

Analysis of the selected psychosocial aspects in families with hemophilia

ABSTRACT

Hemophilia is a rare genetic bleeding disorder caused by deficiency of coagulation factor VIII or IX. Individuals with severe hemophilia experience frequent bleedings, often internal or into joints, leading to joint damage. Hemophilia is treated with a replacement therapy wherein the patients receive coagulation factor. Replacement therapy can be either administered at the time of bleeding (on-demand) or on regular bases multiple times per week to prevent bleeding (prophylaxis).

The study group consists of groups of adolescents with hemophilia (N = 31), parents of at least one child with hemophilia (N = 76) and parents of healthy children (N = 63). Questionnaires assessing demographic background, the course of illness, and prophylaxis adherence of replacement were given to both hemophilia patients and parents. Additionally, children with hemophilia were given Haemo-QoL and Child Attitude Toward Illness Scale. Parents of both ill and healthy children were administered Parental Attitudes Scale and General Self Efficacy Scale.

According to the outcomes:

1. Mothers of hemophiliac pediatric patients tend to be more engaged with their illness and treatment than fathers.
2. Only 16% of children with hemophilia administer prophylaxis treatment by themselves. Others usually get it with help from mothers.
3. General health-related quality of life was rated rather high amongst children with hemophilia and comparable to other research with Haemo-QoL questionnaire. "Friends" and "school and sport" were rated as the lowest dimensions while "treatment" and "feelings toward illness" as the highest dimensions of health related quality of life.
4. Boys with hemophilia have overall positive or moderately positive attitude toward their illness which is comparable with other studies on children with chronic illness.
5. Positive attitude toward hemophilia is related to following dimensions of quality of life: "physical health", "view on yourself", "treatment" and "school and sport".

6. Parents of children with hemophilia tend to be more overprotective than parents of healthy children. Also parents of hemophiliacs scored higher on acceptance scale but lower on parental autonomy attitude than parents of healthy children.
7. There were significant differences among mothers and fathers of children with hemophilia in terms of parenting attitudes. Mothers were more overprotective and scored higher on acceptance than fathers.
8. Parenting attitudes are related neither to quality of life nor attitude toward illness of children with hemophilia.
9. Hemophilia is not related with parental general self-efficacy although mothers scored lower on self-efficacy scale than fathers.
10. Parental self-efficacy is positively related to overprotective parenting attitude and negatively to inconsistent parenting attitude.