# Depression among Parents of Children with Chronic and Disabling Disease

H. Ashkani, Gh. R. Dehbozorgi, A. Tahamtan.

# Abstract

**Background:** The parent's awareness about chronic disabling disease in their children definitely distresses the parents. Children of such parents show behavior & cognitive disturbances with long term negative impact on the family.

**Objective:** The present study was carried out to investigate the prevalence of depression in parents of disabled children.

**Methods:** Following a cross-sectional study, 50 parents of children with chronic disease as target group & 50 parents of children with an acute disease as control group were selected randomly, they were asked to take part in a structured interview & their depression's score was measured using the Beck Depression Inventory (BDI). Data analysis was performed by Student's t test and ANOVA using SPSS software.

**Results:** Depression scores were higher in those who had a child with chronic disease than in the control group (P<0.001). Depression scores were also higher in those who had a leukemic child than other non-leukemic chronic disease (P<0.002). Lower socioeconomic (SES) & parents with lower education level also showed a higher level of depression.

**Conclusion:** When comparing psychopathology in parents of children with chronic disease with that of children with an acute disease, significant differences were observed in depression level. This study emphasizes the necessity of active psychosocial intervention in those parents who have disabled children.

Iran J Med Sci 2004; 29(2):90-93.

**Keywords** • Depression • children • parents • chronic disease• disabling disease

#### Introduction

ny chronic illness might cause a heavy impact on family members. The consequences of chronic childhood diseases are much more pronounced in disturbing the mental health of parents of these children.<sup>1,2</sup> Both patients and parents have to deal not only with their child disease but also should stand with the prolonged therapy schedule which could be as distressing as the disease itself.

Depression is one of the common mood disorders. It is a potentially lethal but highly treatable condition.<sup>3</sup> Suicide is the essential feature of depressive disorders that associates with increased mortality.<sup>4</sup>

Department of Psychiatry, Shiraz University of Medical Sciences, Shiraz, Iran.

Correspondence: H. Ashkani M.D, Department of Psychiatry, Shiraz University of Medical Sciences, Shiraz, Iran Tel: +98 711 6279319 E-mail: psychiat@sums.ac.ir

#### H. Ashkani, Gh. R. Dehbozorgi, A. Tahamtan.

Characteristics		Chronically ill		Acutely ill	
Characteristics		No.	(%)	No.	(%)
Sex of Parent	Male	21	42%	22	44%
	Female	29	58%	28	56%
Sex of Child	Male	28	56%	28	56%
	Female	22	44%	22	44%
Socioeconomic	Low SES	17	34%	11	22%
status (SES)	Relatively good SES	33	66%	39	78%
Education of	Less than high school diploma	32	64%	28	56%
Parent	High school diploma & over	18	36%	22	44%
Age of Parents	<20 years	1	2%	1	2%
	20-40 years	44	88%	47	94%
	>40 years	5	10%	2	4%

Several studies have shown that depressive disorders are more common among the parents of children with chronic disease than normal population,<sup>1,5,6</sup> and that the parents' psychological disorders can affect other siblings thalassemia, leukemia and congenital heart disease are not uncommon in our region. This study was conducted to assess the prevalence of depressive disorders among parents of children with chronic diseases of childhood such as thalassemia major, leukemia, or congenital heart disease.

### **Patients and Methods**

In a cross-sectional study, 50 parents (21 fathers and 29 mothers) whose children suffered from either thalassemia major, leukemia, or congenital heart disease were assessed for presence of depression. The affected children were selected through a simple random sampling of those children who were admitted to Shiraz University affiliated hospitals between September and November 2001.

A comparison group consisting of 50 parents (22 fathers and 28 mothers) whose children had acute diseases (e.g., common cold, gastroenteritis, or fever and febrile convulsion) who had attended the emergency departments of the same hospitals during the study period was also assessed for presence of depression.

Assessment of parents in both groups was done through a one-hour semi-structured interview with one of the parents selected at random in the hospital.

Parent of patients completed the Beck Depression Interventory (BDI).<sup>8</sup> A raw score of 19, corresponding to moderate depression, was chosen as the clinical cutoff point.<sup>8</sup>

Data analysis was performed by Student's *t test* and one-way ANOVA using SPSS software.

## Results

Demographic characteristics of both groups

are shown in Table 1. Parents of children with chronic disease had a significantly (p<0.001) higher mean± SD BDI score (27.1±13.1) than parents of those with acute disease (14.6±8.2). Furthermore, parents of those children with more serious chronic diseases such as leukemia had a significantly higher BDI score than parents of children with less severe diseases like thalassemia or congenital heart disease (Table 2).

# Discussion

This study demonstrated that depression is higher in parents whose children are suffering from chronic and disabling diseases. Like many previous reports,<sup>5,10,11</sup> in this

Like many previous reports,<sup>5,10,11</sup> in this study we employed BDI to determine the level of depression. Originally developed in 1961, it has become one of the most frequently used scales of depression in clinical and research settings. BDI is a 21-item self-report questionnaire designed to assess symptoms of depression in adolescents and adults. Items are rated on a 4-point scale from 0 to 3 in terms of their severity. The revised BDI has a high internal consistency for both psychiatric and non-psychiatric subjects.<sup>8</sup> BDI has also an adequate ability to discriminate between normal, depressed and medical subjects.<sup>9</sup>

In this study, although none of the children but those of comparison group, had acute symptoms at the time of evaluation, none of the parents were normal and all had degrees of depression. This is probably originated from their awareness of the disease,<sup>12</sup> as shown by comparing the level of depression among the parents of leukemic children with those of nonleukemic diseases (i.e., thalassemia and congenital heart disease). The parents of leukemic children as a whole appear to be more prone to develop psychological distress than those of non-leukemic chronically ill children. This finding is in accordance with the results found in other studies.<sup>1,2-14</sup>

Table 2: Mean±SD scores of BDI of parents of children with chronic disease and control groups							
	Educ						
	Less than	High school	р				
	high school	or above					
Chronically ill	29.5±12.2	22.8±14.0	0.08				
Acutely ill	17.3±8.5	11.2±6.6	0.008				

Parents with lower socio-economic status exhibited more depression that may be attributed to their constant long-term financial needs to meet the demands of expensive prolonged treatment needed for these patients. This finding is in keeping with what reported from other studies which also showed greater depression scores among lower socioeconomic groups.<sup>15,16</sup>

In the interviews performed with the parents, a vast majority of parents blamed ill fate and many of them believed that only God could help the child; a belief that can be interpreted as a defense that most of people in our culture who believes in God normally resort to.

The mechanism used by parents for coping with the burden of caring a disabling chronically ill patient were mainly religious and psychological in origin and are among usual mechanisms adopted in Iranian culture.

As a conclusion, skilled counseling the pediatrician in addition to his/her diagnostic and management skills may influence the ongoing care of the child. Implications for health professionals include a need for thorough psychological assessment of the affected children and parents. Another study showed positive changes on the coping and the hopelessness measures in the parents of leukemic children on the benefits of integrating a psychosocial program in the pediatric oncology ward.<sup>21</sup>

It is apparent from the findings of this study that morbidity in chronic childhood disease is not merely related to the disease process itself but there is significant psychosocial morbidity in the patients and their families affecting their overall adjustment.

Inclusion of all psychological and social management in the comprehensive treatment plan for parents will certainly enhance the quality of survival of these ill children as well as a better quality of life for their parents and siblings.

Furthermore, it is suggested that psychiatrists should recognize the factors of parental depression.

The present study is limited to parents of children with either leukemia, thalassemia or congenital heart disease and thereby, given the differences in models of depression demonstrated between different groups, further generalization of findings would be questionable.

### Acknowledgement

The authors would like to express their appreciation to all parents and personnel of the hospitals for their helps and supports.

# Reference

- 1 Rao G P, Malhotra s, et al: Psychological study of leukemic children and their parents. *Indian pediatric 1992;* **29**: 985-90.
- 2 Binglar CM, Feuerstein R C, et al: Childhood leukemia emotional impacts on patent and family. *New England Journal of Medicine 1964;* 280: 414-8.
- Kaplan IH, Sadock JE: Pocket Hand book of clinical psychiatry. Third edition 2001; 10: 128-49.
- 4 Tasman A, Kay J, et al: Text book of psychiatry *1997;* **2**: 1019- 90.
- 5 Raymond K M, Diane LF, et al: Maternal Depression, Assessment Methods, & physical symptoms Affect Estimates of Depressive Symptomatology Among Children with cancer. J pediatr psychol 1999; 17: 313-26.
- 6 Rona RJ, Smeeton NC, et al: Anxiety and Depression in mothers related to severe malformation of the heart of the child and fetus. *Acta pediatr 1998;* **87**: 201-5.
- 7 Fisman. S, Wolf L, et al: A longitudinal study of sibliags of children with chronic disabilities. *Can J Psychiatr 2000;* **45**: 369-75.
- 8 Beck A & Steer R A: The Beck depression interventory manual. San Antonio. Psychological Corp. 1987.
- Beck A T, Steer R A, et al: Psychometric properties of the Beck depression inventory: Twenty five years of evaluation. *Clinical psychology review 1988;* 8: 77-100.
- 10 Tebbi C, Bromberg C, et al: Self reported depression in adolescent cancer patients. *American Journal of Pediatr Hematol oncol* 1988; 10: 185-90.
- 11 Hammen c, Adrian C: Children of depressed mothers: Maternal strain & symptoms predictors of dysfunction. *J abnormal psychiatr 1987;* **96**: 190-198.
- Labbe E E: Emotional states and perceived family functioning of caregivers of chronically ill children. *Psychol Rep 1996;* **79**: 1233-4.
- 13 Hokstra Weebers J E, Jaspers J P, et al: Gender Difference in psychological adoptation and coping in parents of pediatric cancer patients. *Psychol oncol 1998;* 7:26-

H. Ashkani, Gh. R. Dehbozorgi, A. Tahamtan.

36.

- 14 Kovacs M, Lyengar S, et al. Psychological functioning of children with insulindependent diabetes mellitus: A longitudinal study. *J pediatr psychol 1990;* **15**: 619-32.
- 15 Seguin L, Fotvin L, et al: Depressive Symptoms in the late postpartum among low socio-economic status women. *Birth* 1999; **26**: 157-63.
- 16 Daniels D, moos R H, et al: Psychological risk and resistance factors among children with chronic illness, healthy siblings, & health controls. *J Abnormal child psychol 1987;* **15**: 295-308.
- 17 Beeri M, Haramati Z, et al: Parental knowledge and views of pediatric congenital beart disease. *Isr Med Assoc J. 2001;* **3**:

194-7.

- 18 Brown R T, Kaslow, et al: Parental psychopathology and children's adjustment to leukemia. *J Am acad child Adolesc psy-chiatr 1993;* 32: 554-61.
- 19 Menahem S: Counselling sterategies for parents of infants with congental heart disease. *Cardiolol-Young 1998;* 8: 400-7.
- 20 Wills B S: The experience of Hong Kong Chinese parent of children with acute lymphocytic leukemia. *J Pedia Nurs 1999;* **14**: 231-8.
- 21 Macher- licht B, Rajalingam V, et al: Childhood leukemia: towards an integrated psychological intervention programme in Singapore. *Ann Acad Med Sigapore 1998;* 27: 485-90.