

Special Article

Children with Chronic Disease during COVID-19 Pandemic and Nurses' Roles

Capa Zehra, MSc

Institute of Health Sciences, Department of Public Health Nursing, Dokuz Eylul University, Izmir, Turkey

Karadag Gulendam

Associate Professor, Department of Public Health Nursing, Faculty of Nursing Dokuz Eylul University, Izmir, Turkey

Correspondence: Zehra Capa, MSc.Institute of Health Sciences, Department of Public Health Nursing, Dokuz Eylul University, 35320, Izmir, Turkey zehracapa@gmail.com

Abstract

First COVID-19 case was first reported on December 31, 2019, and has become a major public health problem, spreading from China to the whole world in just two months. All people, regardless of age, gender, or health status, were at risk of becoming infected with SARS-CoV-2. The COVID-19 pandemic measures taken in this process have led to the emergence of various obstacles in accessing quality health care for children with chronic diseases. These children faced problems such as not being able to get the necessary treatment and counseling for their illness, not being able to access rehabilitation services, not being able to benefit from tele-health services adequately, and not being able to provide the necessary equipment for the disease in sufficient number. During the pandemic nurses have responsibilities such as; providing physical activity with a balanced diet for children with chronic diseases, preserving mental health, applying the vaccination schedule suitable for the age period without interruption, continuing routine follow-ups, providing the necessary medical equipment for the treatment of chronic disease and cooperation with the school administration. In addition, they have roles to protect these children from COVID-19, such as monitoring the symptoms of COVID-19, ensuring that they wear a mask, and informing them about the ways of transmission.

Keywords: COVID-19, chronic diseases, nurses, children.

Background: Chronic diseases are important for public health because they cause the most deaths in the world. Each year 41 million people die of chronic diseases. Cardiovascular diseases constitute most of these deaths, followed by cancers, respiratory diseases and diabetes (Almis & Yakinci, 2012; Proimos & Klein, 2012; WHO, 2018a; Yenici, Aydinli & Caliskan, 2019). Although morbidity and mortality caused by chronic diseases are mostly seen in adulthood, exposure to risk factors begin in the early stages of life (WHO, 2013b). Depending on many environmental, genetic and vital habits, the prevalence of chronic diseases increases from birth to infancy and childhood. Van Cleave, Gortmaker and Perrin (2010) has defined chronic illness for children and adolescents as "any physical, emotional or mental condition that requires regular use of medication or equipment that prevents the child from attending regular school, regular schoolwork and normal childhood activities with a need of frequent care

or treatment of a doctor or other healthcare professionals." An estimated 1.2 million adolescents and children under the age of 20 die each year of treatable chronic diseases, accounting for 13% of deaths from global chronic disease (UNICEF, 2020a).

Effects of Chronic Disease On Children and Family: The child being diagnosed with a chronic disease affects not only the child, but also the child's mother, father, siblings and inner circle (Table 1).

Effects on the Child: Children with chronic diseases experience various social, psychological and developmental problems, depending on the disease and causes resulting from the disease (Er, 2006). Among children diagnosed with arthritis, chronic pain, joint deformities, growth retardation are widely seen (Akgun Kostak & Ozyazicioglu, 2015). Also, among children with cancer, symptoms such as fatigue, oral mucositis, nausea-vomiting, pain, and alopecia (Gunay &

Polat, 2015) can be seen. Growth and development retardation is frequently encountered in children with chronic kidney disease (Korkmaz & Erdem, 2015). In addition,

hearing-vision disorders seen in childhood negatively affect the development of the child's speech and language skills, causing learning difficulties (Tas Arslan & Geckil, 2015).

Table 1. Effects of Chronic Disease on Children, Parents and Siblings (Oguzhan, and Erden, 2012).

Effects on the child	Effects on the parents	Effects on the siblings
-Stubbornness, disorder, difficulty in adapting dependent behaviors -Depression, emotional distress - School absenteeism, academic and social problems -Grief response -Behavioral problems	-Declining hope for the future -Anxiety and depression -Stress, Guilt, Compliance problems -Over protective approach towards the sick child -Family discussions -Increased maintenance burden	-More identification with a sick sibling Fear of getting sick -Anxiety Feelings of guilt - Insulation, a feeling of loneliness -Anger -Increased responsibility The pressure to be the perfect kid

Chronic diseases in children emotionally can lead to psychological effects such as fear, anxiety, depression, anger, introversion, misunderstanding, anti-social behavior, and conversion (Gultekin & Baran, 2005). Chronic illness can have negative effects on children's developmental stages and their educational achievement (Er, 2006). These children are absent from school more frequently and for longer periods than their healthy peers. Absenteeism problems affect the child's cognitive development, sense of normality and psychosocial well-being. In addition, these children may experience adaptation problems when they return to school after a long time (Boonen & Petry, 2011).

Effects on The Family: Chronic disease also has various effects on parents. The sickness of children is an important source of anxiety and fear for families and causes changes in the family's life. The hospitalization of the child due to chronic illness causes the parents to think that it is a serious health problem combined with financial difficulties for the family, interruption of daily activities, and increased need for care of the child, increase the anxiety levels of parents excessively (Gunay, Sevinc, & Aslantas, 2017). Parents may feel helpless seeing their child in pain. Complications of the disease and

uncertainty of the treatment process, the presence of medical devices or applications, painful procedures, fear of death, external physical changes related to treatment, and witnessing the pain and loss of other hospitalized children increase the anxiety level of families (Oguz Guner, 2020). Due to psychological trauma that is triggered by incomplete recovery of the child's chronic illness, disability, need for constant care, economic expenses, nutritional requirements and uncertainty can symptoms of stress, anxiety and depression can be observed in the family (Yenici, Aydinli & Caliskan, 2019). Technological advances for treating chronic diseases and conditions have enabled children to be cared for at home. This means that parents with many other responsibilities face additional responsibilities and must make time to care for the child. Parents who have children with chronic diseases also experience difficulties in their working life, such as lack of flexible working hours, absenteeism, dismissal and non-supportive attitudes of employers (Kish, Newcombe & Haslam, 2018). Also, the siblings of children with the disease are also affected in various ways (Alderfer, Labay & Kazak, 2003). The quality of life of healthy siblings of children with chronic diseases is greatly affected. Emotions such as depression, aggression, introversion, guilt and

anxiety can be observed in siblings. Many factors determine the psychosocial influence level of siblings, such as the type and severity of the chronic disease, the time elapsed after the diagnosis, the age and gender of the healthy sibling, and the ability to cope with the condition (Dinleyici & Sahin Dagli, 2018). Siblings may experience eating and sleeping disorders, depression, anger, anxiety, guilt and social isolation against their illness. During more serious stage of the disease, the emotional needs of the healthy sibling may be ignored, since all attention is directed to the sick sibling. Therefore, siblings are the unhappiest and emotionally neglected members of the family in the process (Sloper, 2000; Er, 2006; Oguz Guner, 2020).

Problems of Children With Chronic Diseases During The COVID-19 Pandemic: The new type of coronavirus, called COVID-19, has affected the whole world by causing epidemic deaths and has affected the economy in various ways (Fernandes, 2020). All people, regardless of age, gender, or health status, are at risk of becoming infected with COVID-19. Furthermore, there are vulnerable groups at higher risk of developing a severe COVID-19 (Brough et al., 2020; Centers for Disease Control and Prevention; Morbidity and Mortality Weekly Report-CDCMMWR, 2020; Dong et al., 2020; Pathak et al., 2020; Stower, 2020). Children with chronic diseases are also at risk during the COVID-19 period due to their illnesses not being managed properly. For this reason, the management of chronic diseases becomes more important during the pandemic period. Additional diseases such as diabetes, adrenal insufficiency, chronic lung diseases, cancers, immune deficiencies, chronic kidney failure and neurological disorders in children can increase the risk of serious illness and death due to COVID-19 (Erener, 2020; Evliyaoglu, 2020). Children with chronic lung diseases, developmental retardation, congenital defects, type I diabetes, chronic heart disease, neurological disease, cancer, and asthma that impairs lung function are medically vulnerable to both the risk of infection and the severity of the disease (Gotzinger et al., 2020; Munro & Faust, 2020; Pathak et al., 2020). In a study (CDCMMWR, 2020) data from 149,760 laboratory-confirmed COVID-19 cases in the United States were analyzed, 2,572 of the known age of 149,082 cases were children under 18

years of age. It is stated that, there was at least one underlying chronic disease in 80 of 345 pediatric cases, the most common of these; chronic lung disease, cardiovascular disease and immunosuppression. According to the study in which the data of 130 children diagnosed with COVID-19 in Italy in the first months of the pandemic were shared (Parri et al., 2020), 34 of the children had respiratory, cardiac or neuromuscular chronic comorbidities. In the study by Blumfield and Levin (2020) on COVID-19 infection in children, it was stated that 12 patients had another concomitant chronic disease. The COVID-19 pandemic has been a period in which barriers to accessing quality healthcare for children have emerged (UNICEF, 2020b). This situation is also valid for children with chronic diseases. During the COVID-19 epidemic, especially children with a history of cancer were at serious risk of not getting the treatment required by their diseases, as they could not easily access hospitals due to restriction measures and the risk of infection. (Ruggiero, Romano & Attinà, 2020; Sloane, Ozuah & Wasswa, 2020). Cancer diagnosis system was broken because of problems in the referral to a higher health institution (Carpenter et al., 2020). During the COVID-19 pandemic period, when children with cancer are hospitalized for treatment, restricting visitors or allowing only one parent to be present, and not allowing to see siblings, friends and other family members negatively affect these children. In addition, fever, a common side effect of cancer treatment in children, required many tests and examinations for COVID-19. Cases such as taking swab samples for COVID-19 and requiring isolation while waiting for test results have also been extremely negative for children with cancer (Gillam et al., 2020). Difficulties in procuring chemotherapy and supportive medicines due to closed international borders, travel restrictions preventing children who are scheduled for chemotherapy from attending their appointments, decrease in existing blood products due to lack of donors, infection because of assignment of healthcare professionals who care for children with cancer to other services to care for COVID-19-positive patients, and increased risk of transmission are among the other problems experienced by children (Sloane, Ozuah & Wasswa, 2020). Children with diabetes are another group that negatively affected by the pandemic. The pandemic caused disruptions in the drug supply chain, making it difficult for

children with diabetes to access glucose measurement tools, oral antidiabetic drugs and insulins. These situations prevented the collection of sufficient data to evaluate the diabetes of the child, causing disruptions in diabetes management and experiencing various complications (Addala et al., 2021). The quarantine period and hospitals' insecurity in terms of infection risk caused diseases other than COVID-19 to remain in the background. Children with chronic diseases disrupted their routine follow-up or did not care about their health-related complaints, which caused them to admit to the hospital at the last stages of their disease with severe diabetic ketoacidosis (Evliyaoglu, 2020). In addition, the obligation to stay home and restrictions during the pandemic causes weight gain in children with diabetes (DiMeglio et al., 2020). Similarly, children with a developmental disability and neurological problems have also experienced various difficulties during the pandemic. Panda and Sharawat (2020) stated that due to strict isolation measures in some countries, children with epilepsy and neuromuscular disease are deprived of drug therapies. Evidence shows the importance of physical rehabilitation for pediatric patients with chronic neurological disorders, and during the pandemic, the physical health of these children was negatively affected by the disruptions in receiving rehabilitation services (Neves, 2013; Longo, de Campos & Palisano, 2019). The inability of children to receive rehabilitation services for various reasons may cause complications, soft tissue contractures, bone deformities, decline in motor functions, dysphagia and respiratory difficulties (Meireles & de Meireles, 2020).

Simultaneously, the COVID-19 pandemic has resulted in less assistance and inadequate education, especially for children with disabilities (UNICEF, 2020c). Disabled children in social isolation in developing countries have had problems in accessing necessary treatments (Meireles & de Meireles, 2020). Nurses, social workers, speech therapists, and physiotherapists in charge of the rehabilitation of these children could not provide services to the children because of the risk of transmitting the infection. Within the scope of pandemic measures, educational institutions, especially social places considered risky, were closed and distance education was started (Kalac, Telli & Eronal, 2020; The United Nations Educational, Scientific

and Cultural Organization-UNESCO, 2020). With the closure of schools, out-of-school activities decreased and thus children had to spend more time at home (Caron et al., 2020). Increased stress level in the families can increase violence against children (Bhatia et al., 2020). Violence against children is a multifaceted problem with causes at individual and societal levels, and the presence of a child's illness or disability also increases the risk of violence (WHO, 2020c). (The Office of the High Commissioner for Human Rights-OHCHR, 2020; UNICEF, 2020d).

During the pandemic, some countries reported problems with inhaler deficiencies and nonpayment by insurance for equipment used in asthma treatment. This situation creates difficulties for children with asthma who require constant and regular treatment (Sinha et al., 2020; AAP-American Academy of Pediatrics., 2020a). The fact that children with chronic diseases and disabilities are in a higher risk group due to increases both their and their families' anxiety and anger levels. These trigger uncontrollable anger behaviors in the family more than non-pandemic periods (Mertoglu, 2020). Children with Autism Spectrum Disorder do not see familiar faces, their routine habits are disrupted, their education is interrupted, and their violent behavior and behavioral regression in a closed environment pose serious difficulties for the families of children (Kara & Alsancak, 2020).

Recommendations for Children With Chronic Disease During COVID-19 Pandemic; The following recommendations can be made to protect children with chronic diseases from the negative effects of the COVID-19 epidemic and to maintain their health:

- During the pandemic, a healthy diet is critical. Considering the current deaths, the virus is particularly a risk for individuals with chronic illnesses and weakened immune systems. Therefore, healthy and balanced nutrition of children with chronic diseases is critical for the growth and development of children (Turker, 2020; WHO, 2020d).
- The COVID-19 pandemic has been a time when most of us stay home more than usual (Kucuk Bicer & Ilhan, 2020). With the closure of the schools and implementation of the curfew, the children could not perform sufficient physical activities (Bahsi & Korkmaz, 2020). Being

physically active during the pandemic has become even more important as insufficient physical activity brings along many health problems. Children should do physical activity outdoors as much as possible. It is recommended for a child to spend time outside every day, if possible, by following the social distance rules. It is especially recommended for children with autism spectrum disorder to exercise regularly, as it will reduce sleep problems (AAP, 2020b). Furthermore, aerobic activities such as games and indoor walk, and strength activities such as gymnastic weight training, rope pulling, squatting and standing up are recommended to children with adequate abilities (Bahsi & Korkmaz, 2020).

- To minimize the stress that children experience during the pandemic, a flexible but consistent routine should be established daily. Activities appropriate for the age and developmental level of children with chronic diseases should be planned. (AAP, 2020b; WHO, 2020e).
- Routine follow-up and treatment of children with chronic diseases should continue during the pandemic. (Evliyaoglu, 2020). In addition, it should be explained how the child can protect himself from COVID-19 infection and try gaining a correct hand washing habit.
- By discussing the versatile needs of their children with families, it should be ensured that educational activities continue as much as possible in this period and that they do not break away from the education process. For children with chronic illnesses and special needs, a child-specific approach should be adopted (Hamilton, 2021).
- It is important to provide teachers with guidance and resources of online training during the pandemic (UNESCO, 2020). Also, teachers should speak naturally and clearly, not too fast. For children with Asperger Syndrome-Attention Deficit-Hyperactivity Disorder-Special Learning Difficulty/Autism, details such as establishing eye communication and enabling them to participate in lessons by interacting with them should be considered (Kara & Alsancak, 2020; Van Lancker & Parolin, 2020).

The following recommendations can help protect children with chronic diseases from COVID-19 infection:

- Two important ways to help protect children with chronic illnesses from COVID-19 are hand washing and cleaning surfaces that the child comes into frequent contact. It is important to remind family members or caregivers to wash their hands frequently for at least 20 seconds (AAP, 2020b; Ruggiero, Romano, & Attina, 2020).
- For children with chronic illnesses, avoiding 3C (closed spaces, crowded places, close contact) will reduce the risk of spreading the disease. In closed areas, especially with poor air flow where physical distance alone is not sufficient, close contact should be avoided in crowded places (AAP, 2020b).

- It is critical to ensure that some children with developmental, emotional or mental disabilities wear masks and become accustomed to wearing masks. Families can use social story and game methods to help their children recognize masks (AAP, 2020b; Esposito & Principi, 2020). Anyone caring for children with the disease should also wear a mask, especially in confined or crowded places. (Esposito & Principi, 2020; AAP, 2020b).

- People who are in close contact with lip-reading children can use a transparent window face mask. While face shields are not a replacement for a mask, they can only provide extra protection. (AAP, 2020b).

The Role of The Nurses in The Care of Children With Chronic Diseases During The Pandemic: Individuals with chronic illnesses or disabilities should be cared for in terms of physical, mental and social aspects and their illness. Nurses have important responsibilities in providing this care (Akpinar & Ceran, 2019; Cakir & Altay, 2021). Nurses have important roles for children with chronic diseases and their families in the period of the epidemic that has affected the whole world. Providing education and counseling both the child and their families to maintain the physical, psychosocial and educational health of these children are among these roles. Nurses should provide education and counseling to children and their families in line with their needs, such as adequate and balanced nutrition, compliance with diet, physical exercise, compliance with treatment, regular use of medicines, management of chronic disease and life and disease symptoms (Akgaya Alahan, Aylaz & Yetis, 2015; AAP, 2020a). As it is known, chronic illness causes the child and family to be affected psychologically and socially as well. The role of the nurse in this area is to help the patient and family adapt to the lifestyle changes caused by the disease, prevent incompatibilities and increase the child and the family's adaptation to the disease by improving their coping skills (Ozdemir & Tasci, 2013; Durna & Oguz, 2018). It may also be beneficial to provide consultancy to children and their parents on social groups, associations and non-governmental organizations that include children with similar diseases (Cakir & Altay, 2021). Nurses also have responsibilities for the care and follow-up of children with chronic diseases at school during the pandemic. The physical evaluation (height-weight tracking, scans, etc.), following the treatment of the child (creating an individualized care plan, tracking drug use, blood glucose measurement etc.), responding to

emergencies (creating an emergency action plan, keeping drugs to be used in emergency response, etc.), monitoring nutrition (tracking children with special diets, teaching carbohydrate counts to children with diabetes, informing teachers about snacks, supervising the school canteen and cafeteria), physical activity and exercise planning (ensuring children's participation in physical activities, determining exercise time, etc.), and organizing the school environment (improving hygiene conditions, keeping children away from allergens, creating an infirmary, etc.) can be listed among these responsibilities (Best, Oppewal, & Travers, 2018; Cakir & Altay, 2021). It is important to meet the needs of children with chronic diseases during this period. For these children, it is important to maintain supply chains, to ensure access to medicines, to manage diseases and to minimize their adverse effects (Bhutta et al., 2021). Nurses should provide counseling to families in this period and cooperate with other disciplines.

Children with developmental disabilities may have difficulties in understanding and adapting to changes such as not being able to see their teachers/classmates during the pandemic, having to wear masks or staying away from people outside their homes. For these children, nurses should cooperate with school administrators, teachers and family to maintain daily routines as much as possible or to develop new routines (i.e., regular exercise, singing, painting, regular communication by phone with friends, e-mail, social media or video calls) (Poon, 2020). Although inpatient treatment is common practice for children receiving intensive chemotherapy or stem cell transplantation, most children with cancer can be treated in an outpatient setting. The use of outpatient and telehealth services are recommended during this period. Nurses should provide health education to families to adhere to standard precautions, not to contact the child with the sick person to reduce the risk of transmission, and to follow the social distance rule to limit potential exposure (Kotecha, 2020). It might be necessary for children with special needs to visit one or more hospitals for rehabilitation and treatment services. Here, the healthcare team should decide which visits can be made virtually and which ones should be made to face to face. Nurses should play a primary role in this team. In cases where face-to-face meetings are necessary, providing a separate department for these children in the health

institution or making an early appointment can be considered (AAP, 2020b).

Conclusions: The COVID-19 epidemic, which affects the whole world, are still continuing, and children with chronic diseases are adversely affected by this period for various reasons. In this period, nurses have important roles in protecting and improving the health of children with chronic diseases and protecting them from COVID-19 infection. Nurses are among the top responsible group for children to continue their treatment, and developmental process without interruption. Nurses should co-operate with families and other disciplines to provide health education to children and families in order to sustain their health and protect them from COVID-19 infection.

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