Depression among Parents of Children with Chronic and Disabling Disease

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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.


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

Introduction

Any 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.12 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.3 Suicide is the essential feature of depressive disorders that associates with increased mortality.4
Several studies have shown that depressive disorders are more common among the parents of children with chronic disease than normal population,1,5,6 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 convolution) 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).8 A raw score of 19, corresponding to moderate depression, was chosen as the clinical cutoff point.8

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,5,10,11 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.8 BDI has also an adequate ability to discriminate between normal, depressed and medical subjects.9

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,12 as shown by comparing the level of depression among the parents of leukemic children with those of non-leukemic 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.1,2,14
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.\(^{15,16}\)

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.\(^2^1\)

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.

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**Reference**


