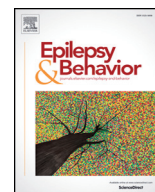




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## Telemedicine, drug-resistant epilepsy, and ketogenic dietary therapies: A patient survey of a pediatric remote-care program during the COVID-19 pandemic

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### ABSTRACT

**Objective:** The purpose of this study was to assess parent satisfaction with the management of ketogenic diet therapies (KDTs) through telemedicine using WhatsApp as the main tool.

**Methods:** Parent satisfaction was longitudinally evaluated through questionnaires. The survey was developed with Google Questionnaire forms and sent via WhatsApp. The questionnaire consisted of 13 items concerning the management of KDTs using telemedicine in the context of the coronavirus disease 2019 (COVID-19) pandemic.

Our population of patients has limited financial resources and low levels of education. Given that many families did not have either computers or WIFI, or any other access to information or communication technology, WhatsApp was chosen as a tool as it was available on the cell phones of all families and the professionals.

**Results:** Our survey showed that 96.3% of the parents were satisfied with the management of KDTs through telemedicine. The main benefits observed were the possibility of continuing treatment during the COVID-19 pandemic and the ease of accessing the professional team from the comfort of their home. Overall, 72.2% of the families would recommend using telemedicine for KDTs in any situation regardless of the pandemic. None of the families reported that they would recommend against treatment by telemedicine. The availability of a social support network (parents WhatsApp group) coordinated by professionals from the KDT team was considered to be useful by most respondents (90%).

**Conclusions:** Our study suggests that management of children with DRE on KDTs through telemedicine is feasible, well accepted by the families, and probably as safe as conventional medicine. WhatsApp may be an interesting telemedicine tool to start and maintain KDTs.

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### 1. Introduction

Evaluating patient or parent satisfaction, in the case of children receiving medical care, is important to assess whether health systems are responding to the needs of the patients, especially in the context of the coronavirus disease 2019 (COVID-19) pandemic. A particularly useful tool for the assessment of parent satisfaction is a questionnaire-based survey. The advantages of a questionnaire are manifold: parents

can answer questions anonymously and do not have to fear negative consequences because of their opinion. Questionnaires are, in contrast to interviews, more economic, faster, and are regarded as more voluntary [1].

Telemedicine is the use of information and communication technology (ICT) applied to different healthcare fields, especially when geographical distance is a critical factor [2,3]. Since the first medical consultation by telephone was documented in 1879, there has been an enormous development in the use of telemedicine, also in the fields of child and adult neurology [4–7]. Although scientific evidence is still insufficient, telemedicine emerges as a valid alternative for conventional medicine or as a complement to reduce disparities and improve access to healthcare [5].

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Over the last few years, there has been extensive development of new telemedicine tools, such as smartphone applications (mHealth). The use of instant messaging services has led to improved communication within medical teams by providing means for fast teleconsultation, information sharing, and early treatment initiation [8,9]. WhatsApp is a communication tool that allows users to send instant messages, photos, videos, and voice messages; to share records; and to make voice and video calls with up to eight people using a mobile internet connection.

Epilepsy is a chronic disease with certain characteristics that make it feasible to be approached remotely, without compromising patient safety and satisfaction [6,10–14]. Different reports comparing telemedicine and conventional medicine show similar results, especially regarding aspects such as seizure frequency, visits to the emergency department, or adherence to drug therapy [10,12]. Advances in ICT have contributed to the rapid development of numerous digital tools used synchronously or asynchronously in the virtual management of epilepsy [13,15].

During the COVID-19 pandemic, telemedicine services have aimed to improve the management of people with epilepsy [16–19].

Ketogenic diet therapy (KDT) is the most common nonpharmacologic treatment for people with drug-resistant epilepsy (DRE). At present, there are four major KDTs: the classic KD, the modified Atkins diet (MAD), the medium-chain triglyceride diet (MCT), and the low glycemic index treatment (LGIT) [20–26]. There are few reports on the management of KDTs for patients with epilepsy through telemedicine as the main resource [27].

Implementation of KDTs in our country dates back the 1970s [23]. The recent trend in all diet modalities is outpatient treatment, avoiding fasting and using lower ketogenic ratios, without modifying effectiveness [23,24].

The purpose of this study was to assess parent satisfaction with the management of KDTs through telemedicine using WhatsApp as the main tool during the COVID-19 pandemic.

## 2. Methods

In Argentina, the nationwide lockdown due to the COVID-19 pandemic began on March 20, 2020 and continues at the time of this report. In the first week of June, we conducted a survey to assess how telemedicine services were responding to the demands of patients on KDTs.

A survey on quality of care was administered to 54 parents of children on KDTs. The age of the patients ranged from 8 month to 18 years. Overall, 17 patients were on the classic KD, seven on a modified classic KD with low fat-to-protein-and-carbohydrate ratios, 20 on the MCT, four on the LGIT, and six on the MAD. This study was approved by ethics committee.

Our study was conducted at two secondary-care KDT centers: a public hospital in the province of Tucumán (Hospital del Niño Jesús) in the north of Argentina following 1565 pediatric patients with epilepsy and a private clinic in the province of Neuquén (Clínica San Lucas) in Patagonia following 933 children with epilepsy (Fig. 1). Both centers are connected with Hospital Nacional de Pediatría J.P. Garrahan (Buenos Aires), a tertiary-care center, for consultation.

Both teams cover a patient population with limited financial resources and levels of education. Given that many families did not have either computers or WIFI, or any other access to ICT, WhatsApp was chosen as a tool as it was available on the cell phones of all the families and professionals.

In both centers, the interdisciplinary KDT team consists of child neurologists specialized in DRE and dietitians and/or medical nutritionists. Possible candidates for KDTs are selected by the neurologist based on the expected benefits in relation to the epileptic syndrome or type of epilepsy and after having ruled out conditions in which the diet is contraindicated [26,27]. Parents have the personal telephone number of the professional team members. They are able to reach out for professional support at any time of the day by means of asynchronous (message) and

synchronous (video call) WhatsApp messages. Most of the queries are about occurrence of epileptic seizures, medication changes, diet or drug adverse effects, modifications in the ketogenic ratio, and weight and height control. By the same means, adherence to treatment, compliance with vitamin supplements, ketonemia or ketonuria, and the results of laboratory tests are monitored.

This work modality had been implemented prior to the pandemic, which, we believe, was key to the feasibility to continue KDT management during it.

The survey was developed with Google Questionnaire forms and sent to the families via WhatsApp. All families with a child on the diet during the COVID-19 pandemic filled out the questionnaire. The parents answered 13 questions related to the care provided by the KDT multidisciplinary team regarding initiation or maintenance of the diet, understanding of how to prepare meals, measuring ketonemia/ketonuria, compliance with the team in the pandemic compared with the pre-pandemic period, accessibility to the professionals, benefits of initiation or follow-up through telemedicine, resolution of emergency situations, evaluation of laboratory results, diet or vitamin supplement adjustments, and modification of prescriptions. The questionnaire is shown in Fig. 2.

## 3. Results

Since the nationwide lockdown began on March 20, 2020, patients in different phases of KDTs have been managed almost exclusively by telemedicine, although patients who for some reason required an in-person consultation had the opportunity to see a physician at the outpatient clinic.

Two months into the lockdown, 54 families from both centers were surveyed.

At that time, 16.7% were in the pre-diet evaluation phase, 7.4% in the initiation phase, 74% in the maintenance phase, and 1.9% were discontinuing the diet. Patients in the pre-diet evaluation phase received instructions on how to reduce carbohydrates. Twenty-three families that received instructions on how to prepare meals through video calls reported that understanding the instructions was easy (65.2%), complex but they were able to manage (30.4%), and difficult and they needed in-person instructions (4.34%).

Understanding how to perform ketonemia/ketonuria controls through telemedicine was easy for 67.9% of the family, complex but they were able to manage for 24.5%, and difficult and they needed in-person instructions for 7.6%.

Almost all families reported a high level of satisfaction with their KDT team both during the pandemic and in the pre-pandemic period (96.3%), while 11.1% of them stated that they were more satisfied than in the pre-pandemic period, and 3.7% were dissatisfied with this modality.

Accessibility to the team members during the pandemic was rated as excellent by 68.5% of the families and good by 31.5%. None of the families considered accessibility to be poor.

The reasons to initiate or follow-up KDTs through telemedicine were the COVID-19 pandemic (83.3%), geographic distance (44.4%), the convenience of being able to consult the team from the comfort of their homes (29.6%), team decision (18.5%), and economic reasons (11.1%).

The main advantages of initiating or following-up KDTs through telemedicine for families were ease of access to the medical staff during the COVID-19 pandemic (77.8%), the convenience of being able to consult the team from the comfort of their homes (63%), and travel cost savings and less absenteeism from work or school (33.3%).

In emergency situations, the response from the team for the resolution of the problem was considered as excellent in 52.1% and good in 47.9%. None of the families rated the response as poor.

The management of indications for and medical evaluation of laboratory results by the KDT team via WhatsApp during the pandemic

was considered by the families as excellent in 58.5%, good in 39.6%, and poor in 1.9%.

The response of the team in making adjustments to the diet or vitamin supplements based on laboratory results was considered excellent by 46% of the families, good by 52%, and poor by 2%.

Assistance in the modifications of recipes when necessary during the pandemic (economic reasons, food availability) through telemedicine was evaluated as excellent (54.7%) and good (45.3%).

The availability of a social support network (parents WhatsApp group) coordinated by the KDT team was considered to be useful by 90.7% of the families, useless by 1.9%, while 7.4% were indifferent.

Most families (72.2%) would recommend the use of telemedicine in any situation regardless of the COVID-19 pandemic. However, 27.8% would recommend using telemedicine only during the pandemic. None of the families would advise against treatment via telemedicine.

The main results of the survey are summarized in Table 1.

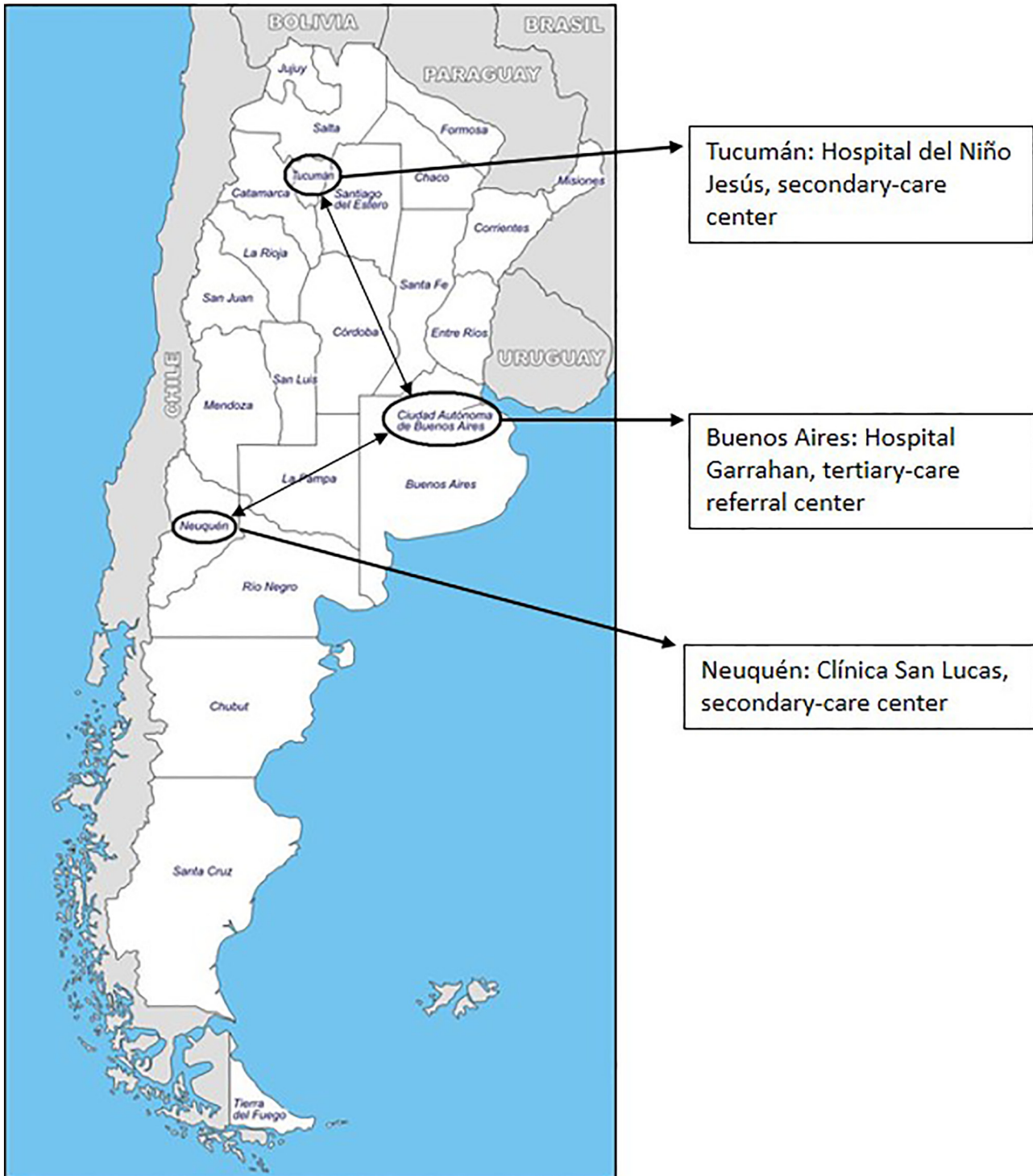


Fig. 1. Geographical distribution of the secondary-care ketogenic diet therapy teams and the tertiary-care referral center.

## Satisfaction survey for parents or caregivers of children with drug-resistant epilepsy, treated via telemedicine by a ketogenic diet therapy (KDT) team during the covid-19 pandemic.

- 1- In what phase of the KDT was your child during the pandemic?  
 a) Prediet evaluation    b) Initiation phase    c) Maintenance phase    d) Discontinuation phase
- 2- If the diet was initiated via telemedicine: How were the instructions on how to prepare food by video call?  
 a) Easy to understand  
 b) Difficult to understand but I could manage through teleconsultation  
 c) Very difficult to understand and we needed in-person instructions  
 d) Not started by telemedicine
- 3- Was it easy or difficult to understand how to perform ketonemia/ketonuria controls?  
 a) It was easy  
 b) It was difficult but I could manage via teleconsultation  
 c) It was very difficult and we needed in-person instructions
- 4- How would you rate your level of satisfaction with the availability of the KDT team during the pandemic compared to the pre-pandemic period?  
 a) Satisfied                      b) More satisfied than in the pre-pandemic period                      c) Dissatisfied
- 5- How would you rate accessibility to KDT team members for communication during the pandemic?  
 a) Excellent                      b) Good                      c) Fair                      d) Poor
- 6- What was the primary reason for starting or maintaining the KDT via telemedicine? (more than one answer may be selected)  
 a) Team decision                      b) Economic reasons                      c) Geographic distance                      d) The COVID-19 pandemic  
 e) Access to consultations from the comfort of your home
- 7- What were the main advantages of initiating or maintaining the KDT via telemedicine? (more than one answer may be selected)  
 a) Travel cost savings and less absenteeism from work or school  
 b) Ease of access to the team during COVID-19 pandemic  
 c) Access to consultations from the comfort of your home
- 8- If your child had an emergency situation (e.g. increased seizures, fever, vomiting): How would you rate the response of the team for the resolution of the problem via WhatsApp?  
 a) Excellent                      b) Good                      c) Fair                      d) Poor
- 9- How would you rate the management of indications for and medical evaluation of laboratory results by the KDT team via WhatsApp during the pandemic?  
 a) Excellent                      b) Good                      c) Fair                      d) Poor
- 10- If dietary and vitamin supplement adjustments were necessary based on laboratory results during the pandemic, how would you rate the response of the KDT team?  
 a) Excellent                      b) Good                      c) Fair                      d) Poor
- 11- If you needed to modify recipes (for economic reasons or food availability), the response via telemedicine was:  
 a) Excellent                      b) Good                      c) Fair                      d) Poor
- 12- Do you think availability of a parent support social network (WhatsApp group) coordinated by the KDT team is:  
 a) Useful                      b) Useless                      c) Indifferent
- 13- Would you recommend telemedicine to someone else?  
 a) Yes, I would, only during the pandemic  
 b) Yes, I would, in any situation regardless of the COVID-19 pandemic  
 c) No, I would not

**Fig. 2.** Patient satisfaction survey for parents or caregivers of children with drug-resistant epilepsy, treated via telemedicine by a ketogenic diet therapy (KDT) team during the COVID-19 pandemic.

#### 4. Discussion

This is the first report assessing parent satisfaction with telemedicine for the management of their children receiving KDTs using WhatsApp as the main communication technology.

Our study indicates that management of children with DRE on KDTs through telemedicine is feasible and well accepted by the families. The

possibility of continuing treatment during the pandemic and the easy access to the team from the comfort of their homes were considered to be the main advantages. Most families would recommend using telemedicine in any situation regardless of the COVID-19 pandemic. None of the families stated that they would advise against treatment by telemedicine. Ninety percent of the respondents considered that having a social support network (parent WhatsApp group coordinated by the KDT team) was helpful.

**Table 1**

The main results of the patient satisfaction survey in parents of children with refractory epilepsy treated with KDTs.

Item survey	Main result (%)
Instructions on how to prepare meals	Easy (65.2%), they were able to manage (30.4%), they needed in-person instructions (4.34%)
Ketonemia/ketonuria controls	Easy (67.9%), they were able to manage (24.5%), they needed in-person instructions (7.6%)
Satisfaction with KDT team	96.3%
Accessibility to the team members	Excellent (68%), good (31.5%)
Reasons to initiate or follow-up KDTs	COVID-19 pandemic (83.3%), geographic distance (44.4%), home comfort (29.6%)
Main advantages of initiating or following-up KDTs	Easy access to the medical staff (77.8%), comfort of home consultations (63%)
Emergency situations (resolution of the problems)	Excellent (52.1%), good (47.9%)
Management of indications for medical evaluation of laboratory results	Excellent (58.5%), good (39.6%)
Making adjustments to the diet or vitamin supplements	Excellent (46%), good (52%)
Assistance in the modifications of recipes	Excellent (54.7%), good (45.3%)
Social support network coordinated by KDT team	Useful (90.7%)
Recommend use of telemedicine in any situation	(72.2%)

WhatsApp is a simple but comprehensive tool to manage KDTs in patients who live far from the treating center or when in-person visits are difficult as has been the case during the COVID-19 pandemic.

Some authors have warned about legal and ethical concerns regarding confidentiality privacy and data security in WhatsApp. Another issue is how to keep clinical data safe. Nevertheless, the main strength of WhatsApp is that it is a free means of communication and available to everybody, even in resource-poor areas [9–13,28,29].

Different studies have defined WhatsApp as an effective telemedicine tool in many healthcare fields [9,28–31]. Nevertheless, we have not found reports of its use in the management of KDTs. On the other hand, other tools have been successfully used for the initiation and maintenance of KDTs. Cervenka et al. demonstrated that the MAD administered solely via e-mail to adults with DRE was feasible, safe, and effective. Tolerability and efficacy were similar to those reported by the same center in patients treated in a conventional office setting by a team of dietitians and neurologists [20]. Recently, Kossoff et al. published their successful experience in starting and maintaining the KD by telemedicine during COVID-19 pandemic in children and adults with DRE at the Johns Hopkins KDT center. In this study, online platforms (e.g., Zoom, Polycom, or Doximity) and phone calls and e-mail were used to contact the families and patients. Recommendations are given on how to manage KDTs during the pandemic [22]. Ferraris et al. retrospectively described the use of remote monitoring of the classic KD by e-mail in 34 children with DRE or glucose transporter type 1 deficiency syndrome during the first year of follow-up [32].

The fast spread of the pandemic has led to priority care for patients with COVID-19, overwhelming health institutions and turning them into potential sources of contagion. It has generated new doctor–patient relationship models. The KDT teams should encourage the use of ICT to optimize access, remote management, and monitoring of KDTs. Information and communication technology is also useful for coordination between different teams, information sharing, consensus building, training, and counseling (telementoring) [33].

Many reports have described the key requirements for developing telemedicine, not only in emergency settings but also in everyday practice [13,34]. The COVID-19 pandemic required immediate government policies, such as the development of telemedicine, ensuring connectivity, cyber and legal security, training of healthcare professionals and patients in the use of ICT, confidentiality, appropriate remuneration, and an adequate ethical framework.

The use of WhatsApp allowed for a comprehensive management of patients with DRE on KDTs in the context of the COVID-19 pandemic, providing the possibility of continuous contact with patients and their families to avoid the loss to follow-up of patients. In addition, it proved to be a fast, easy, and free-of-charge communication tool to monitor these difficult patients receiving a complex treatment that requires strict controls.

Similar to a previous study, our survey showed a high level of satisfaction with this treatment modality among the families of the patients [11]. Nevertheless, the study has several limitations, mainly the

subjectivity of the answers to qualitative questions in the survey. On the other hand, the survey was conducted in an area of limited resources, in a developing country, using popular and free communication tools, such as WhatsApp and Google Questionnaire Forms.

## 5. Conclusions

Our patient satisfaction survey shows parents were pleased with the comprehensive management of KDT through telemedicine. WhatsApp provided easy access to each member of the team for medical and dietary consultation during the COVID-19 pandemic. Most families stated that they would recommend using telemedicine in any situation regardless of the pandemic.

The management of the KDTs in in patients with DRE by telemedicine is feasible and probably as safe and effective as conventional medicine. WhatsApp may be an interesting option in the remote management of a complex nonpharmacological treatment such as KDT coordinated by a well-trained multidisciplinary team.

## Declaration of competing interest

None.

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