Depression and Burden among Caregivers of Children with Autistic Spectrum Disorder

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Objective: *To study depression prevalence and burden among caregivers of children with autistic spectrum disorder and the related factors.*

Material and Method: *This is a cross-sectional descriptive study. Measures included questionnaires, CES-D and burden interview. Patients' diagnoses and functions were obtained from child psychiatrists and developmental pediatricians responsible for the patients.*

Results: *There were 51 participants. The depression prevalence was 5.9%. Concerning the burden, 45.1% of the participants reported little or no burden, and 45.1% reported mild to moderate burden. Only 7.8% and 2.0% experienced moderate to severe and severe burdens, respectively. There was a significant positive correlation between depression and burden ($p = 0.012$). Significant correlations were also observed between burden and months after diagnosed, the number of patient's problems and the number of hours that caregiver spent with patient per day. Moreover, the burden was significantly associated with patient's communication problems and patient's inappropriate odd repetitive behaviors ($p<0.05$).*

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, Autistic spectrum disorder, Burden, Caregiver, Depression*

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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). ASD prevalence is 1:110 in the United States and 1:1,000 in Thailand and is reported increasing overtime(2,3). Caregivers of these children face numerous challenges, and many studies from western countries reported increased psychological distress including depression among them(4-7). In Asia, a study from Taiwan showed that 60 percent of mothers of autistic children had severe depression when assessed by Center for Epidemiologic Studies Depression Symptomatology Scale (CES-D)(8). Factors related to caregiver depression were high levels of patient's behavior problems, early onset of autism, low functioning patients, inadequate social support that caregivers received, caregivers suffering from illness or disability(9,10). Moreover, most families with autistic child reported that they had a high burden level(11,12). The study by Ling Y et al showed that 80 percent of mothers of autistic children had moderate to extremely heavy level of caregiver burden, and there was a positive correlation between depressive symptoms and caregiver burden(8). Factors relating to caregiver burden were severity of patient's symptoms, the number of life problems of caregiver and low level of support that caregiver received(11).

In Thailand, a research indicated that mothers' mental health was related to their capability of taking care of their children(13), but the study did not examine the extent of depression and feeling of burden they had or the associated factors. In order to understand and help the caregivers better, the purpose of the present research was to study the prevalence of depression, burden and related factors among caregivers of autistic children in Thailand.

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Material and Method

This is a cross-sectional descriptive study investigating depression and burden among caregivers of ASD patients.

Participants

Participants were all caregivers who brought ASD patients to the outpatient unit of Thammasat University Hospital from May 1, 2011 to July 31, 2011. 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.

Caregiver depression was measured using CES-D, Thai version. 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. It was translated into Thai version by Duangjai Kasantikul et al. 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 study used score at 26 or more as a cut-off point for depression(14).

Caregiver burden was assessed using burden interview in Thai that was originally developed by Zarit et al and developed into Thai by Chanandchidadussadee Toonsiri et al. 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(15).

Data analysis

SPSS version 16.0 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 $p<0.05$.

The present study was approved by the Human Research Ethics Committee of Thammasat University, Thailand (Ref: MTU-EC-PE-6-012/55; March 30 2012).

Results

Participants included 51 caregivers, of whom the majority was mothers of ASD patients. The level of education, employment status, household income and number of hours spent with patient were varied as seen in Table 1. As for the ASD patients, 84.3% were boys. The mean age of the patients was 6.4 (SD 3.4). Most of them (92.2%) were classified into the moderate and high function group. The patients' problems asperceived by the caregivers were shown in Table 2.

Caregiver depression and caregiver burden

The prevalence of depression among participants in this study was 5.9%. With respect to caregiver burden, 45.1% of participants reported little or no burden, and equally 45.1% reported mild to moderate burden level. Only 7.8% had moderate to severe burden level, and only 2.0% experienced severe burden.

Fig. 1 shows that there was a significant positive correlation between caregiver depression and caregiver burden, with a higher level of caregiver depression associated with a higher level of caregiver burden. 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 as seen in Table 3. From Table 4, caregiver burden was significantly associated with patient's speech delay or communication problems ($p = 0.047$) and the patient's inappropriate or odd repetitive behaviors ($p = 0.042$) whereas the other factors were not statistically correlated to caregiver burden. The statistical analysis concerning caregiver depression and associated factors

Table 1. Dermographic characteristics of cargivers of children with ASD (n = 51)

Characteristic	
Gender	
Male	14 (27.5%)
Female	37 (72.5%)
Caregiver's age (year; mean ± SD)	39.7±9.5
Relationship with patients	
Mother	35 (68.6%)
Father	10 (19.6%)
Relative	5 (11.8%)
Marital status	
Married	31 (60.8%)
Single	17 (33.3%)
Divorced/widowed	3 (5.9%)
Caregiver's level of education	
Elementary school	15 (29.4%)
High school or equivalent	16 (31.3%)
Bachelor's degree or higher degree	18 (34.3%)
Employment status (n = 49, missing data = 2)	
Full-time	27 (52.9%)
Part-time	5 (9.8%)
Unemployed	19 (37.3%)
Household income (baht/month; mean ± SD)	37,829.2±31,028.7
Number of hours spent with patients (hours/day; mean ± SD)	12.4±8.4
Had someone help taking care of patients	
No (only one caregiver)	18 (35.3%)
Yes	33 (64.7%)

Table 2. Demographic characteristic of children with ASD (n = 51)

Characteristic	
Gender	
Male	43 (84.3%)
Female	8 (15.7%)
Patient's age (year; mean ± SD)	6.4±3.4
Patient's problems (can be more than 1 problem)	
Delayed speech/communication problems	33 (64.7%)
Hyperactive and aggressive behaviors	30 (58.8%)
Poor social skills	27 (52.9%)
Inability to perform age-appropriate activities of daily living (ADLs)	24 (47.1%)
Difficulties in eating/sleeping/excretion	18 (35.3%)
Learning problems	18 (35.3%)
Inappropriate/odd repetitive behaviors	14 (27.5%)
Months after having been diagnosed (mean ± SD)	19.9±20.1
Function	
Low	4 (7.8%)
Moderate	26 (51.0%)
High	21 (41.2%)

could not be performed because only few participants reported having depression in this study.

Discussion

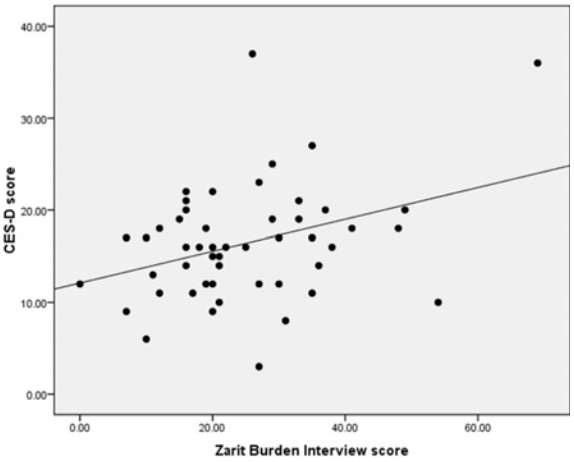
Characteristics of autistic patients and their caregivers

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 (84.3% vs. 15.7% female), similarly to the autism morbidity being higher in male than in female at an approximate ratio of 4-5:1(16). 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%(17) of ASD patients.

Depression in Autistic Children's Caregivers

The present study found depression in 5.9% 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(8). 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(9,10) had found that the disease severity in children affected their mothers' mental health in that children with less severe disease were related to the mothers with better mental health. Past studies(9,19) 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, 64.5% 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(19,21). Lin Y et al only studied teenage autistic patients and their mothers while the present research did all primary caregivers, which included parents and relatives, and autistic children of all ages. This may cause the depression rate in the present study to be lower than that in the group of teenage patients' mothers. The comparison of the two researches suggests that depression may be increased in particular groups of caregivers and also related to the age range of the cared children.



Pearson's correlation = 0.352, p = 0.012

Fig. 1 Correlation between CES-D score and Burden Interview score.

Burden on autistic children's caregivers

Most of the caregivers felt that the children were a small to moderate burden, which is different from the results of Stuart M(11) and Mugno D(12) 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 the 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(10). 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(10,15) and eventually more heavily burdened.

Table 3. Pearson's correlation between demographic data and Thai Burden Interview score (n = 51)

Variable	Correlation (r)	p-value
Patient's age	0.047	0.743
Household income	0.059	0.713
Caregiver's age	0.266	0.065
Months after having been diagnosed	0.305	0.042*
Hours spent with patient per day	0.322	0.024*
Number of patient's problems+	0.484++	<0.001**

+ List of these problems: 1) Inability to perform age-appropriate ADLs, 2) Difficulties in eating/sleeping/excretion, 3) Poor social skills, 4) Learning problems, 5) Delayed speech/communication problems, 6) Inappropriate/odd repetitive behaviors, 7) Hyperactive and aggressive behaviors

++ Spearman's rho correlation; * $p<0.05$, ** $p<0.01$

Table 4. T-test and one-way ANOVA comparision between dermographic data and Thai Burden Interview Score (n = 51)

Variable	Mean ± SD		*p*-value
Patient's gender		df = 8, t = 0.483	0.643
Male	24.5±11.1		
Female	28.1±20.8		
Function		df = 49, t = 1.715	0.093
Low and moderate	27.6±13.6		
High	21.4±10.8		
Problems			
Inability to perform age-appropriate ADLs		df = 49, t = -1.216	0.230
No	23.0±11.6		
Yes	27.4±14.1		
Difficult in eating/sleeping/excretion		df = 49, t = -0.609	0.546
No	24.2±14.1		
Yes	26.6±10.5		
Poor social skills		df = 49, t = -1.009	0.277
No	22.9±12.3		
Yes	26.9±13.3		
Learning problems		df = 49, t = -1.615	0.113
No	22.9±11.5		
Yes	28.9±14.6		
Speech delay/communication problems		df = 49, t = -2.041	0.047*
No	20.2±12.0		
Yes	27.7±12.8		
Inappropriate/odd repetitive behaviors		df = 49, t = -2.092	0.042*
No	22.8±11.7		
Yes	31.0±14.4		
Hyperactive and aggressive behaviors		df = 49, t = -1.526	0.133
No	21.8±13.0		
Yes	27.3±12.5		
Caregiver's gender		df = 49, t = 0.5	0.645
Male	26.4±12.7		
Female	24.5±13.1		
Marital status		df = 49, t = 0.349	0.729
Single/divorced/widowed	25.6±11.6		
Married	24.5±13.8		
Caregiver's level of education (n = 49)		df = 2, F = 0.434	0.651
Elementary school	24.5±9.8		
High school or equivalent	22.9±17.4		
Bachelor's degree or higher degree	27.1±10.7		
Employment status		df = 49, t = -1.911	0.062
Full-time	21.9±9.8		
Part-time/unemployed	28.6±15.1		
Had someone help taking care of patients			
No	27.1±10.4	df = 49, t = 0.837	0.407
Yes	23.9±14.1		

* $p<0.05$

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(10).

The finding that the longer period after the diagnosis was related to the increased feeling of burden may correspond with the early diagnosis for those with severe disease symptoms with many problems or with problems that bother the caregivers so much that they have to bring the children to the physician early. This rationale is consistent with the above factors on the children part. Alternatively, it may be consistent with the increased years for which the caregivers are required to care for the children; this remains to be further investigated.

However, the present study found no correlation between the presence of help and a decreased feeling of burden. This is inconsistent with the report by Oyebode J(21) that showed that family support helped reduce the feeling of burden. It is noteworthy that the present study questioned about the presence of help, not the caregivers' perception of help as to whether it was adequate. The present study also failed to ask about help in other aspects. Different assessing questions may lead to different results.

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(8) and Oyebode J(21). Caregiver burden(8,10) corresponds with depression psychosocial factors(19), 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 depression and burden are, therefore, related.

Expected benefits and applications

The results of the present research can be used in improving the efficiency of autistic children's caregivers as follows.

1) Give precedence to the promotion of communication and the reduction of deviant or inappropriate behaviors as well as educate caregivers so that they have knowledge, understanding and confidence in the management of problems, thus helping to reduce the caregiver burden.

2) Recommend that the caregivers have their own personal time each day so that they will not feel too burdened by spending too much time with the children.

Research limitations

The results of the present study may not represent all caregivers of autistic children as it only focused on the outpatient department of a general hospital, and most patients involved were in the moderate to high function group. In addition, the study only included the caregivers who actually brought the patients to the hospital and were willing to participate; depressed caregivers and those who feel heavily burdened might not have brought the patients or felt as cooperative.

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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Potential conflicts of interest

None.

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ภาวะซึมเศร้าและความรู้สึกเป็นภาระในผู้ดูแลเด็กออทิสติก

ติรยา เลิศหัตถศิลป์, ธรรมนาถ เจริญบุญ, อิสราภา ชื่นสุวรรณ, พนิดา ศิริอำพันธ์กุล

วัตถุประสงค์: *เพื่อศึกษาภาวะซึมเศร้าและความรู้สึกเป็นภาระในผู้ดูแลผู้ป่วยเด็กออทิสติก*

วัสดุและวิธีการ: *เป็นการศึกษาเชิงพรรณนาแบบภาคตัดขวางในผู้ดูแลผู้ป่วยเด็กออทิสติกโดยใช้แบบสอบถาม ข้อมูลทั่วไปของเด็กและผู้ดูแลร่วมกับแบบประเมินภาวะซึมเศร้า CES-D (Center for Epidemiologic Studies Depression Symptomatology Scale) และแบบวัดภาระในการดูแลของผู้ดูแลผู้ป่วยโรคเรื้อรัง (Thai Burden Interview) ข้อมูลส่วนที่เกี่ยวข้องกับการวินิจฉัยโรคได้จากจิตแพทย์เด็กและกุมารแพทย์พัฒนาการเจ้าของไข้*

ผลการศึกษา: *จากผู้เข้าร่วมวิจัย 51 ราย พบผู้ดูแลเด็กที่มีภาวะซึมเศร้า ร้อยละ 5.9 ในด้านความรู้สึกเป็นภาระของผู้ดูแลพบว่าร้อยละ 45.1 ของผู้ดูแลเด็กรู้สึกว่าเด็กไม่เป็นภาระหรือเป็นภาระน้อย ร้อยละ 45.1 รู้สึกว่าเด็กเป็นภาระน้อยถึงปานกลางร้อยละ 7.8 และ 2.0 รู้สึกว่าเด็กเป็นภาระปานกลางถึงมากและเป็นภาระมากตามลำดับ พบว่าความรู้สึกเป็นภาระในผู้ดูแลที่เพิ่มขึ้นสัมพันธ์กับคะแนนภาวะซึมเศร้าที่เพิ่มขึ้นอย่างมีนัยสำคัญ ($p = 0.012$) นอกจากนี้คะแนนความรู้สึกเป็นภาระที่เพิ่มขึ้นสัมพันธ์กับระยะเวลาหลังจากได้รับการวินิจฉัยโรคที่นานขึ้น เวลาที่ผู้ดูแลใช้ในการดูแลเด็กในแต่ละวันที่เพิ่มขึ้น การที่เด็กมีปัญหาการสื่อสาร เด็กมีปัญหาพฤติกรรมไม่เหมาะสม และจำนวนปัญหาของเด็กที่เพิ่มขึ้น ($p<0.05$)*

สรุป: *การศึกษานี้พบภาวะซึมเศร้าและความรู้สึกเป็นภาระในผู้ดูแลน้อยกว่าการศึกษาที่ผ่านมา โดยปัจจัยหรือพฤติกรรมซ้ำๆ ที่แปลกๆ ที่สัมพันธ์กับคะแนนความรู้สึกเป็นภาระที่เพิ่มขึ้นคือ ระยะเวลาหลังได้รับการวินิจฉัยโรคที่นานขึ้น เวลาที่ผู้ดูแลใช้ในการดูแลเด็กในแต่ละวันที่เพิ่มขึ้น การที่เด็กมีปัญหาการสื่อสาร เด็กมีปัญหาพฤติกรรมไม่เหมาะสมหรือพฤติกรรมซ้ำๆ ที่แปลก และจำนวนปัญหารวมของเด็กที่เพิ่มขึ้น*
