

# Coping in Children with Chronic Disease

## Kronik Hastalık Tanısıyla İzlenen Çocuklarda Baş Etme

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**ABSTRACT** Chronic diseases have physical, psychological, social, and academic effects on children. Chronic disease is a stress factor that can cause negative effects on children in different areas. While stress is natural and expected in life, coping should accompany this process. Stress and coping in children with acute and chronic health problems are important issues and are often studied together. Stress can be brought under control when coping is effective. If there is ineffective coping, stress takes over life and can damage physical, emotional, psychological health and social functioning. Children can use more than one coping method to cope with stressors. It is thought that the two factor model (avoidance/approach and problem-focused/emotion-focused) used in coping is not sufficient for children. For this reason, a three-factor model was developed for children. Children who are competent in coping will experience positive emotions as they will have positive experiences. It is stated that coping successfully provides strong psychological health and well-being. Children may need guidance in learning and/or developing coping methods. This study aims to examine the effects of chronic disease on children, the importance and measurement of coping in children with chronic disease, and methods that can be used to improve coping skills in children.

**ÖZET** Kronik hastalığın çocuklar üzerinde fiziksel, psikolojik, sosyal ve akademik etkileri olabilmektedir. Kronik hastalık çocuklar üzerinde çeşitli etkilere neden olabilen bir stres faktörüdür. Stres, doğal ve yaşamda beklenen bir şey olmakla birlikte baş etme bu sürece eşlik etmelidir. Akut ve kronik sağlık sorunu yaşayan çocuklarda stres ve baş etme birlikte ele alınması gereken önemli bir durumdur. Baş etme etkili olduğunda stres kontrol altına alınabilir. Etkisiz bir baş etme durumunda stres hayatı ele geçirerek fiziksel, duygusal, psikolojik sağlık ve sosyal işlevselliğe zarar verebilmektedir. Çocuklar stresle baş etmek için birden fazla baş etme yöntemini kullanabilirler. Çocuklar baş etme yöntemlerini öğrenmede ve/veya geliştirebilmede rehberliğe ihtiyaç duyabilmektedirler. Baş etmede kullanılan ikili modelin (kaçınma/yaklaşma ve problem odaklı/duygu odaklı) çocuklar için her zaman yeterli olmadığı bunun yerine çocuklarda üç faktörlü baş etme modelinin kullanılabilmesi görüşü bulunmaktadır. Baş etmede yeterli olan çocuklar olumlu deneyimler edinceğinden olumlu duygular yaşayacaktır. Başarılı bir şekilde baş etmenin psikolojik sağlık bakımından güçlü olmayı ve iyi oluşluk hâlini sağladığı belirtilmektedir. Bu derlemenin amacı, kronik hastalığın çocuklar üzerindeki etkilerini, kronik hastalık tanısıyla izlenen çocuklarda baş etmenin önemini ve değerlendirilmesini, çocuklarda baş etme becerilerini geliştirmede faydalanılabilecek yöntemleri incelemektir.

**Keywords:** Adaptation; child; chronic disease; psychological

**Anahtar Kelimeler:** Uyum; çocuk; kronik hastalık; psikolojik

Chronic diseases have physical, psychological, social, and academic effects on children.<sup>1,2</sup> Statistical data on chronic diseases in childhood are remarkable. The incidence of children followed with a diagnosis of chronic disease in the world is between 10 and 15%.<sup>3</sup> In the United States, more than 40% of school-age children and adolescents have at least one chronic health problem (National Center for Chronic Disease

Prevention and Health Promotion, 2021), while in our country 5.3% of children aged 0-19 years are diagnosed with a chronic disease.<sup>4</sup> Childhood chronic diseases can have negative effects on children's physical, emotional, psychological, social and academic conditions.<sup>5</sup> Therefore, it is essential that children and adolescents learn to cope with the effects of chronic diseases. Using effective coping methods can

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have positive effects on children's and adolescents' physical, emotional and psychological health, social adaptation level, quality of life and well-being.<sup>1</sup> This study aims to examine the effects of chronic disease on children, the importance and measurement of coping in children with chronic disease, and methods that can be used to improve coping skills in children. The study includes the effects of chronic disease on children, coping and its importance in children with chronic disease, measurement of coping in these children and methods that can be used to improve coping skills.

## EFFECTS OF CHRONIC DISEASES ON CHILDREN

Although the effects of chronic diseases on children are similar, they can also show differences for various reasons. Factors affecting children with chronic disease include disease-related characteristics (disease severity, age at diagnosis, physical and cognitive effects of the disease, pain, etc.), family-related characteristics (family function, mental health of parents, nuclear or extended family, number of siblings, financial situation, etc.), social characteristics/close en-

vironment (cultural attitudes, access to healthcare services, geography, social resources, school life, friends, etc.), and the child's personal characteristics (age, gender, intelligence and communication skills, temperament, coping skills, past experiences, etc.) (Figure 1).<sup>2,6-8</sup>

This chapter has covered the physical effects, emotional effects, psychological effects, social effects, and academic effects of chronic disease on children.

## PHYSICAL EFFECTS

Studies in the literature have reported that different physical effects are seen in children with chronic diseases, depending on the disease. For example, children with Type 1 diabetes mellitus may experience symptoms such as nausea, vomiting, allergic reactions, imbalance in blood glucose, decrease in bone mineral density, and growth retardation.<sup>9</sup> A child with a diagnosis of asthma may have difficulty in breathing, decrease in physical capacity, and allergic symptoms due to acute asthma attacks, while a child with a diagnosis of cancer may have pain, nausea, vomiting, fatigue, and secondary sleep disorder.<sup>10,11</sup> Diarrhea, constipation, enuresis, encopresis, lactose, and

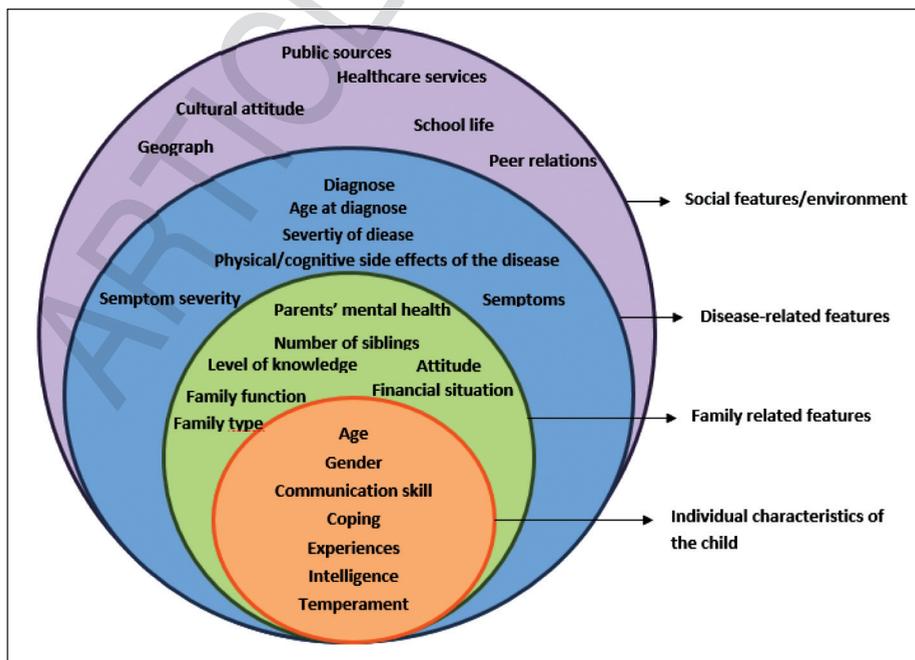


FIGURE 1: Factors affecting children with chronic disease.

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gluten intolerance have been reported among the physical problems of children with neurodevelopmental problems.<sup>12</sup> The physical effects experienced by children with chronic diseases are a source of chronic stress that the child and family must cope with. Here, the child's effective coping can have positive effects on growth and physical development.<sup>5</sup>

### EMOTIONAL EFFECTS

The feeling of trust may not develop in children during infancy. The sense of autonomy may not develop due to the increasing limitations in preschool age. In the preschool period, their sense of independence may be negatively affected, and they may not learn to express their feelings appropriately. At school age, assertiveness, achievement, and feelings of belonging to the group may be affected. Because of adolescents feeling different from their peers, they may experience intense sadness and anger, and moreover, they may experience a lack of self-confidence.<sup>1-8</sup> Some of the other negative emotions are hopelessness, unhappiness, crying, powerlessness, helplessness, fear, and being labeled.<sup>7</sup>

### PSYCHOLOGICAL EFFECTS

Children receiving cancer treatment may experience increased levels of anxiety and depression due to hair loss, amputation, attention deficit, and other physical symptoms.<sup>11</sup> A study found that the late effects of cancer treatment on children's mental health are somatic distress, post-traumatic stress disorder, deterioration in body image, behavioral problems, suicidal thoughts, and the need to strengthen coping.<sup>13</sup> The quality of life and well-being of children who have difficulties in coping with the stress factors arising from chronic disease may decrease.<sup>8</sup>

### SOCIAL EFFECTS

Since self-perception is essential in adolescence, children may experience feelings of inadequacy and social adaptation problems if situations affect their appearance.<sup>1</sup> The social adaptation capacity, quality of life, and well-being level of children who have difficulty coping with the stress factors arising from chronic disease may decrease.<sup>8</sup> It has been reported that anti-social behaviors are observed in children receiving cancer treatment.<sup>13</sup>

### ACADEMIC EFFECTS

Children's school absenteeism may increase due to chronic disease. Academic performance also decreases due to cognitive functions being affected and school absenteeism.<sup>6,8,12,13</sup> Children who are separated from school, teachers, and friends for reasons related to chronic disease may fear academic failure and losing relationships with friends. Children who stay in the hospital or at home instead of going to school may consider this process a negative experience. This period can be even more difficult for children and their families who have problems accepting the disease and refusing treatment.<sup>14</sup> Children are affected by chronic disease in different ways and their coping skills also differ.<sup>6</sup>

### COPING IN CHILDREN WITH CHRONIC DISEASE

Stress and coping in children with acute and chronic health problems are important issues and are often studied together. Stress is an experience or event that depletes an individual's resources. Often very stressful situations include reduced income, worsening of health/immune functions, and deterioration of psychological functions. Stress can be observable/objective (such as chronic disease) or subjective/subjective (perceived threat).<sup>15</sup> Stress is a natural and expected experience in life. But coping must accompany this process. Stress can be controlled when coping is effective. If coping is ineffective, stress takes over life and can damage physical, emotional, psychological, health, and social functionality.<sup>16</sup>

There are various definitions of coping. Coping is the thoughts and behaviors used to manage internal and external factors in stressful situations and/or a dynamic process in which there are varying responses to the stressor.<sup>15</sup> Coping is the cognitive and behavioral response that individuals use to manage or tolerate stress. For individuals following up with a diagnosis of chronic disease, it is the ability to adapt to the difficulties they experience.<sup>6</sup> Lazarus and Folkman define coping as individuals' constant changes of certain internal and external demands that consume their resources or force them excessively, with cognitive and behavioral actions.<sup>5</sup> According to the def-

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inition by MacNeill et al., it is a process in which individuals take cognitive and behavioral measures to manage, reduce or tolerate situations that force their usual resources.<sup>17</sup> Coping methods are consciously chosen and flexible enough to respond to environmental needs and occur at the conscious level.<sup>5</sup>

There are two different models of coping in the literature. These are avoidance versus active approach to coping, and the other is problem-focused versus emotion-focused coping. The models are described below.

#### AVOIDANCE VERSUS ACTIVE APPROACH TO COPING

The individual changes her/his thoughts about the problem. Children who choose this path can find multiple solutions to a problem by following certain problem-solving steps and receiving social support. According to another view, in this approach, the individual takes actions that will distract her/him from the stressor, such as ignoring the problem or forgetting and denying it. It is impossible to clearly determine whether the coping method is effective in individuals using this method. The effect of this method may vary depending on the situation or time in which the method is used.<sup>18</sup>

#### PROBLEM-FOCUSED VERSUS EMOTION-FOCUSED COPING

In problem-focused coping, the individual aims to eliminate the stressor, while in emotion-focused coping, he or she tries controlling the negative emotional reaction to stress.<sup>19</sup> Problem-focused coping strategies include cognitive activities aimed at solving problems, such as obtaining information, taking direct action, and breaking the problem into small parts, and include behaviors such as creating lists of possible solutions and changing the conditions that create the problem.<sup>5</sup> In problem-focused coping, constructive action is usually taken against the stressor. In emotion-focused coping, an attempt is made to reduce the negative emotions that occur after a problematic situation. These interferences include actions aimed at reducing emotional distress, such as seeking social support, expressing emotions and managing negative emotions, avoiding, reducing,

distancing, selective attention, positive reception, and interpreting a negative event favorably.<sup>5</sup>

It is stated that problem-focused and emotion-focused strategies are essential in coping with stressful events.<sup>18</sup> The most commonly used method, especially in children and adolescents, is emotion-focused coping. It has also been reported that emotion-focused coping methods are beneficial against uncontrollable stressors.<sup>17</sup> Conceptualizing and explaining coping methods in different ways does not aim to direct children to a single method. Children can use multiple coping methods to deal with a stressor. For example, a child receiving cancer treatment may use avoidance, emotional regulation, and distraction for nausea, as well as social support.<sup>18</sup>

Strategies in Lazarus and Folkman's coping model aim at a different approach. Therefore, the response to the stressor determines whether the strategy will be problem-focused or emotion-focused. Some behaviors can fulfill both functions (problem-focused/emotion-focused) based on the reason for using them. For example, if it is aimed to gain emotional support, seeking support is emotion-focused. However, if it is aimed to get help or advice, then seeking support is problem-focused. An effective problem-focused coping strategy reduces the threat or distress posed by the threat. An effective emotion-focused coping strategy calms the individual and improves problem-focused coping strategies. Therefore, instead of separating problem-focused and emotion-focused coping strategies into independent categories, it may be more useful to consider them as complementary strategies.<sup>16</sup>

#### THREE-FACTOR COPING MODEL IN CHILDREN

Analysis on coping in children suggests that these two models (avoidance/active and problem-focused/emotion-focused) do not adequately reflect coping. For this reason, a three-factor coping model was developed for children by Compas and Boyer (Figure 2). Considered the most comprehensive for children, this model includes primary control studies, secondary control studies, and the tertiary dimension of disconnection. According to this model, the primary control studies used by children are problem solving, emotional regulation, and ex-

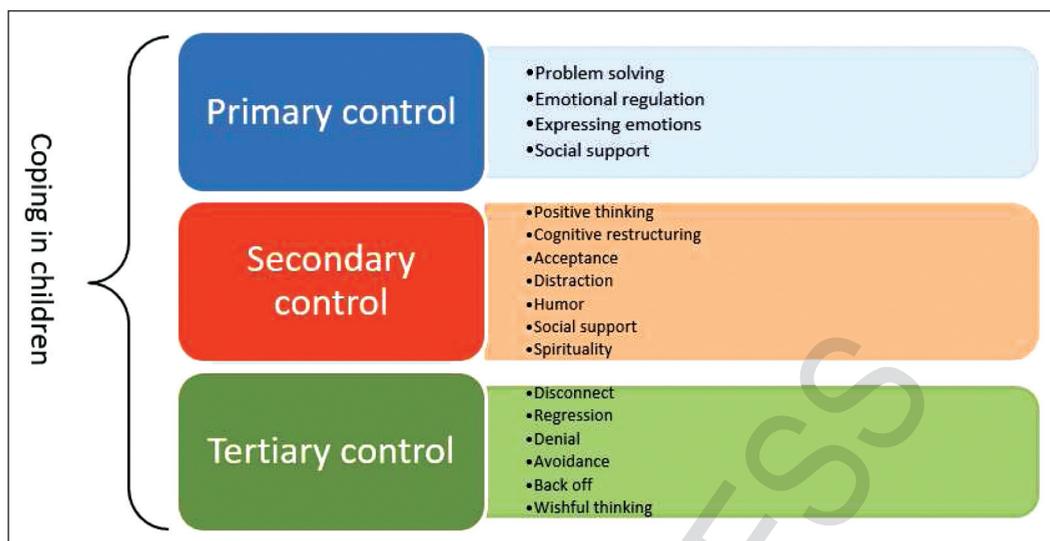


FIGURE 2: Three-factor coping model for children.

pressing emotions.<sup>20</sup> Secondary control studies are positive thinking, cognitive restructuring, acceptance, and distraction. Tertiary control studies, on the other hand, represent the child's attempt to disconnect or regression, and include denial (I try to believe it never happened), avoidance (I avoid thinking about it and forget everything), and wishful thinking (let the problem go away and matters will work itself out).<sup>20</sup>

### THE IMPORTANCE OF COPING IN CHILDREN WITH CHRONIC DISEASE

Children with sufficient coping skills will experience positive emotions as they will have positive experiences. It has been reported that successful coping provides strong psychological health and well-being. Moreover, coping also has a psychological protective function.<sup>5</sup> For this reason, their physical, emotional and psychological health can be improved and their level of social cohesion, quality of life and well-being can be increased by enabling children and adolescents to use effective coping methods (Figure 3).<sup>1</sup> Teaching specific coping strategies to improve adjustment and psychosocial function in children with chronic diseases will be an effective method.<sup>18</sup> Studies on coping strategy in these children have often focused on those diagnosed with cancer, asthma, diabetes, and chronic renal failure.

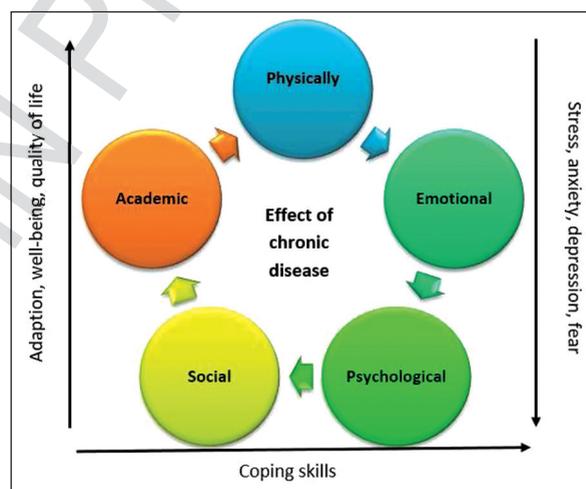


FIGURE 2: Chronic disease process.

Studies examining children's level of coping and its effects have addressed issues such as the effects of individual characteristics, disease-related characteristics, social and parental support on coping, and the importance of teaching effective coping.

Hampel et al. conducted a study on the methods of coping with daily stressors in children with and without chronic diseases (asthma, atopic dermatitis, and cancer). The study suggested that children followed up with a diagnosis of chronic disease resort to passive avoidance less than their healthy peers and cope with social and school-related stress factors

more. Researchers have emphasized the need to direct children with chronic diseases to more effective coping strategies.<sup>21</sup> Volkenant prepared a doctoral thesis on coping and adaptation in children followed up with a diagnosis of chronic kidney disease. The study evaluated children's coping strategies and measured perceived parental support in coping. The study found that children were exposed to stress factors related to specific diseases, parents supported the most in primary coping strategies, and health-related quality of life was negatively affected because of ineffective coping.<sup>18</sup> Doctorate dissertations conducted on technology-based psychosocial counseling and empowerment in children followed up with a diagnosis of cancer in our country have found that active coping skills and coping levels increase in participating children.<sup>22,23</sup>

## EVALUATION OF COPING IN CHILDREN WITH CHRONIC DISEASE

Certain coping strategies used by children with chronic diseases can have positive effects and increase compliance. Therefore, the coping levels of children with chronic diseases should be determined and evaluated regularly.<sup>18</sup> Valid and reliable tools should be used to objectively determine children's coping skills. There are some Turkish scales in our country with validity and reliability, which are used to measure the coping of both healthy children and children with chronic diseases. "Coping Scale for Adolescents", "Coping Scale for Children and Adolescents".<sup>5,24</sup> "Culturally Sensitive Stress Coping Scale for Turkish Children and Adolescents" was developed by Yıldız to measure children's coping in doctorate dissertation.<sup>25</sup> A validity and reliability study of the "Pediatric Cancer Coping Scale" which is used to measure the coping of children with cancer diagnosis, was also conducted.<sup>26</sup>

## METHODS THAT CAN BE USED TO DEVELOP CHILDREN'S COPING SKILLS

The methods that can be used to improve the coping skills of children with chronic diseases can be examined in three different groups: physical, psychological, and combined practices.

**Physical Practices** are various physical movements and techniques practiced or taught by a trained practitioner. Massage and muscle relaxation applications were examined in this group.

**Psychological practices** include a wide and diverse range of procedures or techniques applied or taught by an expert trainer. This includes face-to-face psychosocial interventions such as neurolinguistic programming, cognitive behavioral therapies, motivational interviewing, therapeutic communication and counseling, meditation, imagination, and books.

**Combined practices** include exercises in which both physical and psychological methods are used together: Reiki, yoga, mindfulness, diaphragmatic breathing exercises, and games.<sup>7,27</sup>

Children aged 3 to 18 years can benefit from the methods used to develop coping skills. However, there may be differences in age due to the individual and developmental characteristics of children. The mechanism of action of the method, the frequency and duration of its application may vary according to the child's needs, diagnosis, and treatment.<sup>28</sup> Coping methods can be used to prevent and reduce physical symptoms in children with chronic diseases, to increase their communication skills, self-esteem, self-confidence and hope, to improve their psychological well-being and quality of life, to increase sleep quality, adherence to treatment, and to improve coping skills.<sup>28-31</sup>

Akel et al. investigated the effects of cognitive rehabilitation practices on fatigue and independence in pediatric cancer treatment. The study included the children in the control group (6-12 years old) in a routine therapy program (relaxation, imagery and orientation to activities of daily living). The study aimed to improve the motor and sensory skills of children receiving a routine therapy program and to support their independence through individualized activity training. The intervention group received cognitive rehabilitation practices. In cognitive rehabilitation practices, space-time orientation, indoor-outdoor spatial perceptions, attention, visual-motor structure and thinking processes are gained through the game. According to the results of in-group analysis, a significant decrease was observed in the degree of fatigue in

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the intervention and control groups. It was reported that there was a statistically significant improvement in the functional independence of the children in the intervention group. According to the statements of the participants in both groups, while the degree of fatigue decreased after the practices, functional independence increased.<sup>29</sup> It has been observed that practices that help motivate children receiving cancer treatment can strengthen coping by reducing the degree of fatigue.

In the study by Aghakhani and Bahari, NLP education given to children (7-11 years old) receiving cancer treatment increased their level of hope and quality of life. The study revealed that the change in children's feelings and thoughts positively affects their perception of health/disease and their response to stress.<sup>30</sup> According to the results of group-based hypnosis applied to children (11-17 years old) with cancer diagnosis, Grégoire et al. reported that positive effects were observed on children's fatigue, distress, coping and quality of life.<sup>31</sup> A literature study examining the effect of yoga and mindfulness-based approaches for children and adolescents followed up with the diagnosis of asthma reported that children's stress and anxiety levels decreased.<sup>10</sup> Another study in which breathing, relaxation and imagery were used together, determined that children (7-15 years old) followed up with cancer diagnosis felt relieved, had fun and increased their concentration during and after the practice.<sup>32</sup> Meditation can be effective in reducing the degree of depression, anxiety and stress, and improving sleep and quality of life in children followed up with a cancer diagnosis.<sup>33</sup> Silva and Osório evaluated the effect of an animal-assisted therapy program on the physiological and psychosocial variables of pediatric oncology patients. We observed that the pain and stress levels of the study children decreased and their depressive symptoms improved.<sup>11</sup>

Play can create a therapeutic environment for children with chronic diseases. Because the games allow children to express their feelings and thoughts, reduce stress and facilitate coping. Play can enable children to regulate and restructure their subconscious, cognitively and emotionally. Thus, it can contribute to the acquisition of new behaviors. Play improves children's problem-solving skills, creative

thinking skills and helps develop empathy. Effective games can be developed to support and improve the physical, cognitive, emotional, and social development of children with chronic diseases. Children can be motivated by using games in cases such as hospital admission and preparation for medical procedures in inpatient children.<sup>7</sup>

More advanced digital video games are being developed with modern technology. Improvements in children's characteristics, such as empathy, awareness, and cooperation are observed among the long-term effects of video games. However, there is insufficient data on the long-term effects of digital video games on children's emotional development. However, studies have indicated that children's perceived emotional state improves after digital video games.<sup>34</sup> It is thought that digital video games can improve children's ability to control or transform their negative emotions.<sup>35</sup> They can also help them cope with the side effects of treatments such as nausea, vomiting, pain, and fatigue.<sup>36</sup> In a study by Bakker et al. children and adolescents with chronic fatigue syndrome were shown a video film prepared to prevent fatigue and absenteeism from school. The study found no significant differences in mean fatigue and school absenteeism scores between the intervention and control groups. However, the motivation of the intervention group decreased compared with the pre-application follow-ups. School absenteeism and fatigue were observed in 18% more children than in the control group. It is not recommended to use special video films in children with chronic fatigue syndrome, as it reduces motivation and increases the incidence of school absenteeism and persistent fatigue.<sup>37</sup>

Erdem et al. stated that the characters in children's books generally use functional (primary and/or secondary) coping strategies. These strategies are seeking peer/adult support, collaboration, solution generation, and self-motivation. Additionally, non-functional (tertiary control studies) strategies such as "doing nothing, not knowing what to do, avoiding behavior" used by the characters in some books despite a negative situation are given in the development section and analyzed with functional strategies in the conclusion section.<sup>27</sup> Children's books on the relevant

subject can be prepared and/or children can be made to read an existing book so that the child can realize their own potential, express their emotions and feelings, empathize, and explore problem-solving ways.

## CONCLUSION

Children with chronic diseases and their families may face various physical, emotional, psychological, social and academic difficulties. Being able to cope with these difficulties may affect the development of the child. Children should learn effective coping methods for their physical, cognitive, social, and emotional development. It is seen that methods such as relaxation techniques, breathing exercises, NLP, cognitive therapies, hypnosis, imagination, meditation, and yoga are used among effective coping methods in studies with children. The individual characteristics of the child, the situation with which he/she will cope, the results of the study, the knowledge and skill level of the nurse and her/his experiences should be considered while deciding on the methods to be used in coping. Children may need guidance during coping. Therefore, pediatric nurses

are an important resource in providing professional support. Nurses should evaluate children's coping strategies and levels with appropriate scales during coping management.

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## Conflict of Interest

*No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.*

## Authorship Contributions

**Idea/Concept:** Gizem Çakır, Naime Altay; **Design:** Gizem Çakır, Naime Altay; **Control/Supervision:** Naime Altay; **Data Collection and/or Processing:** Gizem Çakır; **Analysis and/or Interpretation:** Gizem Çakır; **Literature Review:** Gizem Çakır; **Writing the Article:** Gizem Çakır; **Critical Review:** Naime Altay.

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