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Research Article

Evaluation of the Knowledge and Attitudes of Pediatric Neurologists Regarding Ketogenic Diet Therapy and Telemedicine Applications in the Covid-19 Pandemic

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Abstract

Introduction: The Covid-19 pandemic has caused some difficulties in ketogenic diet therapy (KDT) applications. We aimed to evaluate the knowledge and attitudes of pediatric neurologists about KDT and telehealth applications during the pandemic by conducting a survey.

Material and Method: Among all pediatric neurologists in Turkey, those who wanted to participate in the study were included and were asked to fill out a questionnaire consisting of 22 questions. The questionnaire was sent via electronic communication channels (e.g. WhatsApp, e-mail).

Results: Thirty six (64%) of the participants stated that their preference for KDT did not decrease, 40 (73%) stated that there was no change in their preference for KDT in hospitalized patients. Forty-one (73%) pediatric neurologists were in contact with their patients via telemedicine. Fifty-three (95%) of the participants thought that KDT could be easily sustained during the pandemic process and did not need to be terminated, 25 (45%) thought that it was more difficult to use KDT during the pandemic period.

Conclusion: In the present study, it was determined that pediatric neurologists were interested in the use of KDT during the pandemic and thus turned to telemedicine as a method of application. Most of them stated that utilizing KDT during the pandemic period is a personalized and advanced treatment. There is a need to create an infrastructure (medicolegal) so that reference centres with experience in KDT can switch to telemedicine applications. Thus, patients who require KDT would have exposure to best practices during the pandemic.

Keywords: *Epilepsy; Child; Ketogenic Diet Therapy; Covid-19 Pandemic; Telemedicine*

Introduction

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is a novel infectious virus that causes coronavirus disease (Covid-19). The outbreak first appeared in the Chinese city of Wuhan in late 2019 and has continued to spread globally ever since. The World Health Organization (WHO) declared a state of pandemic in March 2020. Since then, the epidemic has significantly affected the lives of people worldwide [1]. Epilepsy is a chronic neurological disease characterized by spontaneous recurrence of unprovoked seizures. The Covid-19 pandemic has led to stay-at-home orders and other measures to encourage social distancing by keeping patients and their families at home, with reduced direct access to doctors, electroencephalograms (EEG), and even anti-seizure medication [2]. Ketogenic diet therapy (KDT) is one of the treatment options for drug-resistant epilepsy (DRE). Dietary therapy has a beneficial effect in patients with epilepsy, but the outcome is largely dependent on adherence to the prescribed diet. The classic ketogenic diet, modified Atkins diet, medium chain triglyceride diet, and low glycemic index diet can be utilized for patients with epilepsy [3]. Each of these dietary therapies requires carbohydrate restriction and patience, which may be a barrier to adherence for some patients. Epileptologists and dietitians need to create an environment that facilitates the continuation of diet therapy for patients. The impact of Covid-19 on society and the pandemic has also affected the continuation of KDT for patients with DRE [4,5]. Therefore, maintaining a certain diet during the Covid-19 pandemic is expected to be difficult in some ways.

In recent years, the use of instant messaging services has led to better communication between medical teams and caregivers by simplifying information sharing, initial treatment initiation, and therapy administration from a wide variety of smartphone applications (apps) and online platforms (e.g. Zoom) [6-8]. During the ongoing Covid-19 pandemic, e-health applications have been used extensively to reduce the risk of cross-contamination arising from close contact. Indeed, the adoption of e-health solutions has been crucial to continue providing information to patients and caregivers as societies seek to "flatten the curve" of the growing number of Covid-19 cases. Interestingly, smartphone applications have been preferred because they are easily accessible, and can support social distancing [9].

The ketogenic diet is a high-fat, low-carb diet and is used to control DRE even in the pandemic situation. However, special attention should be paid to the management of this diet [10]. Indeed, the classic 4:1 ketogenic diet is effective in up to 55% of children with DRE after three months [11]. During the coronavirus epidemic, it has been shown that the use of KDT to manage DRE in children has been well received by families and patients for whom telemedicine is available [12]. For this, special guidelines and therapeutic approaches for the care of patients following a ketogenic diet, especially in the acute medical setting, should be developed [13], because a sudden change in eating habits and continuous monitoring of possible side effects are required during this special treatment [14]. Indeed, the ketogenic diet aims to change brain metabolism from glucose dependence to the use of ketone bodies. For this reason, grain-based foods and fruit and vegetable intake are reduced. As a result, several health risks such as gastrointestinal system disorders, kidney stones, growth retardation, hyperlipidemia, as well as mineral and vitamin deficiencies are possible and should be prevented with the help of health professionals. Related to this, the use of remote monitoring through e-health technologies and telecommunications has recently increased [15] because sufficient information for long-term management of the ketogenic diet is not readily available to patients and caregivers [16].

In the management of KDT, regular outpatient visits are made to organize antiepileptic therapy and to manage problems related to KDT. The measures and restrictions imposed due to the pandemic has affected these types of outpatient visits. In addition, many patients prefer not to go to the hospital except for emergencies due to the risk of infection. Due to this preference, epilepsy patients have begun to be evaluated by telephone and video calls. The use of telemedicine services has become especially important in this period since the duration of the pandemic is yet unknown and patient evaluations cannot be postponed indefinitely. Physicians who do not have access to telemedicine services communicate with their patients through various social communication networks, telephone and video calls and short message services. However, the telemedicine method provides a real-time interactive conversation between the patient and the physician [17] and can be more beneficial for treatment.

Aim of the Study

This survey study aimed to reveal the knowledge and attitudes of pediatric neurologists about KDT and telehealth applications during the pandemic period in.

Materials and Methods

Among all pediatric neurologists in Turkey, those who wished to participate in the study were included and were asked to fill out a questionnaire consisting of 22 questions. The questionnaire was sent via electronic communication channels (WhatsApp, e-mail). As the research was related to Covid-19, approval was obtained from the Ministry of Health of the Republic of Turkey and the Ethics Committee of our hospital.

This study is a descriptive, cross-sectional survey study. A 22-item questionnaire was prepared and distributed using Microsoft Forms via social communication services to all child neurologists in Turkey. Before starting the survey, all participants were informed about the purpose and anonymity of the research. The survey was open for two weeks, with data collected over the period of one month. The study protocol was approved by the Turkish Ministry of Health and ethical approval was obtained from the ethics committee of the University of Health Sciences, Behçet Uz Children's Hospital (202l/12-10). The questionnaire included items about the sociodemographic characteristics of the participants as well as items about their knowledge, attitudes and behaviours related to the use of KDT as a treatment course for patients with DRE during the pandemic period.

Results

Most (87%) of the respondents were between the ages of 36-55 and 37 (66%) were women. Figure 1 shows the age ranges of pediatric neurologists. Thirty-three (59%) of the participants had been working as a pediatric neurologist for 5-20 years, 28 (50%) were presently using KDT and 28 (50%) were not. Thirty-four (61%) of the pediatric neurologists participating in the study had sent patients to another centre for KDT, 50 (91%) were seeing patients who had received KDT at another centre. Forty-four (79%) of the participants stated that the number of patients with DRE did not change after the pandemic, 36 (64%) of them stated that their preference for KDT did not decrease, 40 (73%) stated that there was no change in their preference for KDT in hospitalized patients (such as status epilepticus, infantile spasm). Forty-one (73%) pediatric neurologists were in contact with their patients via electronic communication channels (social media tools such as telephone, e-mail, WhatsApp). Forty-one (75%) participants thought that Covid-19 infection was not affected by KDT. During the pandemic, 47 (85%) of pediatric neurologists considered using the modified Atkin's diet (MAD)or(LGIT) low glycemic index diet as treatment options, 22 (39%) stated that starting KDT with a new AED was a more viable option. Twenty-four (43%) stated that the risk of side effects of KDT is lower than a new antiepileptic drug (AED), 47 (84%) stated that utilizing KDT during the pandemic period is a personalized and advanced treatment. Figure 2 shows the reasons for discontinuing the KDT. Of the pediatric neurologists, 51 (91%) knew that the MAD is an effective and safe type of KDT that can be used without hospitalization, 49 (88%) knew that MAD does not require weighing food, and the risk of hypoglycemia and hyperketosis is less than with the classic KDT. Fifty-five (98%) of the participants knew that in patients with a gastrostomy tube, the formula could be easily converted to KDT formula, which could be paid for by the insurance, and home care services could be used. Fifty-three (95%) of the participants thought that KDT could be easily sustained during the pandemic process and did not need to be terminated, 25 (45%) thought that it was more difficult to use KDT during the pandemic period.

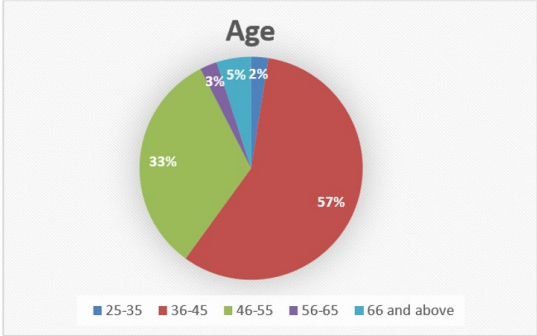

Figure 1: *The age ranges of pediatric neurologists.*

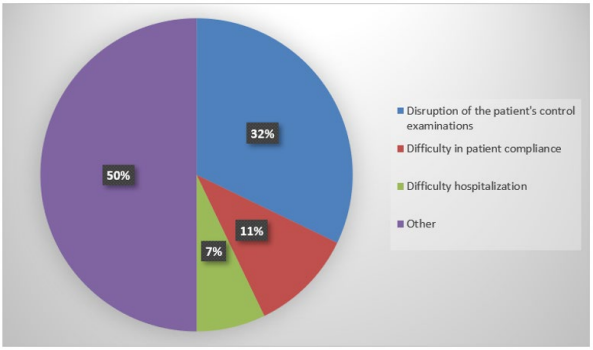

Figure 2: *Reasons for the decrease in preference for ketogenic diet therapy after the pandemic.*

Discussion and Conclusion

In the present study, most of the pediatric neurologists who participated (95%) thought that KDT could be sustained during the pandemic period and did not need to be terminated, while less than half (45%) stated that it would be more difficult to start using KDT during the pandemic. Not all centres offer KDT services, and clinicians and dietitians in those that do may be redeployed to assist with other services during the pandemic. There were also concerns regarding the potential risk of exposure to Covid-19 in a hospital setting where infected individuals are treated [2]. For these and similar reasons, pediatric neurologists may have concerns about the initiation of KDT and may even believe that it is not appropriate or practical to start this type of treatment during a pandemic [3]. In this study, few (39%) pediatric neurologists responded that starting KDT instead of a new AED was the more appropriate option, and 43% believed that the risk of side effects with KDT was lower than with a new AED.

Coronavirus disease (Covid-19), a new infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has significantly affected the lives of people around the world. It is therefore expected that in some ways maintaining a certain diet during the Covid-19 pandemic would be difficult. Pediatric neurologists and dietitians need to be aware of the challenge of maintaining diet therapy during the Covid-19 pandemic. Continuing diet therapy is not only an issue for patients during pandemic times: healthcare providers should help their patients overcome any problems associated with the pandemic by understanding their condition [5].

Post-pandemic, many centres have reported that KDT can be successfully delivered via telemedicine with a creatively initiated, individualized approach and advanced planning. In this vein there are several options available, and all are potentially viable. One option is to continue to admit children to the hospital for classic KDT and use focused education, do not use fasting, use a rapid titration in rate or calories over 24 hours, and provide for a shortened hospital stay through the provision of recorded lectures and/or written materials to enhance learning. The use of recorded or written educational materials could results in a short stay of only 1 or 2 days, for example. The physician can maintain close contact via phone, text, email and/or other electronic means of communication for inquiries and confirmation of the educational experience. A second method is to gradually begin the classic KDT outpatient by using telemedicine visits and training. This approach has been recommended to patients whose caregivers have access to a kitchen scale and other materials, can shop for the required dietary requirements prior to starting the treatment, and who can reliably participate in online training. Online training sessions can also be provided to small groups of 2 to 4 families at a time, provided that all participants agree. Third, MAD is theoretically an excellent option. This diet does not require foods to be weighed, has a reduced risk of hypoglycemia and hyperketosis, is already widely used as an outpatient treatment, is considered safe and effective without fasting, and has many materials and recipes that can be accessed online. The fourth option is to initiate MAD and, if necessary, switch to classical KD. Finally, as long as there is valid insurance coverage, patients with gastrostomy tubes can easily be started on KDT by replacing their normal formula with a ketogenic formula [18]. In the present study, most of the pediatric neurologists had considered using the MAD or LGIT. 88% knew that MAD does not require weighing food, and the risk of hypoglycemia and hyperketosis is less than classical KDT. Most of them (98%) aware that patients with a gastrostomy tube, the formula could be easily converted to KD, paid for by the insurance and home care services could be used.

Numerous factors related to the continuation of dietary therapy, including finances, logistics, access to low-carb foods, and motivation to follow the diet all play a role in the ability to maintain the diet and all have been affected by the pandemic. With regard to dietary treatments, the cost of foods, supplements, and additional laboratory tests must be considered.

There has been an increase in people facing financial difficulties due to loss of job opportunities during the pandemic [19]. Financial support is recommended for patients who may benefit from dietary therapy. Society as a whole should be made aware of the fact that these types of dietary therapies can be lifesaving to some and that the positive health benefits can be jeopardized by the lack of resources brought on by the pandemic. Avenues of providing financial support to such patients should be sought.

One of the challenges when implementing dietary therapy during the Covid-19 pandemic is the need for laboratory testing. Monitoring of physiological ketosis is useful for classic KDT and is accomplished by measuring daily ketone concentrations in urine or blood samples. Patients who continued this type of diet therapy during the pandemic were not only faced with financial problems, but also faced limited access to food. This occurs when people stock up on low-carb foods needed for diet therapy [20]. If the diet is not strictly adhered to, the general condition deteriorates, increasing the likelihood of seizures, which can lead to impaired immune function and various complications [21]. The increase in seizures and their consequences could potentially lead to increased exposure to Covid-19. Therefore, food intake suitable for the prescribed diet therapy is a critical issue for such patients. It is also important to maintain motivation for diet therapy. A previous article reported that patients or their caregivers may discontinue diet therapy for reasons such as increased levels of anxiety or stress caused by Covid-19 during the pandemic [19].

Most of the pediatric neurologists (73%) who agreed to participate in the study stated that there was no change in their preference for KDT in hospitalized patients (status epilepticus, infantile spasm, etc.) due to the pandemic. KDT in children is a therapeutic option for the acute phase of refractory/super-refractory status epilepticus [22]. The use of this dietary therapy is difficult due to the critical condition of the patients and its tolerability. Optimal management of children receiving this dietary therapy should be ensured from the beginning [23]. When administered properly, the ketogenic diet is tolerated [24], and may result in an increased number of patients achieving seizure-free status over time. Then, proper management of the ketogenic diet is also important in order to avoid the paradoxical

phenomenon of worsening seizures, known as the rebound effect in some cases. Thus, the initiation and maintenance of dietary therapy is the result of the simultaneous efforts of pediatric neurologists, dietitians, families, and other caregivers.

Despite all this, no studies have been conducted to date on the efficacy and safety of KDT during the pandemic period, and such studies are still needed.

However, KDT follow-up care using telemedicine options also has potential disadvantages. Laboratory and other routine assessments may be more difficult to obtain. The accuracy of patient height and weight measurement is uncertain, and significant technological limitations remain. It is more difficult to conduct a comprehensive neurological examination via telemedicine in patients with fluctuating neurological symptoms, and physicians and health personnel cannot help if the patient has a seizure during the virtual appointment. To start KDT using telemedicine methods requires more work to be done before starting the therapy to ensure patients and caregivers are ready for the first day of the diet. In-depth, detailed information (i.e., to stop the KDT so that the KDT is not enough) can be less personal when done by video call. Ketogenic diet therapy with telemedicine, both in terms of initial start-up and maintenance, may not be suitable for young infants, those at elevated risk for complicated hypoglycemia or metabolic problems, families who do not have access to technology, and families who may not be able to access emergency medical care if necessary [12].

Overall, both initiating and maintaining KDT can continue successfully in a pandemic crisis. It is a very suitable non-pharmacological option for DRE in children and adults and families should not be discouraged or prevented from accessing this type of therapy. In fact, due to advantages provided by telemedicine methods, it is worth continuing this type of application post-pandemic. The overall opinion, after the results of this research have been considered, is that the development of an appropriate infrastructure (medicolegal) is necessary so that reference centres with experience in KDT can switch to telemedicine applications.

Author Declaration

- There is no conflict of interest in our study.
- No funding was received fort his work.
- We confirm that the manuscript has been read and approved by all named authors.
- We confirm that the order of authors listed in the manuscript has been approved by all named authors.

Availability of Data and Material

- Data can be accessed upon request.
- Code availability does not apply to our work.

Authors' Contributions

All authors whose names appear on the submission

1) Made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data; or the creation of new software used in the work;
2) Drafted the work or revised it critically for important intellectual content;
3) Approved the version to be published; and
4) Agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Ethics Approval

This study was performed in line with the principles of the Declaration of Helsinki.

Ethical approval for our research was obtained from the clinical research ethics committee of Dr. Behcet Uz Children's Training and Research Hospital (2021/12-10).

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