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REVIEW

The Impact of Childhood Chronic Diseases on Child and the Family

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ABSTRACT

This study aims to examine the effects of chronic childhood illnesses on children and their families. It addresses the physical, emotional, social, and educational challenges faced by children while also focusing on how families cope with these difficulties. Through a literature review, the study analyzes common chronic illnesses in childhood and their impacts on children and their families based on existing research. Additionally, it highlights the psychosocial challenges encountered during the treatment process and emphasizes family-centered care approaches. Chronic illnesses significantly affect children's lives, imposing physical, emotional, social, and academic limitations. In addition to health issues, these children may experience emotional difficulties such as social isolation, depression, anxiety, and academic failure. For families, their child's illness leads to significant changes in daily life, altering family roles and increasing psychosocial stress. Healthcare services for children with chronic illnesses should not be limited to medical management alone but should also adopt an approach that provides emotional and social support. Encouraging children's active participation in family-centered care and treatment processes is essential to improving their quality of life. Families should also be provided with appropriate support, and professional guidance should be available to reduce family stress and anxiety levels. A holistic approach to disease management is crucial for ensuring that these children can lead a healthy life in the long term.

Introduction

A chronic disease is "a physical, emotional, or mental condition that prevents a child from attending school regularly, completing schoolwork, and participating in age-appropriate activities and that requires regular use of medication or special equipment and constant supervision and monitoring by a physician or health care professional" (Mokkink et al., 2008; Engin et al., 2021). The definition of chronic disease is based on a combination of criteria, including the duration of symptoms, limitations in activities of daily living, and the need for health care services (Suris, 2004; Er, 2006). Although the frequency and severity of symptoms may vary, a chronic condition is one that persists throughout an individual's life. Childhood chronic diseases are classified as those caused by chromosomal abnormalities (Down syndrome), genetic inheritance (sickle cell anemia, cystic fibrosis), teratogenic exposures, birth trauma (cerebral palsy), or acquired conditions (rheumatic fever, epilepsy) (Alves, 2015).

The diagnosis of a chronic disease causes permanent changes in a child's daily habits, interpersonal relationships, and interactions with health care services (Van der Lee et al., 2007). These changes result from the need to control and implement preventive measures for chronic diseases. Chronic diseases are generally incurable, but with proper management, individuals can lead active lives. Disease management includes elements such as symptom monitoring, medications, lifestyle changes, and physical therapy (Morton, Everard, and Elphick, 2014). Given the need for medications, medical technology and special diets, chronic disease has a significant impact on the lives of children and their families (Er, 2006). Chronic disease encompasses more than just a physical health condition and has emotional, social, and economic implications for both the individual and their family (Herzer et al., 2010). Today, scientific and technological advances in chronic disease management have contributed significantly to increased survival rates among children. This review addresses the impact of childhood chronic disease on children and their families, as well as the principles of approaches to managing these conditions.

Prevalence of Childhood Chronic Diseases

The population of children with chronic diseases is increasing, and chronic diseases have become one of the most important health problems in all industrialized countries and worldwide (Suris et al., 2004; Yeo and Sawyer, 2005). The prevalence of childhood chronic diseases varies between countries/regions. According to studies conducted in our country, the prevalence of asthma, one of the most common chronic disease in childhood, is reported to be 7.4% (Yesilkaya et al., 2017). Additionally, the prevalence of type 1 diabetes, another prevalent chronic disease in childhood, is reported as 0.75/1000, with approximately 20,000 children diagnosed with diabetes (Sekerel et al., 2020). According to the 2020 report of the World Health Organization (WHO), approximately 3.000 children aged 0-14 are diagnosed with cancer annually in our country, and the survival rate for cancer has increased by 72% in the last five years (WHO, 2020; Kutluk and Yesilipek, 2022).

Epidemiological studies show that one in every four children suffers from a chronic health issue (Sawyer, 2007). According to population-based studies, 10-13% of adolescents have a chronic disease that significantly limits their daily activities or requires long-term care and supervision (Jin et al., 2017). Globally, the prevalence of chronic diseases in children is reported to be between 10-20%, with 10% of these children experiencing severe symptoms (Mokkink et al., 2008). Thanks to significant advancements in healthcare, although full recovery is not possible for many diseases, successful symptom control has been achieved. These advancements provide a longer life expectancy while also necessitating living with the disease for many years. For example, today, children with kidney failure can survive through dialysis and transplantation methods, but they face numerous symptoms that require management. Providing high-quality disease management for children living with chronic disease is crucial for them to lead happy and fulfilling lives.

The Effects of Chronic Diseases on Children

Chronic disease limits a child's ability to live independently and engage in social interactions, and requires ongoing medical interventions, including hospitalization. Children with chronic conditions are at higher risk of developing emotional problems compared to their peers without chronic diseases, and they have been shown to exhibit lower levels of academic, physical, and social functioning than healthy children. In addition to regressive behaviors, chronic diseases may cause developmental delays or retardation. For example, children with renal failure have been found to have significantly lower verbal and visual perception abilities (Er, 2006). Children with chronic diseases are 1.5 to 3.4 times more likely to develop emotional problems compared to their healthy peers (Hunt, 2009). Children react to chronic disease in different ways, with pain, cognitive difficulties, and physical appearance being the key factors influencing these reactions. The onset of a chronic condition may occur during a child's development and can lead to changes in the routines of both the child and the family (Engin et al., 2021). Until the clinical condition is confirmed, children try to adapt to new circumstances, cope with pain, potential limitations, and the fear of death.

With the development of treatment methods for chronic diseases, children's life expectancy has increased, but new morbidities and psychosocial issues have emerged (Engin et al., 2021). Chronic conditions affect the child's physical, emotional, and intellectual health. Studies have shown that children with chronic disease experience more emotional and behavioral problems compared to their healthy peers. The most common issues observed in these children are internalizing problems such as adjustment disorders, stress reactions, depression, anxiety disorders, and post-traumatic stress disorder (Emiroglu & Akay, 2008).

The pain, fatigue, and other physical symptoms experienced during the disease process, frequent hospital visits and admissions due to the need for regular treatment, emerging complications, changes in physical appearance, the uncertainty of the prognosis, and the limitations in daily life pose a risk for emotional problems (Ozbay, 2013). Problems with school attendance can lead to disruptions in the child's education and a decline in academic performance. School absenteeism and the inability to participate regularly in extracurricular activities mean that the child has fewer opportunities to make and maintain friendships. Separation from peers and limited opportunities for social interaction can cause these children to withdraw socially and feel helpless or different compared to children without chronic disease (Kansra et al., 2021). Social withdrawal is a major source of concern for children with chronic diseases. Children may avoid participating in activities due to the fear of negative reactions from peers, which can lead to a lack of interpersonal relationship skills and a decrease in self-esteem (Bakula et al., 2019). Additionally, due to the fear of social stigma, children who are afraid of the social consequences of their friends knowing about their chronic disease often resort to hiding their disease and treatment. Studies show that adherence to disease management is associated with perceived social stigma, which can further jeopardize the child's health condition (Kansra et al., 2021).

Children with chronic diseases are often required to manage symptoms that affect their health and lifestyle, as well as ongoing treatments. These children are at higher risk of developing social, behavioral, or cognitive health issues, such as low self-esteem, poor social skills, disruptive behaviors, substance use, depression, and anxiety. A sense of alienation from their peers is an indicator of their frustration in managing their condition. Additionally, these children are exposed to multiple stressors, and the prevalence of depression, anxiety, and adjustment disorders in both the child and the family is notable (Hunt, 2009).

The onset of a chronic disease during childhood leads to an abrupt interruption of "normal" life. The beginning of chronicity in a child’s life hinders their connections with peers, as well as significant moments with friends and family (Alves, 2015). Children often feel "different," socially isolated, and restricted in their activities. When they are unable to cope with these emotional challenges, feelings of anxiety, sadness, depression, defiance, and anger are frequently observed. These children grow up by dealing with the chronic condition that limits different aspects of their lives and by learning to incorporate the hospital environment into their daily routines. Due to repeated hospital admissions and long stays, children require special attention, which further increases the risks to their developmental process (Alves, 2015).

Children with chronic diseases account for 35% of all pediatric hospitalizations, with an average hospital stay of 1.6 to 3 days (Bell et al., 2020). Beyond recovery for the child, the hospital means that their loved ones, who are their natural source of support and security, have their daily lives changed and they enter a new routine that is often very different from their normal life. Hospitalization, painful procedures, and prolonged stays can lead to the development of post-traumatic stress disorder (PTSD). In PTSD, increased stress, emotional problems, treatment non-compliance, and a decline in quality of life are frequently observed (Sekerel et al., 2020).

Recurrent disease and treatment processes can significantly affect a child's school attendance and academic performance, which may lead to the loss of professional and economic independence in adulthood. Children with chronic disease may experience difficulties in school performance, including reduced attention and concentration, poor motivation, resistance to school assignments, and absenteeism (Hu et al., 2022).

In children with chronic disease, severe or insufficiently controlled symptoms, flare-ups, and frequent hospitalizations can lead to school absenteeism, low school engagement, and poor academic outcomes (Bregnballe et al., 2007). Priority conflicts may arise between disease management and school requirements, such as missed appointments on school days or refusal to undergo treatment on those days. Children with chronic diseases are more likely to miss school due to their condition or the treatment they require compared to their healthy peers. School attendance can be affected by the severity of symptoms, and the lost school time for these children can vary from 13% to 35% (Crump et al., 2013). Additionally, if a child does not have a supportive group of friends and teachers at school who are aware of their disease and accept them as they are, feelings of being "different" may lead to issues with self-esteem and self-image (Bregnballe et al., 2007). School absenteeism and lack of participation in recreational and sports activities also put these children at high risk for social isolation (Yeo & Sawyer, 2005). Parents of children with chronic diseases should maintain close contact with the school to ensure that teachers are aware of their child's special needs. Communication and collaboration between parents, the school nurse, and teachers will help identify school-related issues promptly.

The Effects of Chronic Disease on the Family

Chronic disease is a multifaceted experience with many layers, interactive, interconnected and spanning multiple domains. Chronic disease encompasses more than physical disease processes and involves multiple impacts on the lives of both children and families (Mitchell et al., 2020). When a child is diagnosed with a chronic disease, it means the beginning of a stressful process for both the child and the family. Families try to manage the child's disease while trying to maintain their normal family life. When a child is diagnosed with a chronic disease, it creates great upheaval in the lives of families and often leads to stress and anxiety. Families with children with chronic diseases have to cope with extraordinary circumstances. After diagnosis, families face changes that affect many aspects of their lives, such as medical diagnosis (medication, procedures, surgical intervention, hospital visits, hospitalizations, etc.), daily chores, schoolwork, work life and social activities, in addition to managing “normal” family life (Kratz et al., 2009). These changes that occur after the diagnosis create stress and tension on family members.

The presence of a chronic disease has a profound impact on the well-being of every family member, including healthy siblings. In the family, the burden of the presence of the disease can create tensions in all areas of life - physical, emotional, social, behavioral, behavioral, personal and material domains - preventing the family from maintaining its routines (Cardoso Vaz, 2018). The change in responsibilities and roles of family members leads to an inevitable change in family functioning and lifestyle, which in turn affects the overall family dynamic and functioning. Family dynamics can be disrupted when the child needs more time, special equipment, medication and other adaptations than other children. Emotionally, stress and uncertainty about the future, an upcoming procedure or intense worry about the child begin to dominate the thoughts of family members. Socially, families may feel isolated and lonely from extended family members and friends, or overburdened by the extra attention they receive (Mitchell et al., 2020). There are changes in the roles and relationships of family members and this disrupts the normal functioning of the family. All these disruptions in family routines are particularly difficult for sick children or siblings in early childhood. Family routine in early childhood development gives children a sense of security, helps them develop self-discipline and boundaries, and allows them to cope with change by leading to clear and predictable expectations (Golics et al., 2013).

Chronic disease is an emotionally challenging source of stress for families. It changes the roles of family members, disrupts the hierarchy, affects family communication, interpersonal relationships, financial status, and leads to disruptions in family relationships, family structure, and family integrity (Mitchell et al., 2020). The stressors that families face after a child is diagnosed with a chronic disease are multifaceted, including symptoms, the treatment process, interpersonal conflict, uncertainty, loss, and most often related to daily role functioning. Chronic disease presents children and families with a combination of acute stress and long-term chronic stress. Stress is often an uncertain, unpredictable, uncontrollable, dysfunctional experience for children and their parents, and its severity is related to the amount of care the child requires. Resources for coping with stress depend on both the child and the family, as well as the level of understanding and perception of the situation. Stress can be chronic and prolonged, related to upcoming treatment, recovery, or survival (Alves, 2015). Parents losing their jobs, siblings and sick children missing school, painful ongoing procedures or treatments, uncertainty about the future, emotional and behavioral problems in the child, marital disharmony and conflict, too much or too little social support, and financial constraints are cited as long-term stressors in the family. These parents, compared to parents without sick children, experience higher levels of role strain, greater stress associated with the parental role, frustration, and conflict over division of labor and expectations. Parents may also show increased levels of anxiety and overprotectiveness, have lower expectations for their sick child and siblings, and fail to set boundaries or provide consistent discipline for their children.

The most common determinants of well-being in families with a child with a chronic disease include resilience, the presence of supportive social support, the disease process, balancing family needs, effective communication, and active coping. Many factors, such as family cohesion, shared love, emotional attachment, mutual understanding, and helpfulness, play an important role in mediating the impact of disease on the family. The availability and use of coping resources also influences the way the family and siblings adapt to the disease, and the family is more vulnerable when resources are not available. Lack of resources is also a risk factor for emotional distress and maladjustment (Toledano & Luna, 2020). Parents have to cope not only with disease management, but also with the fear, sadness, grief, anger, despair and long-term disease associated with the loss of a healthy child and therefore the loss of the previous way of life. Research shows that mothers experience higher levels of parental stress, anxiety, and depression (Compas et al., 2012). While mothers experience more parental stress, depression, and feelings of burnout, fathers are generally less functionally involved in the disease management process. At the same time, parents are the primary source of emotional support for the child and an important link between the child and the healthcare team.

Siblings can also be affected by the disease in a variety of ways, both positive and negative. Healthy siblings may experience behavioral and emotional problems and decreased school performance due to changes in their routines, fatigue, high anxiety, and increased attention from their parents. Studies show that siblings of children with chronic diseases are at high risk for emotional effects such as anxiety, restlessness, depression, and sadness (Sharpe & Rossiter, 2002; Vermaes et al., 2012). The status of the sick child, family stressors, perceptions of the sibling's health, coping strategies, parents' emotional state and level of functioning, family functioning, changes in roles and functioning, social support, and financial resources are risk factors that play a role in affected siblings (Alderfer, 2010). Families of children with chronic diseases may lose control in managing their lives with changing routines and the presence of a chronic disease. Informing, supporting and empowering the family in the process of living with a chronic disease, care and treatment of the child will facilitate the child's adaptation to the new situation and thus minimize negative emotions. At the same time, parents' attitudes toward managing their child's disease and adapting to the new lifestyle will contribute positively to the child's self-control in adulthood (Kratz et al., 2009).

Approach to Childhood Chronic Diseases

Children with chronic diseases need supportive, planned and integrated health services. At the same time, these children need comprehensive strategies to effectively manage chronic conditions. It is important for health care professionals to monitor how chronic disease affects the child's appearance, socialization, school life, and emotional health, and to set appropriate goals for the child.

Concrete short-term goals should be developed with the child and family to help the child regain functionality in all areas. The child's active participation in periodic evaluation of the treatment plan should be encouraged, and the child and family should be counseled to take ownership and control of the disease. The child and family should be informed about the treatment process and treatment options. The approach to the child and family should be appropriate to the child's developmental level. The family is an important source of support for treatment compliance, and the adoption of a family-centered care philosophy at every stage of the approach is of great importance in terms of positive health care outcomes. The basic principles in approaching children and families with chronic disease are given in Table 1 (Table 1).

Table 1. Basic principles in approaching children and families in childhood chronic diseases

Assessment of the child and family's knowledge and skills regarding disease management
Disease management education
Planning the disease management plan in accordance with the daily routines of the child and family.
Discussing facilitators and barriers to the management plan
Providing written guides for disease management
Developing short-term goals
Regular assessment of adherence to the disease management plan
Avoiding judgmental attitudes regarding any shortcomings in disease management
Providing support from important individuals and peers for the child and family
Making the management plan as simple as possible for the child and family
Encouraging participation in support groups

Conclusion

Childhood chronic disease is a significant challenge not only for the child, but also for the family. These conditions require ongoing medical management, emotional support, and adjustments to daily routines, which can have a profound impact on various aspects of the child's life, including physical health, emotional well-being, social interactions, and educational performance. The increasing prevalence of chronic diseases in childhood highlights the urgent need for comprehensive health strategies that address both medical and psychosocial aspects of care. While advances in medical treatments have improved survival rates, children with chronic diseases still face ongoing challenges in adjusting to their condition, and the emotional and social consequences for both the child and their family are significant. By providing family-centered care, encouraging active participation in treatment, and offering consistent support for emotional and social development, we can improve the quality of life for these children and their families and enable them to overcome the challenges of chronic disease.

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Conflict of Interest

Authors disclose no potential conflicts of interest.

Ethics Statement

Not applicable.

Informed Consent

Not applicable.

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