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An examination of the symptoms of anxiety and parental attitude in children with hemophilia

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Background/aim: Hemophilia is an inherited disease with serious repercussions. Psychiatric symptoms are frequently seen in children and adolescents with hemophilia. The aim of this study was to assess symptoms of anxiety in children with hemophilia and parental attitude towards children with hemophilia.

Materials and methods: 42 boys were assessed according to child and adolescent psychiatry. Anxiety symptoms and parental attitude were obtained by the State-Trait Anxiety Scale, the Self-Report for Childhood Anxiety Related Disorders (SCARED) and the Parent Attitude Research Instrument (PARI).

Results: The mean age was 11.6 ± 2.5 (range; 7–16). State anxiety scores (44.02 ± 6.9) were higher than trait anxiety scores (32.7 ± 7.5). The most interesting results were high scores related to overprotective mothering (47.9 ± 9.7) and the application of strict discipline (39.4 ± 9.1). The total SCARED scores obtained were (23.25 ± 11.3).

Conclusion: Assuring a high quality of life is important for children and adolescents with chronic illness. Quality of life is negatively affected by psychiatric symptoms (e.g. anxiety symptoms, depression, intra-familial stress symptoms) in children with hemophilia. This study suggests that high anxiety scores and problems related to parental attitude can be seen in children and adolescents with hemophilia. These problems caused by parental attitude and anxiety symptoms should be considered in the treatment of hemophilia.

Key words: hemophilia, child, psychiatry, family, psychology

1. Introduction

Hemophilia is a hereditary bleeding disorder that is due to defective and/or deficient coagulative factors. The clinical manifestations of hemophilia A and B, due to deficiency of factor VIII and IX respectively, are clinically indistinguishable and occur in mild, moderate and severe forms (1). Hemophilia is quite rarely seen - about 1 in 10,000 people. Mortality in individuals with hemophilia has been decreasing for ten years due to successful prophylactic treatment. The long term effects are bleeding, severe arthropathy, muscle damage, immobility and decreased quality of life. Some patients are hospitalized frequently and it affects their lives; especially children's education and social life can be affected by these hospitalizations. In addition, other problems such as high cost of prophylaxis and family distress are experienced in families with children with hemophilia during the treatment.

Hemophilia and its impact on life has been researched for the past ten years (2,3). Quality of life in patients with hemophilia can be damaged by the consequences of this illness because of its important symptoms. Patients with hemophilia can enter a downward spiral. HRQoL (Health related quality of life) studies had been done in some cases with chronic illness. These studies assessed health related quality of life in children with hemophilia (4,5). They conclude that hemophilia and its treatment affect HRQoL. They emphasized that prophylaxis is preferable to on-demand therapy (5). HRQoL may be better for hemophilia patients treated prophylactically.

Living with hemophilia causes a number of daily and long-term challenges for patients and their families. The first aspect of problems in patients with hemophilia is a decrease of HRQoL. The second aspect is the development of some psychosocial problems. Overtime some psychiatric symptoms can be seen in children with

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hemophilia. Depression in children with hemophilia was found to be significantly higher than in the healthy control group. Mothers of children with hemophilia were found to be more depressive and anxious (6).

Hemophilia and its long-term psychological effects is a very important issue. But there are not enough studies on the psychological consequences of hemophilia. Hemophilia being a rare inherited disease, psychiatric symptoms are frequently seen in children and adolescents. The aim of this study was to assess symptoms of anxiety and parental attitude in children with hemophilia.

2. Materials and methods

2.1. Participants

Forty-two male patients between the ages of 7 and 16 diagnosed and followed as hemophiliac (hemophilia A) by the Hemophilia Society of Turkey were mentally assessed by child and adolescent psychiatrists. Mothers of these individuals were also included in the study. Informed consent was obtained from both parents and children.

2.2. Measurements

Assessments of anxiety symptoms and parental attitude were obtained by the State-Trait Anxiety Scale (STAI), the Self-Report for Childhood Anxiety Related Disorders (SCARED) and the Parental Attitude Research Instrument (PARI).

SCARED is a self-report questionnaire that measures symptoms of DSM-IV linked anxiety disorders in children. A total score of ≥ 25 may indicate the presence of an Anxiety Disorder. Score of ≥ 30 is considered more clinically significant (7). This questionnaire was filled in by parents and children with hemophilia.

The Parental Attitude Research Instrument (PARI) is a very important assessment tool for parent attitudes. This instrument assesses maternal attitudes and mothering behavior. There are 60 items and 5 subscales in PARI. Subscales include overprotective mothering, democratic attitude and equality, rejection of homemaking role, marital conflict, and strict discipline (8). The validity and reliability study was done by LeCompte et al. (9).

STAI (Spielberger CD. 1973) is a self-reported anxiety instrument used with parents. It is considered the most reliable standard for anxiety evaluation. It contains two separate 20-item subscales that measure trait (baseline) and state(situational) anxiety. The STAI - state scale assesses to anxiety states (10). The validity and reliability study was done by Öner and Le Compte (11). On this scale, 40 points and above demonstrates significant levels of stress.

2.3. Statistical analysis

All of the findings were assessed by SPSS 15.0 for Windows program. Pearson Correlation test and t test (one sample test) were used for statistical analysis. Also, frequency of

sample and other measurements were arrived at by this program.

3. Results

In this study 42 child and adolescents were assessed. All of the patients were male because of the nature of the inherited disease. The mean age was 11.6 ± 2.5 years (range; 7 – 16). The mean age of mothers was 43.02 ± 7.4 (range;30–65). Patients had different socioeconomic status. 27.9 percent (n = 12) had a low level of socioeconomic status. 51.2 percent (n = 22) had middle and 18.6 (n = 8) had a high level of socioeconomic status. Two families were living in rural areas.

STAI scores were obtained from STAI scales. State anxiety scores (44.02 ± 6.9) were higher than trait anxiety scores (32.7 ± 7.5). The correlations are assessed between age and STAI scores. There was positive correlation between age and state anxiety score ($P < 0.001$ r : 0,592). There was no correlation between age and trait anxiety scores.

The most interesting results were high scores concerning the tendency to overprotection in mothers (47.9 ± 9.7) and demonstration of strict discipline (39.4 ± 9.1). All of the PARI subscale scores obtained are shown (Figure 1).

Correlations among PARI subscores were obtained. There were positive correlations between overprotective mothering and marital conflict ($P < 0.001$ r : 0,713). Also, another positive correlation was obtained between marital conflict and strict discipline ($P < 0.001$ r : 672).

Total SCARED scores were obtained (23.25 ± 11.3). Fifteen mothers showed significant anxiety disorder according to SCARED total scores (scores of ≥ 25). Sixteen children with hemophilia showed significant anxiety scores considering SCARED total scores. These findings are presented in figure 2.

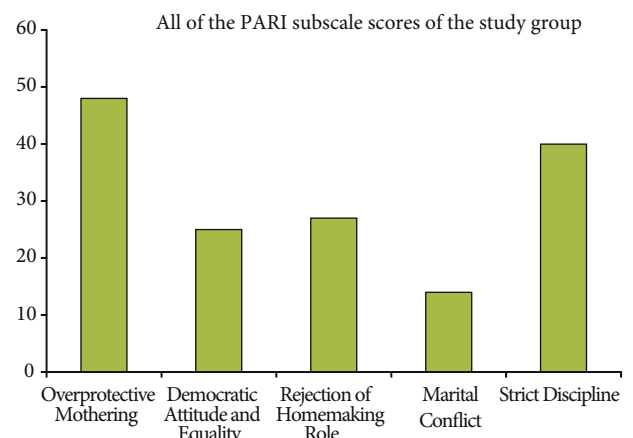


Figure 1. All of the PARI subscale scores of the study group.

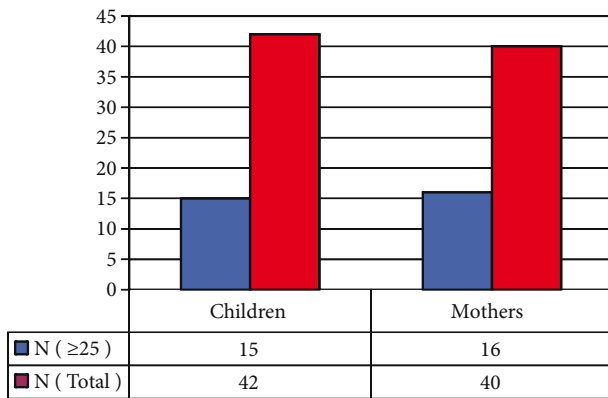


Figure 2. Children and mothers anxiety scores.

4. Discussion

Quality of life is important in children and adolescents with chronic illness (12). Ozturk and his colleagues found that depression scores in children with hemophilia were significantly higher than the control group. Somatic symptoms and hostility subscale scores were also significantly higher in comparison to the control group (6). Hassan et al. conducted a cross-sectional study that was carried out on 50 adolescent hemophilia A patients. He found that 34 of patients had depressive symptoms (13). Another study examined the depression, anxiety and suicidal behavior in children and adolescents with hemophilia. It suggested that the rate of major depressive disorder was 6.0%. The proportion of patients with suicidal tendencies was very high (14). There have been varying results concerning depression rates in patients with hemophilia due to the depression scales used. In addition, all of studies similarly concluded that depressive symptoms are commonly seen in patients with hemophilia. Quality of life is negatively affected by psychiatric symptoms (e.g. anxiety, depression, intra familial stress) in children with hemophilia. According to our results, anxiety levels of individuals with hemophilia were rated as high. Anxiety is also correlated with suicidal ideation. Suicide is common in children with severe depression and anxiety. However all anxiety problems aren't seen as a suicide risk. The risk of suicide is increased by these symptoms in patients with hemophilia. Quality of life and anxiety level should be considered by clinicians during treatment.

The high financial cost of hemophilia and poor self-image that results from hemarthropathy is an important concern for patients with hemophilia (15). Hemarthropathy can be prevented by factor prophylaxis in children with hemophilia. Especially adolescents can be more negatively affected by hemarthropathy due to their age related psychological condition. We found that there was a positive correlation between age and state anxiety points. This result indicates that the child's age is important

for awareness of the illness. If hemophiliac children receive psycho - education concerning their illness and its long term effects, it can be useful in alleviating anxiety symptoms.

Blood disorders may be caused by HIV or/and other viral infection such as HCV and HBV during blood transfer. Mothers learning of the presence of HIV infection in their children and adolescents are significantly affected by psychological stress (16). There were no boys with HIV in the sample because none of the boys registered at the clinic are HIV positive.

Evans et al. examined the emotional and behavioral problems and family functioning in children with hemophilia. In this study more emotional, behavioral and family functioning problems were revealed in the hemophilia group when compared with the healthy group; however, the differences did not reach statistical significance (17). Madden et al interviewed 24 mothers of sons with hemophilia aged between 3 and 18 years. Maternal responses varied from acceptance to severe psychological distress. They found that fears about the medical consequences of hemophilia were more common in mothers (18). Our results show that there were very clear correlations among family functioning scores. Especially, strict discipline and an overprotective maternal attitude could be seen in these families. Hemophilic children can suffer as a result of this parental attitude. In our study mothers were found to be overprotective; fear of bleeding makes the family keep the child at home to avoid risk of trauma. This study suggested that high anxiety scores and parental attitude problems can readily be seen to effect children and adolescents with hemophilia. Thus, parental attitude problems and anxiety symptoms should be considered in the treatment of hemophilia.

Transition from pediatric services to adult health care facilities is a very important problem for patients with hemophilia. It appears to have a stronger impact on parents of patients with hemophilia than on the patients themselves (19). But our patients have not undergone this transition to adult health care facilities.

Some limitations were faced in this study. Firstly, there was no control group in our study. Secondly, no circumcision history could be obtained for our population. Thirdly, we did not use the CBCL (Child Behavior Checklist) that is a tool assessing general psychopathology.

In conclusion, our results demonstrate the need for further studies concerning psychiatric and family conditions in children with hemophilia. Most significantly, our study reminds that psychiatric factors must not be ignored in the treatment of children and adolescents with hemophilia. Moreover, those working with such patients must be sensitive to the warning signs of deeper psychiatric problems so that these may be addressed in a timely manner. In this study we did not aim to effect psychiatric diagnosis. It can be evaluated in future studies.

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