THE EFFECTS OF CHILDREN WITH INHERITED METABOLIC DISEASES ON PARENTS

Selda Bülbül, Aliye Gülbahçe

Kırkkale University Department of Pediatric Nutrition And Metabolism

Introduction: The Center for Disease Control and Prevention (CDC) defines chronic diseases as conditions that last one year or longer, require continuous medical attention, and limit activities of daily life (1). Along with the low socioeconomic level, unhealthy living conditions, sedentary life and poor eating habits have increased the frequency of chronic diseases. Therefore, correcting the lifestyle of individuals has gained importance in delaying and preventing the emergence of these diseases (2). Recent developments in medicine and the ease of access to health services resulted in lower deaths from acute illnesses. However, the frequency of chronic diseases among the causes of death in children has increased at the same time (3).

Chronic diseases negatively affect children's mental and physical wellbeing, causing disruptions in their social interactions. Frequent hospital visits, hospitalization, diet practices and various medical treatments affect many areas in children’s daily lives, preventing them from closely bonding with school and friends. Parents have to deal with their child’s suffering, fear of death, and reluctance to accept the treatments (4). While the rate of psychological disorders in 10-20 years in healthy children, this rate has increased to 60% in children with chronic diseases (5).

The attitudes of families play an important role in children’s acceptance of the disease and adherence to the treatments. A 2005 study by Logan et al. which investigated in pain children, concluded that regulation of family behavior is important regarding the acceptance of the disease by children (6). Bad parental behaviors and poor relationships within the family cause problematic behaviors, disruption of daily activities and an increase in clinical diseases related to the disease. Those also cause children to experience difficulty in the adaptation process of the disease (4).

The presence of an individual with a chronic disease in the family impairs the quality of life of all family members and also causes them to experience emotional difficulties (5). Many parents undergo a great deal of stress because of the consequences of their child’s care and the anxiety they have about their child’s wellbeing. In addition, adverse family conditions (such as the discussion about who the child inherited the disease from), conflicts within the family, extra financial obligations related to the medical care, time constraints and difficulties experienced while managing the disease contributes to the anxiety experienced by the parents. This situation puts parents at risk for both psychiatric and physical illnesses. And the burden of care on parents can lead to arguments leading to divorce and situations that make life harder, such as leaving work.

Providing psychological and social support to the parents and siblings of the child with a chronic disease is of utmost importance. This support should be aimed at both the child and the family. To claim the burden of caring for those who have a child with a chronic disease and the measures to be taken to ensure family integrity and welfare, new comprehensive studies are needed.

Aim: In this study, we aimed to discuss the problems and the changes experienced by the families who have a child with a chronic disease after the diagnosis of the disease.

Methods: In this cross-sectional descriptive study, 40 patients were selected by simple random sampling method from the list of 255 patients with the diagnosis of chronic metabolic disease in our pediatric nutrition and metabolic diseases clinic. The patients were reached from the phone numbers registered on the hospital information system. The telephone numbers of 4 patients could not be reached, 6 patients were excluded from the study because they did not agree to participate in the study, and the parents of 30 patients who were accepted to participate were included in the study. A pre-prepared form consisting of a total of 8 open-ended questions that shows the demographic characteristics and conditions of the families was filled in by the researcher via phone calls to parents.

Results: The median age of 30 participants (70% mothers) was 32.9 years (21.47 years) and the median age of sick children was 69.1 months (6-216 months). 56.7% of the children were receiving a special diet. 46.7% of the participants were high school graduates, one mother never had been to school and she learned to read and write to be able to do hospital procedures for her child. 16.7% of the children were taken care of by both parents. The rate of job change after the diagnosis in at least one of the parents was 13.3%, and the rate of families that had to change the city where they lived was 23.3%. While 50% of the participants defined their economic status as moderate, 50% told that they encountered financial difficulties resulting from the disease. 23.3% of the participants restricted their social life because of the fear of recurrent hospitalization of their child due to an infectious disease, and 6.7% of them limited their social life because they were upset when asked about the appearance of their child. While the rate of participants who had a better relationship with his or her spouse after the diagnosis was 26.7%, the rate of parents who got divorced was 3.3%. Answers given by the participants are shown in Table 1.

Table 1. Examples of the given answers to the selected questions by the participants

<table>
<thead>
<tr>
<th>Question</th>
<th>Participant ID</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has there been any change in the behavior of your other children after your child was diagnosed?</td>
<td>1</td>
<td>I couldn't take care of any other child properly because I was distracted by my other child. After my other child is sleeping, I watch my other child.</td>
</tr>
<tr>
<td>Has there been any change in your relationships with family members and family?</td>
<td>2</td>
<td>My other two sons are very close to each other and they even tell me secrets.</td>
</tr>
<tr>
<td>Has there been any change in your social life and well-being with your family after your child was diagnosed?</td>
<td>3</td>
<td>My child was very supportive and helped other family members with his disease. My spouse never blamed me; he even sacrificed for our child and was unable to accept the situation that we are in. Because of my sadness, I was unable to give medications to my child until recently. Therefore, my spouse felt obligations to his child was being him.</td>
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Discussion: Parents who learned that their child has an incurable disease; may demand aggressive treatments that have unproven medical benefits, increase pain and discomfort, affect their quality of life in order to minimize their child’s suffering. Despite having financial difficulties or time constraints related to the treatment, they may want to continue with aggressive treatments that have unproven medical benefits (7). Family members may come up their plans (career plan, etc.) because they are concerned about the chronically ill child’s needs and they feel obliged to make more sacrifices towards their family members (8).

Because of the concerns and obligations that they have, parents have to make sacrifices from their financial situation, social life and daily needs to care for their child with a chronic disease. Parents may find it difficult to balance between taking care of their sick child and other responsibilities in life. They may find themselves in a situation like doing not anything other than taking care of their child and avoiding other responsibilities of daily life. With the increase of chronic disease, parents may develop mood disorders, family communication may deteriorate and parents may unwittingly show behaviors that may disturb their child. Support. Support for the parents of children with a chronic disease should be planned to cover the experienced problems and behaviors of the parents, miscommunication among family members and the child's mental health and treatment (4).

Conclusion: When their children are diagnosed with a chronic disease, social and psychological support should be provided to all family members quickly.

REFERENCES: