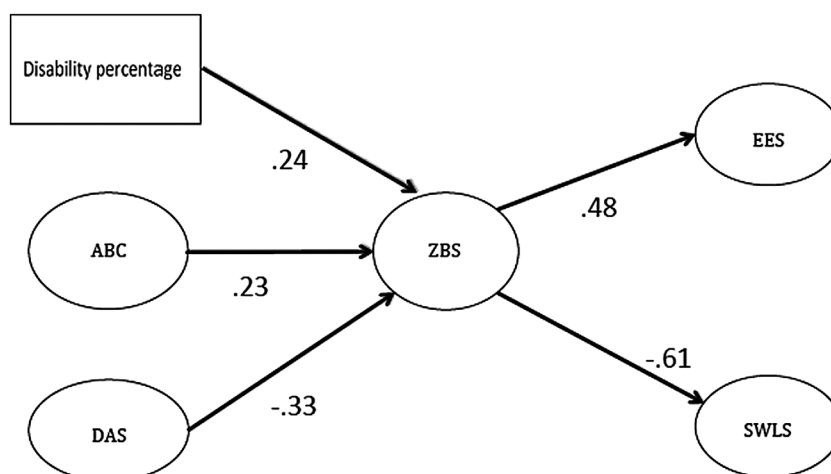
### 3. Results

The socio-demographic characteristics of the groups are presented in Table 1. Two groups were similar in terms of their age and marital status; however, mothers of the children with ASD had lower total years of education.

Also, the mothers of children with ASD have more children compared to the other group. Male/female ratio was higher for the children with ASD compared to TDC. The mean ages of the children were similar in the two groups.

Table 2 presents the clinical data and statistical comparison of the groups. According to these results, caregiving burden and overall EE (both dimensions of C/H and EOI) were higher in the mothers of children with ASD. Life satisfaction (SWLS) and perceived social support (MSPSS total and subscale scores) of the mothers of children with ASD were lower than the mothers of children with TDC. There was no difference between the groups in terms of the PTG or the dyadic adjustment (DAS).





**Figure 1** The model of the associations between caregiving burden and autism-related behavior, disability percentages, dyadic adjustment, expressed emotion, and satisfaction with life

The two groups were different in terms of the education and the number of children, which can affect the caregiving burden. Therefore, an ANCOVA was performed to compare the groups in terms of the ZBS scores by taking these two variables as covariates. The ANCOVA yielded a significant group effect ( $F = 37.48, p < 0.001$ ), while the interaction effects (education of the mother X ZBS and number of children X ZBS) were not significant (respectively  $F = 0.12, p = 0.73$ ;  $F = 1.59, p = 0.21$ ).

The ZBS total score in mothers of children with ASD ( $n = 62$ ) was positively correlated with the disability percentage of the child, the ABC total score, the EES total score and the EES-C/H subscale score (respectively  $r = .35, p = .006$ ;  $r = .31, p = .014$ ;  $r = .28, p = .029$ ;  $r = .29, p = .021$ ). The ZBS total score was also positively correlated with the ABC-social and adaptive skills and the ABC-body and object use subscales (respectively  $X = 13,53 \pm 5,21, r = .32, p = .01$ ;  $X = 13,05 \pm 7,96, r = .28, p = .03$ ). The ZBS total score was negatively correlated with the SWLS total score, the DAS total score, the DAS-dyadic consensus, the DAS-affective expression and the DAS-dyadic satisfaction subscales (respectively  $r = -.51, p < .001$ ;  $r = -.31, p = .014$ ;  $r = -.28, p = .025$ ;  $r = -.34, p = .007$ ;  $r = -.28, p = .03$ ).

According to these results we generated a model by using the SEM analysis. We have included the variables which were correlated with the ZBS total score in the SEM analysis. Figure 1 presents this model which explores the associations between some factors like the ABC, disability percentages, the DAS and caregiving burden (ZBS) as well as the outcome variables like the EES and the SWLS in mothers of children with ASD. The model was found to be in good agreement with the data ( $\chi^2 [99, N = 62] = 126.57, p < .05, \chi^2/df = 1.28, CFI = .92, RMSEA = .07$ ). This model explains that disability percentages ( $\beta = 0.24, p < .001$ ) and autism-related behaviors of children with ASD ( $\beta = 0.23, p < .01$ ) are two factors which are

significantly associated with the caregiving burden. The poor dyadic adjustment ( $\beta = -0.33, p < .001$ ) is also associated with higher caregiving burden that in turn results with higher EE ( $\beta = -0.61, p < .001$ ) and low satisfaction with life ( $\beta = -0.48, p < .001$ ).

#### 4. Discussion

The present study primarily investigated the caregiving burden in mothers of children with ASD compared to TDC as well as the possible contributing factors such as socio-demographic features, severity of ASD symptoms, dyadic adjustment, PTG, and perceived social support as well as some related psychological phenomena like EE and satisfaction with life. The results of the study supported higher caregiving burden in the mothers of the children with ASD. The discrepancy between the two groups in terms of education and the number of children did not affect this result. Moreover, several factors that may contribute to higher caregiving burden in these mothers were evaluated, which is an important strength of the present study. One of these factors are disease-related factors like autism-related behavior problems and disability percentages. Both were positively correlated with the burden and significant predictors of the burden in the model. Lin (2011) also reported a moderate level of burden in Taiwanese mothers of adolescents with ASD. Although different instruments were used and there was no control group in that study, the results were in parallel with ours, regarding associations between burden and autism-related behaviors, as well as the severity of the ASD.

There was no difference in terms of dyadic adjustment between the two groups. However, poor dyadic adjustment also seems to be a contributing factor in higher caregiving burden in these mothers. Although we did not find any difference between the groups, some previous studies also supported our model. Hartley et al. (2011) did not find any difference in terms of parenting burden between

mothers and fathers of ASD children, they reported marital satisfaction as a predictor of parenting burden. Another study by Kwok *et al.* (2014) found perceived stigma and perceived caregiving burden as significant predictors of mothers' marital satisfaction.

Autism-related behaviors that are measured with the ABC were related to the caregiving burden. In several studies (Bromley *et al.* 2004; Hastings *et al.* 2005; Lecavalier *et al.* 2006), compared to other autism symptoms, behavior and conduct problems were more strongly related to parental stress in parents of children with ASD. Such symptoms (especially negativism, aggressive behaviors, irritability etc.) impair their relationship and they impede the parents from giving support and care to their children.

In the present study, the mothers with ASD children had lower life satisfaction that was also presented as a significant outcome of burden in the model. Lu *et al.* (2015) also examined and compared social support and life satisfaction in Chinese parents of children with ASD by using the same evaluation methods. Parents of children with ASD scored significantly lower on social support, and life satisfaction than controls.

We found that overall EE and its dimensions were higher in ASD mothers compared to TDC. Also the overall EE and criticism/hostility dimension of EE were both positively correlated with caregiving burden in ASD mothers. However, these results are not in parallel with previous research. One study by Griffith *et al.* (2015) showed that although mothers were more critical of their ASD child compared to a typically developing sibling, there was no difference in terms of overall EE and EOI. Orsmond *et al.* (2006) investigated the relationship between the caregiving burden and EE in the mothers of adult/adolescents with ASD and they found that maternal C/H and EOI were not associated with caregiving burden. On the other hand, in children with intellectual disabilities, Hastings *et al.* (2006) found that maternal EE, C/H and EOI were cross-sectionally related to children's externalizing behavioral problems and to maternal distress. In a longitudinal study, Greenberg *et al.* (2006) found that high EE was related to increased levels of maladaptive behavior and more severe symptoms of autism over time. C/H predicted internalizing problems and asocial behavior over time, but there was no relationship involving EOI as a predictor or being predicted by the behavioral problem domains. Overall EE and C/H predicted autistic symptoms over time but no bidirectional effects and again no effects relating to EOI were found. Our results showed a significant relationship between the burden and the EE that was presented as an outcome of burden. Since the stress/burden of the mothers increase, their irritability, feelings of guilt or self-victimization may result with judgemental and protective attitudes toward their children. Besides, some of the results of the previous studies are controversial, so in these mothers further studies especially qualitative ones that investigate EE and

its components in detail are necessary. This is because EE is an important phenomenon that should be considered in psychosocial interventions to families with ASD children.

Perceived social support was also lower in mothers with ASD children; however, it was not associated with caregiving burden and it was not included in the model. This result is quite confusing because previous research has highlighted the importance of perceived social support in this group (Benson 2012; Sencar 2007). Stuart ve McGrew (2009) reported that social support as well as symptom severity was strong and consistent predictors of increased burden in caregivers of children with ASD. Similarly, comparing parents of children with ASD with parents of children without ASD, one study conducted by Sivberg (2002) found that parents of children with ASD had much higher levels of family burden and lower social support.

Phelps *et al.* (2009) hypothesized that higher stress which performed the task of a trigger in these parents would have led to higher PTG. However, PTG was not significantly correlated with stress, but was positively correlated with enrichment. Zhang *et al.* (2013) reported moderate levels of PTG in mothers of children with ASD in China and found a positive correlation between positive coping and the PTG. We did not find any difference between the groups in terms of PTG, which was not associated with caregiving burden either. Therefore we did not consider PTG in the model. Although, we have used the PTGI for the assessment of PTG which is a widely used instrument (Linley *et al.* 2007) cultural factors may be responsible for this negative result.

There are a small number of studies in the Turkish mothers of the children with ASD. One of these studies (Karpat and Girli 2012) investigated the grief of the parents of the children with pervasive developmental disorders, which was predicted by several factors such as being the mother, lower education, shorter marriage duration, poor social support, dyadic cohesion, and dyadic satisfaction. Secondly, Çengelci (2009) did not find any difference between the burn-out of mothers of children with ASD and Down Syndrome and showed an association between lower education and higher burn-out in these mothers.

According to the model presented in this study, all of these factors should be considered together in the psychosocial interventions in order to improve satisfaction of life as well as the well being and the mental health of the mothers with ASD children. Since marital relationships are so important, fathers also need to be involved in the rehabilitation programs.

#### 4.1. Limitations of the current study

The present study evaluated only the mothers, but not the fathers of the children with ASD because it is widely accepted that mothers are generally the primary caregivers

of these children. Furthermore, mothers had higher levels of distress, depression and anxiety compared to fathers in much of the previous research (Firat 2016; Karpat and Girli 2012). These results may also arise from cultural factors; such as in conservative societies women take more responsibility in terms of childcare. However, it is also important to consider how siblings and other members of the family are affected. Therefore, further studies should concern this limitation. Another limitations of the present study are the small sample size and that these mothers were living in an urban area in Turkey; therefore, the results of the study cannot be generalized to whole mothers of ASD children in Turkey, especially the ones in rural areas. The gender of the child might affect the burden of the mothers, but the effect of the gender of the child could not be assessed in this study since most of the children with ASD were boys. However, this limitation is inevitable because ASD are typically more prevalent in boys than in girls (Wing 1981).

#### 4.2. Conclusions

The present study which highlights higher maternal caregiving burden associated with severe disability, behavioral symptoms and poor dyadic adjustment in Turkish children with ASD is important since several factors contributing to caregiving burden are evaluated with standardized measures. Higher caregiving burden was also responsible for lower life satisfaction and higher EE in these mothers and these factors may lead to significant stress and psychiatric problems both in mothers and their children. Although there are several studies that investigated the distress in parents of the children with developmental disabilities in general, caregiving burden in ASD was not evaluated elsewhere in detail. Results of the present study suggest that these mothers need professional guidance and psychosocial support during the parenting process. Further studies that aim to investigate the whole family including the father and the siblings are also necessary. Alongside the studies, fathers should also be included in the rehabilitation process since dyadic adjustment is related to maternal burden. Mothers of children with severe autism-related behaviors and higher disability may have the priority in the rehabilitation programs. Furthermore, EE should be evaluated and insight-oriented behavioural therapies can be provided for mothers with high EE.

#### Conflicts of interest

The authors declared that they have no potential or competing conflicts of interest.

#### Ethical approval

This article does not contain any studies with human participants or animals performed by any of the authors.

#### References

- Akmanis, B. 2010. Investigation of the levels of hopelessness according to social support perceived mothers of children with autism, Unpublished master thesis. Maltepe University, İstanbul.
- Barrowclough, C. and Hooley, J. M. 2003. Attributions and expressed emotion: A review. *Clinical Psychology Review*, 23, 849–880.
- Benson, P. R. 2012. Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(12), 2597–2610.
- Berksun, O.E. 1992. Family factor in Schizophrenia: Expressed Emotion Scale development and adaptation experiment. Unpublished Thesis. Ankara.
- Blacher, J. and McIntyre, L. L. 2006. Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, 50(3), 184–198.
- Brobst, J. B., et al. 2009. Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38–49.
- Bromley, J., et al. 2004. Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), 409–423.
- Boyd, B. A. 2002. Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208–215.
- Butzlaff, R. L. and Hooley, J. M. 1998. Expressed emotion and psychiatric relapse: A meta-analysis. *Archives of General Psychiatry*, 55(6), 547–552.
- Christensen, D. L., et al. 2016. Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *Journal of Developmental & Behavioral Pediatrics*, 37(1), 1–8.
- Council of Europe. 2002. *Assessing disability in Europe, similarities and differences*. Strasbourg: Council of Europe Publishing.
- Çengelci, B. 2009. A comparison of level of anxiety, hopelessness and burnout syndrome of mothers who have children with diagnosis of autism or down syndrome. *Ege Eğitim Dergisi*, 10(2), 1–22.
- Diener, E., et al. 1985. The satisfaction with life scale. *Journal of Personality Assessment*, 49, 71–75.
- Dirik, G. 2006. Posttraumatic growth and psychological distress among rheumatoid arthritis patients: An evaluation within the conservation of resources theory. Unpublished Master Thesis. Middle East Technical University, The Graduate School of Social Sciences, Department of Psychology, Ankara.
- Eisenhower, A. S., et al. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, 49(9), 657–671.
- Eker, D., et al. 2001. Factorial structure, validity, and reliability of revised form of the multidimensional scale of perceived social support. *Turkish Journal of Psychiatry*, 12(1), 17–25.
- Estes, A., et al. 2013. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain Development*, 35(2), 133–138.
- Firat, S. 2016. Levels of depression and anxiety among parents of autistic children. *Cukurova Medical Journal*, 41(3), 539–547.
- Fırsıoğlu, H. and Demir, A. 2000. Applicability of the dyadic adjustment scale for measurement of marital quality with Turkish couples. *European Journal of Psychological Assessment*, 16(3), 214–218.
- Gabriels, R. L., et al. 2005. Repetitive behaviors in autism: Relationships with associated clinical features. *Research in Developmental Disabilities*, 26(2), 169–181.



- Gau, S. S. F., et al. 2012. Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 263–270.
- Given, B., et al. 2001. Caregiver role strain. In: M. Maas, et al., eds. *Nursing care of older adults: Diagnosis, outcomes and interventions*. St Louis: Missouri, pp. 679–695.
- Greenberg, J. S., et al. 2006. Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *American Journal on Mental Retardation*, 111(4), 229–249.
- Griffith, G. M., et al. 2015. Mothers' expressed emotion towards children with autism spectrum disorder and their siblings. *Journal of Intellectual Disability Research*, 59(6), 580–587.
- Hartley, S. L., et al. 2011. Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal of Intellectual and Developmental Disabilities*, 116(1), 81–95.
- Hastings, R. P., et al. 2006. Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation*, 111(1), 48–61.
- Hastings, R. P., et al. 2005. Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35, 635–644.
- Hayes, S. A. and Watson, S. L. 2013. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629–642.
- Hoffman, C. D., et al. 2009. Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 24(3), 178–187.
- Inci, F. H. and Erdem, M. 2008. Psychometric properties of the Turkish Version of Caregiver Burden Scale. *Atatürk University Journal of Nursing School*, 11(4), 85–95.
- Karpat, D. and Girli, A. 2012. The analysis of grief marital adjustment and perceived social support of parents of children with pervasive development disorder. *Ankara Üniversitesi Eğitim Bilimleri Fakültesi Özel Eğitim Dergisi*, 13(2), 69–89.
- Köker, S. 1991. Normal ve sorunlu ergenlerde yaşam doyumu düzeyinin karşılaştırılması [Comparing the level of life satisfaction in normal and problematic adolescents]. Unpublished master thesis. Ankara Üniversitesi, Ankara.
- Krug, D. A., et al. 1978. *ABC—Autism behaviour checklist*. Portland, OR: ASIEP Education.
- Kwok, S. Y. C. L., et al. 2014. Marital satisfaction of Chinese mothers of children with autism and intellectual disabilities in Hong Kong. *Journal of Intellectual Disability Research*, 58(12), 1156–1171.
- Lecavalier, L., et al. 2006. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172–183.
- Lin, L. Y. 2011. Factors associated with caregiving burden and maternal pessimism in mothers of adolescents with an autism spectrum disorder in Taiwan. *Occupational Therapy International*, 18(2), 96–105.
- Linley, P. A., et al. 2007. Confirmatory factor analysis of the posttraumatic growth inventory. *Journal of Loss and Trauma*, 12(4), 321–332.
- Lu, M., et al. 2015. Self-esteem, social support, and life satisfaction in Chinese parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 17, 70–77.
- Orsmond, G. I., et al. 2006. Mother-child relationship quality among adolescents and adults with autism. *American Journal on Mental Retardation*, 111(2), 121–137.
- Ozlu, A., et al. 2009. A reliability and validity study on the Zarit Caregiver Burden Scale. *Archives of Neuropsychiatry*, 46(Supplement), 38–42.
- Öztürk, M. 2012. The Report of Disabled Truth in Turkey. The Society of “Canda Ozur Olmaz”, Istanbul.
- Phelps, K. W., et al. 2009. Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 34(2), 133–141.
- Republic of Turkey Ministry Family and Social Policies, 2013. Regulation on disability criteria, classification and health committee reports to be given to disabled people. Date of Official Gazette. 28603.
- Sencar, B. 2007. Research of interrelationships between social support and stress level that the families of autistic child perceived. Unpublished master thesis. Dokuz Eylül University, İzmir.
- Singer, G. H. 2006. Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111(3), 155–169.
- Sivberg, B. 2002. Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, 6(4), 397–409.
- Spanier, G. B. 1976. Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15–28.
- Stuart, M. and McGrew, J. H. 2009. Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3(1), 86–97.
- Tedeschi, R. G. and Calhoun, L. G. 1996. The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9(3), 455–471.
- Tedeschi, R. G. and Calhoun, L. G. 2004. Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, 15, 1–18.
- Unluer, E. 2009. Investigation of relationship between perceived social support and hopelessness level of the mothers who have the child with autism between the age 2-6. Unpublished master thesis. Marmara University, İstanbul.
- Wing, L. 1981. Sex ratios in early childhood autism and related conditions. *Psychiatry Research*, 5(2), 129–137.
- Yılmaz İrmak, T., et al. 2007. An investigation of validity and reliability of autism behavior checklist (ABC). *Turkish Journal of Child and Adolescent Mental Health*, 14(1), 13–23.
- Zarit, S. H., et al. 1980. Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20(6), 649–655.
- Zhang, W., et al. 2013. Relationship between coping, rumination and posttraumatic growth in mothers of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(10), 1204–1210.
- Zimet, G. D., et al. 1988. The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30–41.