

# Evaluation of Families' Views on Disease Management by Applying Telemedicine During the COVID-19 Pandemic

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## Abstract

The Coronavirus disease-2019 pandemic has led to the spread of telemedicine management of ketogenic diet therapy (KDT) in children with drug-resistant epilepsy (DRE). In this study, we evaluated the views and satisfaction of families about telemedicine and KDT management. Families of 25 children who underwent KDT for DRE were included in the 17-item questionnaire. Nearly half of the families had a primary education level. Most children with DRE were in the process of maintaining KDT. 88% of the families were applying KDT with telemedicine due to the pandemic. 60% of families found it difficult to start KDT via telemedicine, but 96% reported that reaching the KDT team via telemedicine was sufficient. The necessity of laboratory analyzes and evaluation of the results of the KDT team was evaluated as good in 72%, and their response when dietary changes or vitamin addition was required was evaluated as good in 68%. All families were satisfied with the management of the KDT team in emergencies. 60% of the family recommended others to follow the KDT with telemedicine at all times and 40% recommended them during the pandemic period. According to the results of our study, in selecting patients who will be started with telemedicine and KDT, it should be noted that the families have sufficient education levels. The use of the telemedicine method may be a good option in the presence of an experienced and trained team in KDT management.

**Keywords:** Telemedicine, ketogenic diet therapy, drug-resistant epilepsy, childhood, parent

## Introduction

Drug-resistant epilepsy (DRE) is defined as the inability to control seizures despite the use of two antiseizure drugs as monotherapy or in combination at the maximum tolerated dose. Dietary therapy has a beneficial effect on patients with epilepsy, but the outcome is largely dependent on

adherence to diet.<sup>1</sup> Ketogenic diet (KD) therapy (KDT) is a dietary therapy for people with the most common non-pharmacological DRE. The KD switches brain metabolism from glucose addiction to the use of ketone bodies. For treating epilepsy in children, four different KDTs are used: Classical KD, modified Atkins diet, medium chain triglyceride-KD and low glycemic index therapy.<sup>2-4</sup>



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Particularly during the Coronavirus disease-2019 (COVID-19) outbreak, it is important to assess child and/or family satisfaction with whether health systems meet the patient's needs. A survey-based study can be a useful tool to evaluate parental satisfaction. Surveys can have many advantages: family members can answer questions together, which can alleviate their fears. On the contrary, surveys are accepted more economically and faster than face-to-face interviews.<sup>5</sup>

Telemedicine involves the application of information and communication technology (ICT) in various healthcare domains, particularly when the geographical separation plays a pivotal role. From the initial recorded instance of a telephone-based consultation in 1879, remarkable advancements have occurred in leveraging telemedicine within child and adult neurology spheres.<sup>6-9</sup> Telemedicine is emerging as a feasible substitute for conventional medicine or as a supplementary approach to diminish and enhance disparities in healthcare access.<sup>7</sup>

In recent years, there has been significant progress in the advancement of novel telemedicine technologies, including smartphone applications. During the ongoing COVID-19 pandemic, e-health applications have been extensively used to reduce the risk of cross-contamination from close contact. Indeed, the adoption of e-health solutions has been crucial as we continue to provide information to patients and caregivers, while also trying to straighten the curve of rising COVID-19 cases.<sup>10</sup> During the COVID-19 pandemic, healthcare professionals sought to enhance the care of individuals with epilepsy through the utilization of telemedicine services.<sup>11-13</sup> Amidst the COVID-19 pandemic, the implementation of KDT for children with DRE through telemedicine has been practical and warmly welcomed by families and patients in Argentina<sup>14</sup> and the United States.<sup>15</sup> In Italy, although the use of e-health technologies and telecommunication and remote monitoring has increased recently, sufficient information for the long-term management of KDT is not readily available to patients and caregivers. Therefore, the free access of patients and caregivers to different e-health resources should play a key role in the dietary management of DRE. Specific guidelines and therapeutic approaches should be improved for patients following KDT, particularly in the acute medical setting.<sup>16</sup> A sudden change in eating habits (leakage) and constant monitoring of possible side effects are required during the administration of this particular treatment.<sup>17</sup> Numerous studies have been published regarding using telemedicine as the primary means for managing KDTs in patients with DRE.<sup>18,19</sup>

In this study, we determine the views and satisfaction of families of children with DRE regarding supervising KDT via telemedicine during the COVID-19 pandemic. Thus, awareness will be created for patients to be exposed to better practices during the pandemic.

## Material and Method

Twenty-five families who wanted to participate were included in the study, among the families of children with DRE who underwent KDT, who were followed up by the pediatric neurology department of our hospital.

KDT was initiated and followed by the KDT team in our hospital. As a pediatric neurologist in this team, A.Ü. and U.Y., Z.A. as a dietitian, S.B. was involved as a KD nurse. In this period, pediatric neurology fellows M.Y., İ.B.P. and Dr. P.K. have been found as pediatricians. They were asked to fill out a questionnaire consisting of 17 questions sent by phone or e-mail. Consent was obtained from the patient and/or their families while conducting the survey. The questions were about KDT management via telemedicine during the COVID-19 pandemic, so Ministry of Health approval was obtained. KD training was given by the dietician and KDT nurse in our hospital in the ward where the patient is inpatient and in outpatient clinics if the patient is followed up. In patient education, information about the disease is given and treatment options are discussed. It provides appropriate patient selection, and the necessary information about the KD is given to the family (for outpatients or inpatients). Evaluates patient/family readiness for a 2-month trial period of KDT; willing to life-type changes, evaluate support systems, monitor the patient's condition, monitor seizure activity, teach the signs/symptoms of ketone elevation/hypoglycemia, disease management plan, reducing side effects (constipation/diarrhea, kidney stones, etc.), define emergency seizure management information about emergency medicine, first aid for seizures, problems are discussed when to call the 112 emergency room/when to go to the emergency room.

This study is a descriptive cross-sectional survey. Ethical approval was obtained from the ethics committee of the University of Health Sciences Turkey, Dr. Behçet Uz Children's Training and Research Hospital with the number 2021/12-11, date: 08.07.2021. The questionnaire included questions about the sociodemographic characteristics of the families and their views and satisfaction with disease management by applying telemedicine for KDT during the COVID-19 pandemic.

## Statistical Analysis

Categorical information will be analyzed through relative frequencies, whereas numerical data will be evaluated using either the median or mean, depending on their distribution characteristics (whether they follow a normal distribution or not). When comparing categorical factors, we will employ either Pearson's  $\chi^2$  test or Fisher's exact test. On the other hand, for numerical attributes, a comparison will be made using either the t-test or the nonparametric Mann-Whitney U test. We will consider a significance level of less than 0.05 as indicating statistical significance.

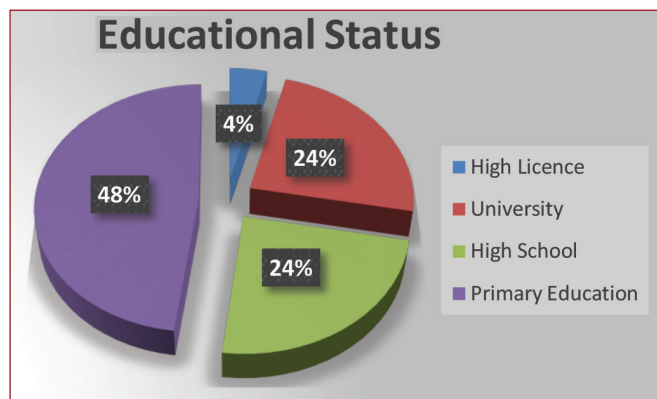
## Results

The study included 23 (92%) mothers and 2 (8%) fathers who agreed to participate in the survey. The mean age was 33.7 years. Of the families, 12 (48%) had primary education, 6 (24%) had high school, 6 (24%) had a university, and 1 (4%) had a master degree (**Figure 1**). The income level of the families was medium in 22 (88%) and high in 3 (12%). The place of residence was determined as 13 (52%) families in the province

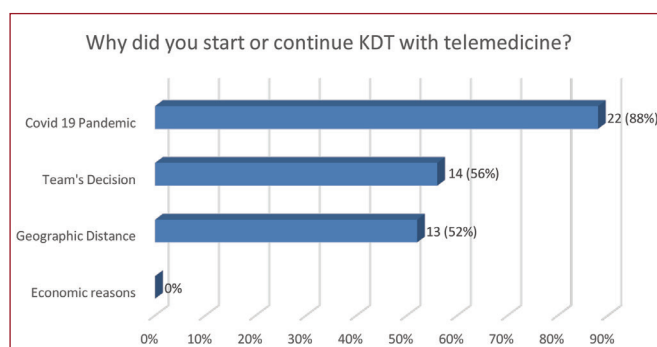
and 12 (48%) families outside the province. During the pandemic, 1 (4%) patient was in the pre-diet evaluation phase, 5 (20%) patients were in the initial phase, and 19 (76%) patients were in the maintenance phase.

**Figure 2** shows the reasons for starting or continuing KDT via telemedicine. To the question of whether it would be easy to prepare food via video if the initiation of KDT was done with telemedicine; 1 (4%) answered as easy to understand, 9 (36%) difficult to understand, but I can do it via teleconsultation, 15 (60%) answered as very difficult to understand and we need face-to-face communication. To the question of learning how to control ketonemia/ketonuria with telemedicine, 1 (4%) answered as easy, 9 (36%) difficult but manageable by teleconsultation, 15 (60%) very difficult to understand and need to be done face-to-face. **Figure 3** shows the advantages of starting or continuing KDT with telemedicine.

Reaching the KDT team during the pandemic was evaluated by 24 (96%) as adequate and 1 (4%) as insufficient. **Figure 4** shows the necessity of laboratory data and the evaluation of the results by the KDT team through WhatsApp during the pandemic process. When the child had an emergency, 18 (72%) answered good and 7 (28%) answered excellent to the question of how you would evaluate the team's response to solving the problem. Twenty three (92%) stated that the KDT team provided family support



**Figure 1.** Educational status of parents who use ketogenic diet therapy.



**Figure 2.** Reasons for starting or continuing ketogenic diet therapy with telemedicine.

*KDT; Ketogenic diet therapy*

groups via WhatsApp as beneficial, while 2 (8%) did not find it beneficial.

**Figure 5** shows the answers given to the question of how you would evaluate the KDT team's response if changes in diet or adding vitamins are required during the pandemic according to laboratory results.

**Highlights**

- Telemedicine remote monitoring of ketogenic diet therapy (KDT) in children with drug-resistant epilepsy is possible and is likely to be as safe and effective as conventional medicine.
- In the remote management of a non-pharmacological treatment such as KDT, the education level of the family should be considered in a patient selection.
- Telemedicine may be a good option for KDT management, as long as it is coordinated by a well-trained multidisciplinary ketogenic diet team.

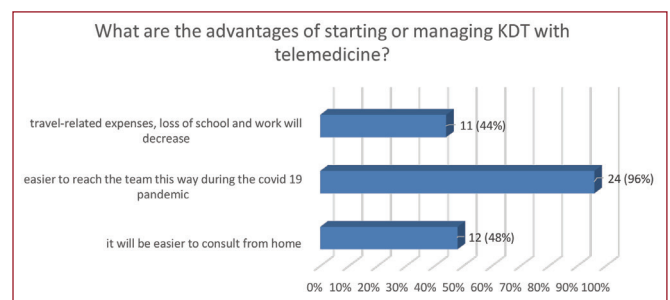
To the question of what is the probability of receiving a response via telemedicine when you need a change in recipes (for economic reasons or because of difficulty in accessing food), 22 families (88%) answered good and 3 families (12%) answered excellent.

**Figure 6** shows how parents evaluated their communication with the KDT team during the pandemic. Fifteen (60%) parents recommended treatment with telemedicine only during the pandemic period, while 10 (40%) always recommended treatment with others.

## Discussion

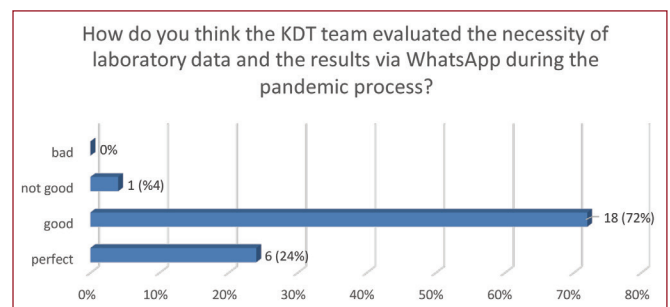
During the COVID-19 pandemic, the management of patients with epilepsy can be facilitated with telemedicine services. In our study, it was found that pediatric neurologists and families of children with epilepsy used the telemedicine method while maintaining KDT, and patient satisfaction was good in this regard.

In a survey conducted by Semprino et al.<sup>14</sup>, they found that the management of children with DRE who received KDT was applicable via telemedicine and was accepted by the families. They reported



**Figure 3.** Advantages of initiating or managing ketogenic diet therapy with telemedicine.

*KDT; Ketogenic diet therapy*



**Figure 4.** Evaluation of the necessity of laboratory data and results by the ketogenic diet therapy team through WhatsApp during the pandemic process.

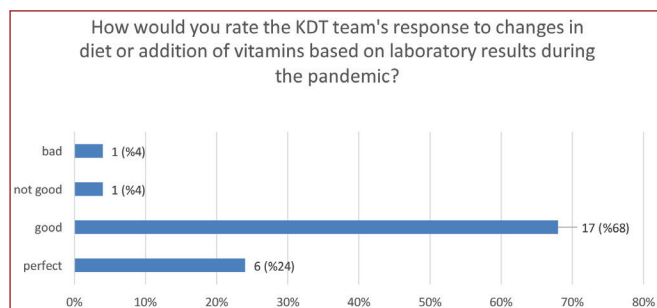
*KDT; Ketogenic diet therapy*



that during the pandemic, they were more likely to continue KDT with telemedicine and the team could be easily reached from the convenience of their home. In contrast to our investigation, the majority of families expressed a preference for telemedicine adoption in all circumstances, irrespective of the COVID-19 pandemic. None of the families indicated any opposition to telemedicine interventions. In our study, the fact that most families preferred the telemedicine application during the pandemic and that they preferred face-to-face education outside the pandemic made us think that it may be related to socio-cultural situations. Similar to our study, ninety percent of the participants reported positive outcomes from a social support network (the WhatsApp family support group) administered by the KDT team.

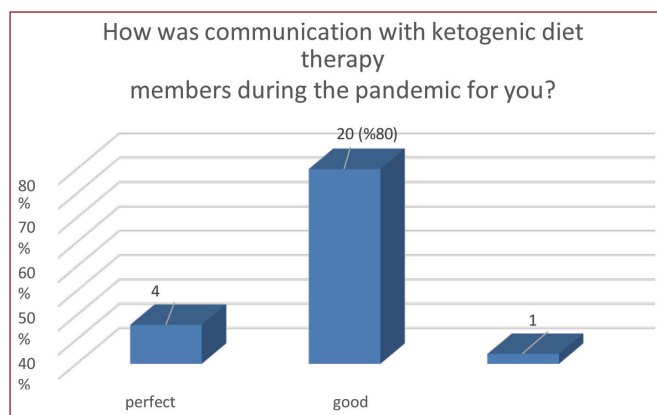
In an Italian study, they evaluated the feasibility, patient acceptability, and satisfaction of family caregivers using different web materials, including smartphone apps, websites, and videos, for the management of KDT. Specifically, they conducted an analysis designed specifically for children with DRE and aimed to compare the beneficial effects of paper-based and web-based information materials on KDT. The use of e-health applications in the daily management of the KD is a promising tool, especially valuable in attempting to start or maintain a diet during the ongoing COVID-19 pandemic.<sup>20</sup>

Recently Kossoff et al.<sup>15</sup> shared their successful outcomes in implementing and maintaining KDT using telemedicine for both children and adults at the Johns Hopkins KDT center during the COVID-19 pandemic.



**Figure 5.** Changes in diet or adding vitamins according to laboratory results of the ketogenic diet therapy team during the pandemic.

KDT; Ketogenic diet therapy



**Figure 6.** Changes in diet or adding vitamins according to laboratory results of the ketogenic diet therapy team during the pandemic.

KDT; Ketogenic diet therapy

The study employed various online platforms such as Zoom, Polycom, or Doximity to communicate with families and patients through phone calls and e-mail. The authors provided recommendations on effectively managing KDT during the pandemic. Initial virtual visits lasted between 60 and 120 min, with additional time allocated to educate patients and caregivers about telemedicine services before the actual visit. Depending on the clinic's requirements and the patient's needs, dietitians attended the televisit, followed by a separate phone call or responses to questions via the secure messaging system in the electronic medical record. The workflow was further improved by including a medical assistant who engaged with patients and families before the visit, guiding them on how to connect to the telemedicine session 15 min before it began. During 8 h, they could virtually see 8 children. Parents received an email a week ahead of their appointment, requesting them to install Zoom™ on their devices with cameras and providing necessary information in advance, such as final height and weight, updated medication list, completed forms (including the ketogenic formula), and a list of questions to ask. Each appointment involved discussions with both the neurologist and dietitian, starting with a 20-minute interaction with the parents, followed by a 10-minute video-observed physical examination, and concluding with 15 min of follow-up, including planning diet and medical changes, ordering medication, and interpreting lab tests if needed. The majority of families expressed satisfaction with the experience and appreciated the convenience of avoiding hospital travel and potential exposure to COVID-19. Despite the 2018 KDT consensus guideline for pediatrics recommending that classical KD be initiated in the hospital, 80% of the panelists considered it optional and a reasonable approach during the pandemic, according to 92% of them.<sup>21</sup>

In our study, a significant portion of the parents (60%) stated that if the initiation of KDT was done via telemedicine, it would be difficult to prepare food and learn ketonemia/ketonuria control via video, and they would prefer face-to-face learning. Considering that 48% of the parents were primary school graduates, it was thought that this might be due to the low educational level of the families. The educational status of the families should also be considered when selecting patients who will start KDT with telemedicine.

Ferraris et al.<sup>19</sup> conducted a long-term remote study on classical KDT via e-mail in 34 children with DRE or glucose transporter type 1 deficiency syndrome, reporting that this approach was effective and feasible. In our study, based on laboratory results, most parents (92%) rated the response of the KDT team as good/excellent when dietary changes or vitamin additions were required during the pandemic. ICT plays a crucial role in sharing information, building consensus and coordinating between different teams, particularly for training and consulting through telemonitoring.<sup>20</sup> The rapid spread of the epidemic has shifted the healthcare landscape toward prioritizing care for COVID-19 patients, leading to the transformation of healthcare facilities

into potential sources of transmission. Consequently, new doctor-patient relationship models have emerged. To optimize the access, remote management and monitoring of KDTs, KDT teams should actively promote the use of information and communication technologies. In our study, most of the parents (96%) stated that monitoring via telemedicine was advantageous because they could reach the KDT team more easily.

During the COVID-19 pandemic, there was a pressing need to employ WhatsApp and prioritize the advancement of telemedicine. This entailed ensuring connectivity, cyber, and legal security and educating healthcare professionals and patients about the proper utilization of ICT. Moreover, confidentiality, fair remuneration, and the establishment of a robust ethical framework was also crucial elements that required urgent attention.

In the context of the COVID-19 pandemic, using WhatsApp has provided constant contact and tight control of families as a fast, easy and free communication tool for monitoring patients with DRE using KDT, so that these difficult patients who receive complex treatment do not lose their follow-up. In our research, parents rated the requirement for laboratory data and the assessment of the KDT team's results via WhatsApp during the pandemic as highly satisfactory, with 96% indicating a good/excellent evaluation.

Similar to a previous study, our survey showed high satisfaction with telemedicine and KDT management among patients' families.<sup>21</sup> However, the study has several limitations, while a significant proportion of parents reported satisfaction with questions about maintaining KDT, suggesting that starting KDT via telemedicine may be a better option for parents with higher levels of education. On the other hand, the research was carried out in a developing country, in an area where resources are limited, by using widely used and cost-free communication tools such as e-mail, WhatsApp, and Survey Monkey Survey Forms.

The all-inclusive telemedicine management of KDT has facilitated convenient access to each team member for medical and dietary guidance throughout the COVID-19 pandemic. The majority of families expressed their endorsement of telemedicine adoption in any circumstance, with less regard for the pandemic. Previous literature also recommends the use of telemedicine not only in emergencies but also in daily practice.<sup>14,22</sup>

## Conclusion

Telemedicine's remote monitoring of KDTs in patients with DRE is feasible and potentially just as secure and efficient as conventional medical practices. According to the results of our study, starting KDT via telemedicine may only be more appropriate for families with a sufficient level of education. Therefore, this issue should be considered in the selection of patients who will be starting telemedicine and KDT. Telemedicine could be a viable alternative, given that it is overseen by a proficient, diverse team in the remote administration of a nondrug therapy like KDT.

**Ethical Approval:** Ethical approval was obtained from the ethics committee of the University of Health Sciences Turkey, Dr. Behçet Uz Children's Training and Research Hospital with the number 2021/12-11, date: 08.07.2021.

**Informed Consent:** Consent was obtained from the patient and/or their families while conducting the survey.

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**Conflict of Interest:** The authors have no conflicts of interest to declare.

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