

Alexithymia among Arab mothers of disabled children and its correlation with mood disorders

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ABSTRACT

الأهداف: دراسة أعراض فقد التعبير الانفعالي (أعراض الكسثيميا) لدى أمهات الأطفال المعوقين في المملكة العربية السعودية وبحث فيما إن كان أعراض فقد التعبير الانفعالي مصاحبا لصعوبة المزاج و بعض العوامل الديموغرافية.

الطريقة: أجريت دراسة استطلاعية تتابعية خلال الفترة من يناير 2011م حتى 2012م على 86 أم (يشكلن مجموعة الدراسة) اللواتي يعتنين بأطفال لديهم إعاقة جسمية، أو عقلية، أو حسية والذين يراجعون مستشفى تأهيلي متخصص، الرياض، المملكة العربية السعودية. كما شملت الدراسة أيضا على 32 أم لأطفال أصحاء والتي تشكل (مجموعة الضابطة). استخدم مقياس المستشفى للاكتئاب والقلق لقياس أعراض مزاج الأمهات. كما استخدم مقياس تورنتو-20 لفقد التعبير الانفعالي (الكسثيميا) لتقدير درجة أعراض الكسثيميا. كما تم جمع المعلومات الديموغرافية للأمهات والأطفال.

النتائج: كان متوسط عمر الأطفال المعاقين 5.6 ± 3.1 والأطفال الأصحاء 6.3 ± 3.7 المدى من (1-14) عام. ومعدل عمر الأمهات في مجموعة الدراسة 33.9 ± 6.1 (العدد=86) والمجموعة الضابطة 35.2 ± 7.3 عام. أظهرت الدراسة أن أمهات الأطفال المعاقين لديهن درجة عالية بدلالة إحصائية من أعراض الكسثيميا ($p=0.001$)، ودرجة متوسطة عالية بدلالة إحصائية على مقياس القلق ($p=0.042$) ومقياس الاكتئاب ($p=0.021$). هناك علاقة ارتباطية دالة إحصائية بين درجة الكسثيميا مع درجة اكتئاب الأمهات ($p=0.0001$) وقلق الأمهات ($p=0.0001$). لكن لا توجد أي ارتباطات بين الكسثيميا وعمر الطفل ($p=0.303$)، أو عمر الأم ($p=0.235$)، ومدة الإعاقة ($p=0.0941$).

خاتمة: إن الإمهات اللواتي يعتنين بأطفال معاقين يظهرن أعراض الكسثيميا والذي يرتبط بزيادة مشاكل المزاج. في هذا المقال نناقش علاقة النتائج بالممارسة العيادية.

Objectives: To study alexithymia among mothers with disabled children in Saudi Arabia, and to explore if alexithymia is associated to their mood difficulties, and certain demographic variables.

Methods: We conducted a prospective study during January 2011 to April 2012, on 86 mothers (study group) caring for children with physical, mental, or sensory disabilities treated at a major tertiary rehabilitation hospital in Riyadh, Saudi Arabia. A total of 32 mothers (control group) with healthy children were also included. The Hospital Anxiety and Depression Scale (HADS) was used to measure the mood symptoms of mothers. The Toronto Alexithymia Scale (TAS-20) was administered to assess the degree of alexithymia. The demographic data of mothers and children were also collected.

Results: The mean age of children with a disability was 5.6 ± 3.1 , and for healthy children was 6.3 ± 3.7 (range 1-14) years. The mean age of mothers in the study group ($n=86$) was 33.9 ± 6.1 , and in the control group ($n=32$) was 35.2 ± 7.3 years. Mothers of children with disabilities had a significantly higher degree of alexithymia ($p=0.001$) and a significantly higher mean score of HADS-anxiety ($p=0.042$) and HADS-depression ($p=0.021$). Alexithymia had a significant correlation with mother's depression ($p=0.0001$) and anxiety ($p=0.0001$). No significant correlations were found between alexithymia and child's age ($p=0.303$), duration of disability ($p=0.0941$), and mother's age ($p=0.235$).

Conclusion: Mothers caring for disabled children have higher features of alexithymia, and this is correlated to their elevated mood problems. Clinical implications are discussed.

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Child with a disability may cause stress for parents who have the responsibility of undertaking every day care of such children, often even after their disabled children become adults.¹ The stigma of the disability and the prolonged parental grief of the parents regarding child's limited development and parents' worries about the future of their children with disability, all add to parents' emotional burden.² Naturally, it is expected that such parents with long-term stress caused by caring for disabled child, would have more physical and psychological problems compared with parents of healthy children.^{3,4} The nature of the disability itself is a factor contributing to the challenges faced by such parents of disabled child and the way they cope and deal with it.⁵ Studies reported elevated rates of depressive symptoms and feelings of increased psychological distress have been reported by mothers of children with chronic illness or disabling conditions.⁶

Alexithymia is characterized by difficulty identifying and describing subjective emotions and feelings; difficulty distinguishing between feelings and the bodily sensations of emotional arousal, lack of fantasy, and an externally orientated cognitive style.⁷⁻⁹ Researchers have suggest that these features might be due to a deficit in the cognitive processing of emotions.⁷ It is assumed that such characteristic is developmentally related feature of individual personality. Alexithymia is related positively to neuroticism and depression, anxiety, psychoticism and introversion; and negatively to extraversion and sociability.^{8,10} Studies reported that Alexithymia has been found in many different pathologies: somatoform disorders, alcoholism, drug addiction, posttraumatic stress, asthma, depression, eating disorders, and so on.^{7,11} One relevant study has found that parents of children with autism spectrum disorder (ASD) have higher level of alexithymia, and this was related to higher impairments of children.¹² Few research has been carried out on caregivers (namely, mothers or parents) of disabled children, and we are not aware of -if any-published Arabic data on alexithymia in general or on caregivers either. It is not clear if parents (or specially mothers in our case) could develop alexithymia after they experience the burden of caring for their disabled child. Research is lacking and theoretical issues are not addressee yet. In our previous study, we reported the presence and the degree of mood problems in mothers

with disabled children.¹³ In this present study, we aimed to examine if mothers with disabled children suffer from features of alexithymia and how this might be related to other mood problems. In addition, we would like to see if any demographic variables would be associated with alexithymia.

Methods. We conducted a prospective study during the period of January 2011 to April 2012, in 86 mothers (study group) of children with physical, mental or sensory disabilities treated in a tertiary rehabilitation hospital, Riyadh, Saudi Arabia. The child was classified to have sensory problem if she/he suffers from hearing or vision difficulties. Mental disabilities referred to cognitive/intellectual difficulties (including language problems). Physical disabilities cover all motor problems and impaired activities of daily living (ADL) caused by diseases such as cerebral palsy (CP). The treating consultant (physiatrist) diagnosed all children, and who provided specific diagnoses of children's type of disability. A control sample consisted of 32 mothers (control group) with healthy children. Convenience sampling method was used to select the respondents, who were caring for their children at the hospital.

Inclusion criteria. Mothers of disabled children aged ≥ 1 year and ≤ 14 , those children are considered to have a physical, mental or sensory disability were included in this study. Our data covers children with a number of disabilities, not very homogenous single type of disability. This is partly related to sample size, and to the admission criteria in the hospital. The degree of disability is also varied, but all children of the study sample need hospital rehabilitation.

Exclusion criteria. Mothers with severe or chronic medical conditions (such as stroke, and uncontrolled diabetes mellitus), history of severe psychological disorder, and acute medical condition within the last 12-months were excluded from this study.

The control group was recruited from personal contact (community), were informed that we were conducting a study in the rehab hospital about the impact of the child's illness on families, and that we needed families without physical or psychological pathology as a control group.

Ethical approval. The study was approved by the Research and Ethical Committee of the hospital. Written informed consent was obtained from all mothers. The participation of mothers of hospitalized children is voluntary and the data collected during the study has been handled confidentially.

Measures 1. Mood. The mood symptoms measurements were assessed for the mothers using

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Hospital Anxiety and Depression Scale (HADS),¹⁴ Arabic version. This mood scale is very simple and easy to use by most people with no major language problems, and has no cultural or psychological sensitive questions. In addition, it is known to have a very high validity and reliability. The HADS consists of 7 items for anxiety (HADS-A) and 7 for depression (HADS-D). The items were scored on a 4-point scale from zero (not present) to 3 (considerable). The item scores are added, giving sub-scale scores on the HADS-anxiety and the HADS-depression from 0-21 each.¹⁴

2. Alexithymia. The 20-item Toronto Alexithymia Scale (TAS-20) was developed more than a decade ago and become the most widely used instrument for assessing alexithymia in both research and clinical practice.^{7,12} Over the years, there has been an accumulation of evidence that the scale is reliable and valid. A 20-item self-report scale that has 3 factors: Factor 1 = difficulty in identifying feelings; Factor 2 = difficulty in describing feelings to others; and Factor 3 = externally orientated thinkings were found in many studies.^{7,15} The cut-off score of 60 reported by Taylor et al¹⁶ was used. The normal procedure of translation and the back translation was carried out and showed very good similarities to the original English version. This was carried out by 2 Arabic speaking psychologists with postgraduate training and degrees in psychology, one with a PhD (Hathab AA) and another with a Master degree. Back translation was carried out by one of the authors (Muwafak H). A small study of

reliability of the scale was carried out on 10 mothers. The scale has showed reasonable reliability degree on repeated measure (Chronbach =0.73).

3. Demographic data. The demographic data of mothers covered the following: age, marital status, level of education, family income, mother's employment, and numbers of children (both with and without disabilities).

Statistical analyses. All the data were analyzed using the Microsoft Excel 2002 (Microsoft Corporation, Seattle, WA) and Statistical Package for Social Sciences Version 16 (SPSS Inc, Chicago, IL). The demographic of mothers of disabled children and demographic data of disabled children are presented as numbers as well as percentage, whereas the Anxiety, Depression and total HADS data presented as mean \pm SD. Student's *t* test and Pearson's correlations also performed. *P*-values less than 0.05 were taken as statistically significant together with the 95% confidence interval.

Results. The mother's (both study and control samples) demographic data (marital status, level of education, nationality, income, employment, number of children, and social status) are shown in Table 1. The mean age of children with disability (study sample) was 5.6 \pm 3.1 and healthy children (control) 6.3 \pm 3.7 (range 1-14) years. There were no significant differences in age of disabled and healthy children (*p*>0.05). The mean age of mothers in the study group (n=86) was 33.9 \pm 6.1 and the control group (n=32) was 35.2 \pm 7.3 years. There

Table 1 - Demographic data of mothers of disabled children and control mothers.

Variables	Study group (n=86)		Control group (n=32)	
Gender				
Male	53	(61.6)	20	(62.5)
Female	33	(38.4)	12	(37.5)
Level of education				
None	8	(9.3)	3	(9.8)
Primary	1	(1.2)	3	(9.37)
Intermediate	14	(16.3)	4	(12.5)
High school	22	(25.6)	12	(37.5)
University and above	41	(47.7)	10	(31.3)
Nationality				
Saudi	74	(86)	27	(84.4)
Non-Saudi	12	(14)	5	(15.6)
Monthly income				
SR <5000	47	(54.7)	23	(71.9)
SR 5000-9000	25	(29.1)	4	(12.5)
SR \geq 10000	14	(16.3)	5	(15.6)
Number of children				
1	13	(15.1)	6	(18.7)
2	4	(4.7)	3	(9.4)
>2	69	(80.2)	23	(71.9)
Number of disabled children				
1	74	(86)	-	
\geq 2	12	(14)	-	

Data are expressed as number and percentage (%)

Table 2 - Demographics of children with disabilities (N=86).

Variables	Study subject n (%)	
Type of disability		
Physical	57	(66.3)
Mental	10	(11.6)
Physical + mental	9	(10.5)
Physical + sensory	2	(2.3)
Mental + sensory	1	(1.1)
Physical + mental + sensory	4	(4.7)
Sensory	3	(3.5)
Permanent disability		
Yes	64	(74.4)
No	22	(25.6)
Duration of child disability		
0-4 years	51	(59.3)
5-7 years	18	(20.9)
\geq 8 years	17	(19.8)
Help needed for daily activities		
Yes	77	(89.5)
No	9	(10.5)
Child needs help for		
Single activity	19	(22.1)
\geq 2-3 activities	10	(11.6)
> 3 activities	40	(46.5)
All activities	17	(19.8)

Data are expressed as number and percentage (%)

Table 3 - Differences between study group and control on child's age, mother's age, depression, and anxiety.

Variables	Study group (mean±SD)	Control (mean±SD)	P value
Child age	5.60 ± 3.14	6.3 ± 3.7	Not significant
Mother age	33.9 ± 6.1	35.2 ± 7.3	Not significant
Depression	7.19 ± 3.56	6.28 ± 4.3	0.021
Anxiety	8.9 ± 4.1	7.3 ± 3.4	0.042

Groups compared by t-test: *p*-values <0.05 were taken as statistically significant (95% confidence interval)

Table 4 - Correlation of alexithymia, depression, anxiety and age variables in the study group

Variables	Alexithymia	Anxiety	Depression	Child's age	Mother's age	Duration
<i>Alexithymia</i>	1					
<i>P</i> -value						
<i>df</i>						
<i>Anxiety</i>	0.391	1				
<i>P</i> -value	0.000					
<i>df</i>	84					
<i>Depression</i>	0.351	0.682	1			
<i>P</i> -value	0.000	0.000				
<i>df</i>	84	84				
<i>Child age</i>	0.116	-0.81	-0.03	1		
<i>P</i> -value	0.303	0.463	0.980			
<i>df</i>	84	84	84			
<i>Mother age</i>	0.119	-0.243	-0.125	0.437	1	
<i>P</i> -value	0.235	0.012	0.201	0.00		
<i>df</i>	84	84	84	84		
<i>Duration</i>	0.008	-0.14	0.143	0.732	0.312	1
<i>P</i> -value	0.941	0.904	0.200	0.000	0.004	
<i>df</i>	84	84	84	84	84	

Pearson's correlations: *p*-values <0.05 were taken as statistically significant (95% confidence interval)

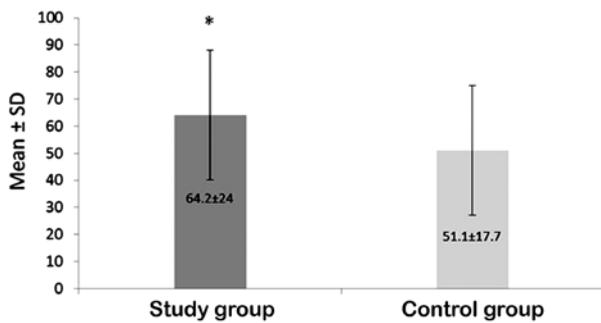


Figure 1 - The difference in the occurrence of alexithymia among Arab mothers of disabled children compared with controls. **p*=0.001 study group versus control

were no significant differences between the study and control groups in terms of mother's age either (*p*>0.05).

Type and characteristics of disabilities among children with disabilities are shown in Table 2. The anxiety and depression scores of mothers (study and control sample) are shown in Table 3. Mothers of children with disabilities had significantly higher score of HADS-anxiety (*p*=0.042) and HADS-depression

(*p*=0.021) as compared to mothers of control group. The comparison of alexithymia data (TAS-20) between control mother and study group is shown in Figure 1. The results show that mothers of disabled children had significantly higher (*p*=0.001) degree of alexithymia than control mothers. The correlation of alexithymia, anxiety, depression, child age, mother age, duration of disability are shown in Table 4. The alexithymia had significant correlation with mother's depression (*p*=0.0001) and anxiety (*p*=0.0001). However, there were no significant correlations found between alexithymia and child age (*p*=0.303), duration of disability (*p*=0.0941) and mothers' age (*p*=0.235).

Table 4 also shows some interesting correlation between the age of mothers and their anxiety. We are not certain why mother's age is correlated to anxiety, but may be mothers over the years have become more worried about the lack of improvement of their child disability despite many interventions.

Discussion. With the birth of a disabled child, parents experience a complex feeling that resembles the

feeling of losing someone beloved.¹⁷ The reaction to a loss has patterns of shock, denial, bargaining, depression, and acceptance-adjustment in adults.¹⁸ Daily care routine, economic problems, receiving appropriate help and education are the basic hardships of the parents of a disabled child. Diagnostic misperceptions, behavioral and health problems, and feeling of loneliness in parents also add to these difficulties.^{19,20} The more the child is disabled the more she/he becomes dependent on parents and hence, parents will experience more mood and anxiety problems as well as burden.²¹ Studies showed that the parents of a child with autism experienced higher anxiety due to social development impairment, delay or absence of speech development, stereo-typic movements, hyperactivity, and lack of eye contact.²²⁻²⁴ The mothers of autistic children were reported to be more introverted and neurotic than the normal control group²⁵ and the parents of children with autism and down's syndrome were reported to be overanxious, oversensitive, stern in manner, and sensitive to be frustrated with criticism.²⁶ Research on parents of disabled children has shown that most mothers have clinical signs of depression on assessment.²⁷ We found in a previous study on sample of Saudi mothers of disabled children that those mothers have mood problems compared with controls.¹³ In this present study, we also found that mothers with disabled children reported more anxiety and depression as compared to control mothers. This is a replication data on similar sample to indicate the presence of a degree of depression and anxiety among mothers who care for a disabled child. Our current data have explored if those mother also have a problems of alexithymia. Alexithymia and depression have been examined and found to be a separate psychological presentation²⁸ and not the same psychological problem.

The main question of this study was whether mothers of disabled children show features of alexithymia. The study found that when compared to control mother, mothers with disabled children showed significantly higher alexithymia score on the TAS-20 (Arabic). Further, alexithymia is significantly correlated with anxiety, and depression, independently. Here, we can assume that mothers have difficulties with mood and emotion in general as indicated. Further, they seem to have problems dealing with emotion or expressing them. We think that this problem of alexithymia (difficulties in handling emotion) would put further pressure and stress on mothers. This should be explored in future research. However, alexithymia was not correlated with child age and mother age. This is not surprising since burden of caring is indicated in other studies regardless of disability.^{2,5,21} The strong point of the study is that it

is the first time we examine the concept of alexithymia in Arabic population and particularly in mothers with disabled children. The second question was related to the notion that alexithymia might also show correlation to mood problems. This is also a positive result confirming our clinical observation. The current study may also add to this debate. One important theoretical question the present study may raise is that certain stress or negative emotion may cause one to develop alexithymia or alexithymia-like features. By that we mean that those people with a burden can develop significant difficulties dealing and handling their own emotions. Simply put, the mothers with disabled children developed alexithymia (and mood problems) after their experience with caring for disabled children, which it is in itself a stressful experience. If it is the case then we have to consider the concept from a new and different stand point of view. It has been highlighted above that theoretically, it has been suggested that the origin of the problems related to early developmental problems in emotional development and related to attachment. In this study, we found that mothers with disabled children show alexithymia presumably not acquired prior to their caring for children with disability (as compared with mothers with healthy children).

Study limitations. The study needs to improve on the scale validity and has better norms before final conclusion to be made. The study may have slightly smaller controls. In addition, the study may need to validate alexithymia with other psychosomatic features as indicated in the early research development. Alexithymia measure is a self-report and this may limit our understanding of the problem, but it has been suggested that this is also the best way to examine one's emotion and their perception of it.

Further research should examine more specifically the type of disability and the level of alexithymia. Moreover, it would help to see on a big sample at what stage (early years, or late years of caring for their disabled child, for example) mothers show higher degree of alexithymia and mood problems. Here, we can provide time-sensitive psychological support. Further, we need to examine mothers caring for children with other chronic disease and to see if they have similar problems of alexithymia.

If we have good understanding of the way and the nature of mood and emotional difficulties (alexithymia) experienced by parents, (particularly mothers) and caregivers, then we could have better clinical and rehab services for those families. This would be of value because they are the key figures caring for the patients.

It would also help to improve the quality of life of children and their parents.

In conclusion, the findings of this study indicated that mothers of disabled children show features of alexithymia, anxiety, and depression compared to their counterpart. Our findings suggest that more attention needed to consider mothers' psychological status, to enable them to support and improve rehabilitation strategies at home. Future research on similar population will consider their coping and the stress that they may go through due to the burden of caring for a child with disability. Clinical and administration recourses have to be placed for such mothers.

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