



THE AGA KHAN UNIVERSITY

eCommons@AKU

Paediatrics and Child Health, East Africa

Medical College, East Africa

12-2021

Qualitative exploration of feasibility and acceptability of the modified Atkins diet therapy for children with drug resistant epilepsy in Kenya

Pauline Samia

Violet Naanyu

J. Helen Cross

Richard Idro

Paul Boon

See next page for additional authors

Follow this and additional works at: https://ecommons.aku.edu/eastafrica_fhs_mc_paediatr_child_health



Part of the Pediatrics Commons

Authors

Pauline Samia, Violet Naanyu, J. Helen Cross, Richard Idro, Paul Boon, Jo Wilmshurst, and Stanley Luchters



Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Qualitative exploration of feasibility and acceptability of the modified Atkins diet therapy for children with drug resistant epilepsy in Kenya



Pauline Samia^{a,b,c,*}, Violet Naanyu^{d,e}, J. Helen Cross^f, Richard Idro^g, Paul Boon^h, Jo Wilmshurst^{i,j}, Stanley Luchters^{c,k,l}

^a Department of Paediatrics and Child Health, Medical College, Aga Khan University, Nairobi, Kenya

^b Brain and Mind Institute, Aga Khan University, Kenya

^c Department of Public Health and Primary Care, Ghent University, Belgium

^d School of Arts & Social Sciences, Moi University, Kenya

^e AMPATH Research, Eldoret, Kenya

^f UCL BRC NIHR Great Ormond Street, Institute of Child Health, London, United Kingdom

^g Makerere University, Department of Paediatrics and Child Health, Kampala, Uganda

^h Department of Neurology, Ghent University, Belgium

ⁱ Department of Paediatric Neurology, Red Cross War Memorial Children's Hospital, Cape Town, South Africa

^j Institute of Neurosciences, University of Cape Town, South Africa

^k Department of Population Health, Medical College, Aga Khan University, Nairobi, Kenya

^l Department of Epidemiology and Preventive Medicine, Monash University, Australia

ARTICLE INFO

Article history:

Received 4 September 2021

Revised 20 September 2021

Accepted 25 September 2021

Available online 2 November 2021

Keywords:

Drug-resistant epilepsy

Modified Atkins diet

Children

Acceptability

Feasibility

Low resource setting

ABSTRACT

Purpose: Approximately one-third of children with epilepsy have clinical syndromes characterized by drug resistance. Modified Atkins dietary therapy (MADT) can reduce seizures and improve health outcomes for these children. This intervention is yet to be consistently offered as standard of care in sub-Saharan Africa.

Objectives: This study aimed to assess feasibility and acceptability of MADT for children with drug-resistant epilepsy and identify enabling strategies for implementation and adherence to the MADT.

Methods: This qualitative inquiry utilized in-depth interviews with purposively selected caregivers and adolescent patients having used MADT for drug-resistant epilepsy. A qualified team consisting of a social scientist and an interviewer carried out the interviews with consenting participants. Thematic analysis was done independent of the clinicians.

Results: This study enrolled 17 participants including 14 caregivers of children aged 1–17 years, and three adolescents. Caregivers were predominantly trained professionals living in urban areas who had attended the epilepsy clinic for at least one year. Duration of continuous MADT use ranged from two weeks to two years. Among participants who indicated that they could afford to provide the MADT, it was less costly to provide for younger children and for those living in rural areas. At the time of the study, majority of the caregivers had ceased administration of the MADT, more than half of whom reported barriers including cost of food, child refusal of foods, and inconsistent dietician support. Social support was a key enabler to successful implementation and continuation of the diet. Majority of the participants considered MADT to be an effective and acceptable intervention for management of epilepsy.

Conclusions: Among participants in this focused Kenyan group, implementation of MADT was found to be feasible particularly for younger children living in rural areas. Majority of participants evaluated MADT to be an effective and acceptable intervention for management of epilepsy. Cultural factors did not influence feasibility or acceptability of MADT in this study.

© 2021 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Abbreviations: AKUH-N, Aga Khan University Hospital Nairobi; ASM, Anti-seizure medications; CG, Caregiver; ICF, Informed Consent Form; IDI, In-depth Interview; KES, Kenyan shillings; LMIC, Low- and middle-income countries; MADT, Modified Atkins diet therapy.

* Corresponding author at: Aga Khan University, East Africa, 3rd Parklands Avenue, East Tower Block, Fourth floor, P.O BOX 30270, 00100 Nairobi, Kenya.

E-mail address: pauline.samia@aku.edu (P. Samia).

<https://doi.org/10.1016/j.yebeh.2021.108362>

1525-5050/© 2021 The Author(s). Published by Elsevier Inc.

This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

1. Introduction

An estimated one-third of children with epilepsy have clinical syndromes characterized by drug resistance, necessitating palliative interventions [1–3]. Global evidence indicates that dietary therapies are efficacious when offered to children with drug-resistant epilepsy, with reduction in the number of seizures, reduction in hyperactivity, and improvement in cognition reported [4]. The modified Atkins diet is a more relaxed diet to implement in comparison to the classical or medium chain triglyceride Atkins diet [5–7]. Although low carbohydrate, the allowance of unlimited protein improves palatability thus enhancing compliance. The modified Atkins diet has been effectively used to treat drug-resistant epilepsy in both children and adults [5,6]. The efficacy of modified Atkins diet therapy (MADT) at three and six months post-implementation has proven to be successful with over 50% of patients achieving greater than 50% reduction in seizure frequency [7,8]. One study found that the most effective seizure control approach was using a “patient-tailored diet” where families worked independently to find the most appropriate level of fat intake and ketosis for their child’s therapy [5]. This resulted in over 90% seizure freedom and resulted in better compliance [5]. The MADT has gained popularity in some resource-constrained settings due to its flexibility allowing adaptation into local diets [9]. However, implementation of this efficacious non-pharmacologic intervention has lagged behind in sub-Saharan Africa compared to other parts of the world [10].

The burden of epilepsy is significantly higher in low- and middle-income countries (LMIC) partly because of a preponderance of infectious diseases as well as occurrence of multiple potentially preventable causes including perinatal events and head trauma [11]. In 2016, an estimated 45.9 million people with active epilepsy; whose peak prevalence was 5–9 years of age lived in LMIC [12]. The prevalence of active convulsive epilepsy in children aged below 9 years ranged from 2 per 1000 to 12 per 1000 [13–15]. Drug-resistant epilepsy portends a poor outcome for patients due to associated premature mortality, various comorbidities, social implications and an overall poorer quality of life [1,3,16]. These observations make it imperative that feasible palliative care treatments such as MADT are urgently implemented in regions with the greatest burden of children with drug-resistant epilepsy.

The epilepsy treatment gap is documented to exceed 80% in some rural areas of Kenya due to stigma, lack of public awareness, unavailability of appropriate anti-seizure medications, and financial incapacity that hampers access to health services [17,18]. Utilization of dietary therapies, including MADT, has been proposed as an intervention to aid in the closure of the epilepsy treatment gap [9,10,19]. Acceptability of MADT in various settings has been linked to healthcare worker support to mitigate against factors such as illiteracy and distance, flexibility in allowing slower reduction of the carbohydrate portions, use of patient support groups, and utilization of available local foods in the implementation of MADT [20–24]. There are minimal data available on utilization of dietary therapies for children with drug-resistant epilepsy in Sub-Saharan Africa. Despite the undisputed efficacy of dietary therapies in other parts of the world, barriers to widespread implementation in sub-Saharan Africa remain unknown. This study sought to explore caregiver’s and adolescent’s experience with the MADT; and potential enabling factors which could be harnessed to facilitate scalability of this therapy.

2. Material and methods

2.1. Study design and participants

This qualitative study employed in-depth interviews (IDI) and was conducted between August and September 2020. A qualified team, including a senior social scientist and one research assistant carried out the interviews independent of the clinical practitioners. The research assistant was competitively recruited on the basis of the level of education, with demonstrated IDI facilitation and note taking experience. A two-day training was conducted with a focus on introduction to the study, research ethics, data collection methods, study tools, data management, the consent and assent process, and documentation.

The dialog centered around MADT intervention that had been offered to patients at the Aga Khan University Hospital in Nairobi (AKUH-N). The study sought to assess the feasibility and acceptability of MADT for children with drug-resistant epilepsy, and their caregivers. Fig. 1 provides a summary of the diet as recommended at the Aga Khan University Hospital, Nairobi.

A qualified dietician scheduled an appointment for each family to introduce the MADT and provide guidance on quantities of foods to be used, types of foods that were most suitable, and those to be avoided. The session also included information on where to obtain the foods locally and sample recipes were provided. Caregivers were informed that the aim of the dietary changes was to ensure no more than 20 g of carbohydrates were to be consumed on any given day and that the main source of energy would be provided by fats. The child was allowed as much protein as they needed for growth which was typically 35% of the total calorie intake and were to consume adequate amounts of water (4–6 glasses per day). Regular meals in 4–5 portions for children younger than three years and 3–4 meals for those older than three years as well as daily exercise or occupational therapy three times per week as were recommended. Families were informed that constipation, dehydration, and vomiting as well as feeling sluggish during the initial days were potential side effects and measures to avoid and manage these unwanted effects were discussed. These measures included increasing the oral water intake, and in severe cases where the child was not able to retain food due to vomiting they were asked to report to the emergency room at AKUH, N. Addition of water, berries, whole grains, and exercise was advised to help manage constipation and if this persisted, patients were referred for review by the pediatrician. Reviews with the dietician were scheduled initially after two weeks, then after every three months. Calcium and vitamin supplements were prescribed to mitigate against potential nutritional deficiencies while on a highly restricted diet [25].

The study was conducted at the AKUH-N pediatric neurology clinic in Nairobi. Eligible study participants were primary caregivers of children aged 2–17 years with drug-resistant epilepsy as per ILAE recommendations [25], who were on MADT, or had utilized MADT in the preceding 10 years; who were able and willing to provide written informed consent to participate in the study; and children above 8 years of age who had undertaken MADT previously and were able to provide assent for the study and were able to participate in an IDI. In qualitative studies, saturation is the point at which no new data are obtained on evaluation of the interview record and is commonly used to determine the sample size. Previous reviews have indicated that minimal additional data are

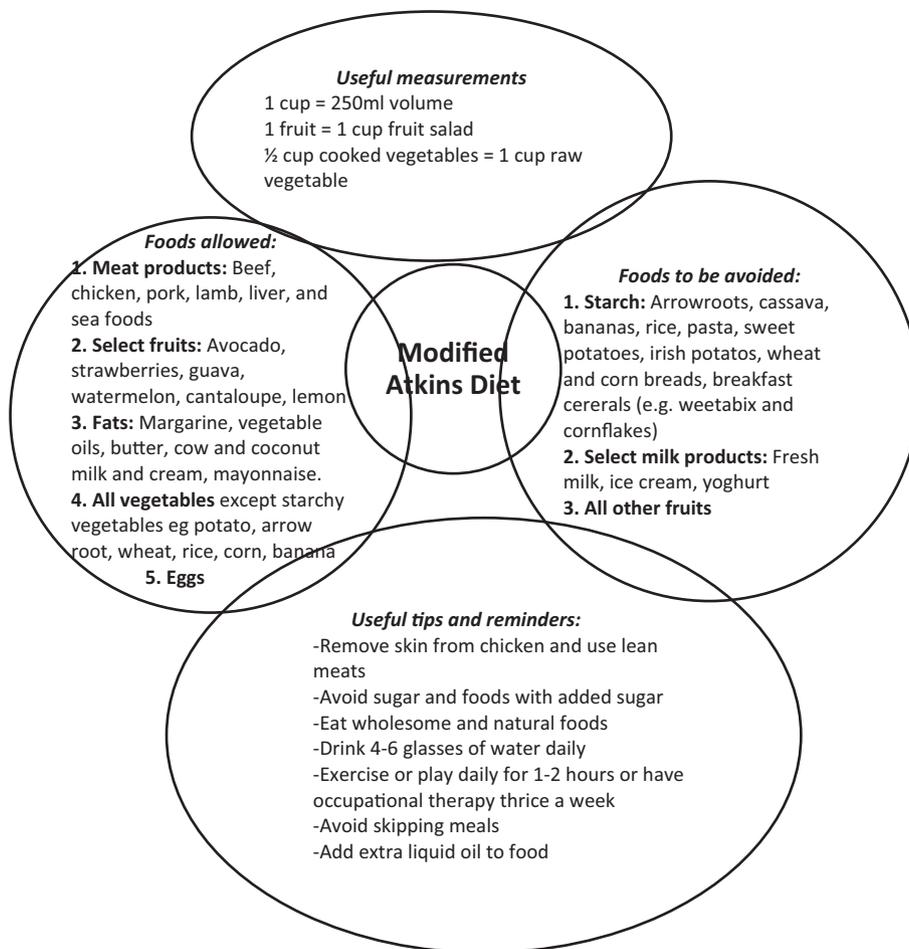


Fig. 1. The Modified Atkins Dietary therapy (MADT) applied at the Aga Khan University Hospital, Nairobi.

rarely obtained by interviewing greater than 20 individuals for a specific category of participants [26,27]. Hence, this study aimed to purposively select 20 participants to include 15 caregivers and 5 children with drug-resistant epilepsy. All tools utilized during the IDI are provided in [Appendix 1](#).

2.2. Recruitment and data collection

Participants were identified from the medical records of the AKUH-N pediatric neurology clinic and invited to participate in the study. Primary caregivers were contacted by telephone prior to a regular hospital clinic visit and informed of the study. During the next regular clinic visit, the research assistant engaged caregivers again and explained the study in full. Caregivers who gave consent to participate in the study were invited for the IDIs at AKUH-N at a date convenient to the care giver within the following two weeks. Transport was reimbursed for the second visit.

The semi-structured IDI guide captured details on the length of time the diet was undertaken for, food components that were utilized, effect of the diet on seizure frequency, cost of the diet to the family, and adverse effects and challenges encountered. The IDI guide also included preparedness of the family to undertake the diet, their understanding of MADT, their expectations regarding outcomes, enabling factors, and challenges encountered during implementation of the diet. The interview guide included open-ended questions initially, then more focused probes were employed in the latter part of the interview process.

Socio-demographic data were collected including caregiver's age, gender, profession, income, education, marital status, and residence. Information on duration of epilepsy clinic attendance, duration of child's epilepsy diagnosis, and duration of MADT use was also documented.

2.3. Ethical considerations

Prior to any data collection event, consent (and assent as appropriate) was obtained. [Appendix 2](#) provides the document utilized in this process. For minors, a standardized assent document was used to ensure they understood and were fully willing to participate in the IDI. Consent documents were available in English which all caregivers were conversant with and each participant signed two copies. Kiswahili translations of the consent documents were also available. One copy of the signed form was given to the study participant while the study team stored the second copy. For the verbal assent, the RA documented and signed all forms to confirm that the minor had been informed and that they had agreed to participate in the study. All signed copies of consent and assent forms were stored in a locked cabinet at the end of each data collection session. The social scientist monitored the progress of protocol implementation to ascertain all safety, consent, and assent regulations were being observed. Interviews were administered in English and lasted 20 min on average for adolescents and 35 min for the caregivers. Sessions were undertaken at a quiet and private office at the AKUH-N. Adolescents were interviewed in the absence

of their parents. This study was guided by a protocol approved by the Aga Khan University (AKU) Institutional Ethics Review Committee (no. 2020/IERC-93(v2)). Additional permission to conduct the study with adherence to institutional COVID prevention policies and from the National Commission for Science, Technology and Innovation (NACOSTI) was sought and granted. Measures to prevent transmission of Coronavirus Virus Disease 19 (COVID 19) including consistent use of masks and hand sanitization were implemented during data collection. Confidentiality of study participant data was ensured throughout the study.

2.4. Data analysis

Following completion of interviews and transcription of recorded data, all transcripts were analyzed using NVivo 12 software. The study followed phases of thematic analysis as described by Braun and Clarke [28]. Three coders familiarized themselves with the data and generated initial codes across the data set. They coded all the transcripts and consequently searched for themes by collating identified codes and gathering data that were relevant to each theme. They then reviewed, defined and named all themes, and produced an analysis report. Appropriate vivid quotes were used to support described themes.

3. Results

3.1. Demographic findings

This study successfully engaged 17 participants including 14 caregivers and three adolescents with drug-resistant epilepsy. One male and 13 female caregivers were interviewed. All caregivers reported tertiary-level education except one who attained secondary school level education. Caregivers' age ranged from 19 to 40 years, eleven of them were married, and all were involved in diverse occupations. Thirteen caregivers lived in urban areas and one in a rural area. Duration of their child's epilepsy diagnosis and clinic attendance ranged from 1 to 14 years, while the duration of MADT use ranged from 2 weeks to 24 months. At the time of the study only three caregivers were still administering the MADT.

Seven caregivers earned more than 100,000 Kenya shillings per month while ten caregivers earned between 50 and 100,000 Kenya shillings per month. (1 USD = 108 Kenya shillings.)

3.2. Feasibility of the MADT

Six caregivers indicated financial ability to provide the MADT. One participant reported that it was easy to implement the diet for her child because he was only two years old, hence the diet was more affordable while another caregiver who lived in a rural area found the MADT affordable. Four caregivers who had to purchase most of the food supplies from supermarkets found the MADT costly and estimated that 5000 to 10,000 Kenya shillings (46–93USD) was required over and above their regular budget each month. All caregivers indicated that foods required to implement the MADT were available in local shops and markets.

Ten caregivers who continued the MADT for at least six months indicated that support from extended family and their spouses was very important in enabling them implement the MADT. Three caregivers felt they could not cope with the diet without additional support; one was single and the other two had a spouse who was not engaged in the implementation of MADT. Caregivers also considered dietician support as key in enabling them adhere to meal plans that had been provided at the initial consult. Lack of familiarity with the MADT was one of the reasons these sentiments came to the fore. When asked what other support could potentially

help a family successfully implement MADT, caregivers expressed the need for support from other caregivers who had utilized the therapy and considered this just as important as professional dietician support.

Five caregivers elaborated on strategies which enabled them adhere to the MADT including; avoidance of social gatherings, informing friends and family of the child's needs and providing packed food for the child to carry with them to school and social events. Majority of the caregivers reported having to make changes to their shopping patterns due to restrictions on choices of food that could be utilized, MADT cost-related challenges and time taken to prepare meals for the family. Some caregivers blended and mashed the food to ensure the child would find it palatable. The most illustrative quotes on feasibility of MADT are provided in [Table 1](#).

3.3. Acceptability of MADT intervention

Twelve caregivers felt that MADT was an appropriate and safe intervention for management of epilepsy in children, with five of them indicating that they preferred MADT over medication. Majority said they were satisfied with the MADT, despite observed negative effects such as constipation and weight loss. Reduction in hyperactivity and improved stability on walking were functional improvements linked to positive evaluations of MADT. One caregiver expressed that persistence in providing the diet eventually led to the child's acceptance of MADT.

All adolescent participants were aged between 12 and 17 years of age, and had all encountered challenges while undertaking the MADT. They described avoiding foods prescribed for MADT that they did not like, the inconvenience of having to carry snacks from home to school, or having a home meal delivered to school. Adolescents reported benefits of the MADT in terms of seizure control, reduction in body weight, and improved vitality which motivated them to continue the therapy. One child was still using the MADT at the time of the study. Two adolescents reported satisfaction with MADT and considered the intervention to be appropriate for management of epilepsy in other children. The most illustrative quotes on acceptability of MADT are provided in [Table 2](#).

4. Discussion

This qualitative study highlights the experience of caregivers and adolescents who utilized MADT as part of management for drug-resistant epilepsy. There are minimal data from sub-Saharan Africa on this topic and knowledge gained from this study serves to provide insights on this under-explored subject. Indeed, recommendations that dietary therapies should be provided for children living with drug-resistant epilepsy in LMIC settings have been made [10,29–31], and guidelines provided [25,32]. However, implementation of ketogenic therapies for management of epilepsy as standard of care in Kenya remains largely in abeyance. Despite the development of newer medications in recent years, approximately one-third of all appropriately treated patients with epilepsy continue to have active epileptic seizures [33]. A large treatment gap for epilepsy has been described in Kenya specifically, which further contributes to the local burden of the disease [17,18]. Scale-up of utilization of Ketogenic dietary therapies in the country would contribute to reduction of the epilepsy treatment gap and would be more sustainable than access to newer and more expensive anti-seizure medications or other interventions such as epilepsy surgery and vagal nerve stimulation for which the infrastructure has yet to be created.

Table 1
Feasibility of MADT in Kenya.

Theme	Sub theme	Illustrative quote
Feasibility of MADT	Availability of foods	<p>"The availability of the food... I think if you have money then the food is there. You can easily get it." (CG 7)</p> <p>"It was a bit of a challenge but I must admit that I stood up to the challenge because availability of the foods, cost factors, even the preparations required extra effort. But I made sure that I stood up to the challenge, I did well." (CG 13)</p> <p>"I am not very sure of the total cost... but the local food is available it is relatively cheap. The price... I think it is affordable, I think it is affordable" (CG 2)</p>
	Cost of MADT	<p>"Yeah! Considering that by the time he was starting the diet he had just clocked 2 years. So, feeding a 2-year child is not as expensive as feeding a full-grown adult. Yeah." (CG 12)</p> <p>"I believe that if there was a way professionals could find a way of reaching out to those who live in rural areas, it would be good. I believe it would be cheaper for those living there, cheaper than buying medicine, because if one finds out a certain kind of food that works for them, especially in their local market, the diet could work for them." (CG 3)</p> <p>"I used it [the MADT] for a short time. I cannot say that I am okay with it because it is a bit pricey getting these foods from the supermarket, unless there is an option of foods that I can afford... but for now, it is something that I am not able to do." (CG 1)</p>
	Family support	<p>"Because of my child's condition, family knew that he had a special diet. Every time we would go visiting, they would call and ask what they should prepare for him. I would say they were very supportive and you would never find them trying to sneak him sweet things because they understand. So, even when they are out there, they are very cautious. They know what he is supposed to eat. They are very supportive. (CG 3)</p> <p>"He was the sole provider. His Dad provided everything and he would also help feeding him when it was very difficult. Sometimes, the baby became irritable and he would assist in feeding the child. I remember that the child would wake up at night and his dad would have only three or four hours of sleep" (CG 8)</p> <p>"At first it was difficult because there was no support from my husband. It was quite difficult, so I was trying on my own but it reached a point, it was so impossible. I gave up. Yeah" (CG 5)</p>
	Dietician support & Peer support	<p>"... I think we just attended the session with the dietician once and you see now this is a journey, it is a struggle you need somebody who is backing you up and every now and then if you want to ask a question you need to have someone who is there for you ..." (CG 10)</p> <p>"It was not very easy to follow and was new to us. Given that we were told some protein sources like beans had traces of carbohydrates... It means that it was not easy to do it because you had to be so cautious. That is why that diet would be easier when it's done when you are working hand in hand with a dietician properly... a dietician who understands and will advise you on the process." (CG 14)</p> <p>"I feel like a dietician would be advising you based on what they have learnt and what the book says and all that; which is okay. But I also feel that if they engage someone who has been there... has used the diet... someone who is walking in the same shoes, it would be better." (CG 3)</p>
	Adaptations to enhance compliance	<p>"I would always pack her food. When she would go to school, I would pack her meals. So, she never ate anything apart from what I prepared at home." (CG 13)</p> <p>"Ooh! So, number one there is no social event that he attends. There are no birthdays, yeah. There is no going out. There is no... like zero. Simply because we don't want to introduce him to certain environments. Places that he sees other kids eating stuff that he can't eat. So, basically that's the reason why we don't take him out. But he will interact with kids in the court and play with them, so long as someone is there watching him. Yeah, so we leave no room to chance (laughs)... (CG 12)</p>

4.1. Feasibility of MADT

It is encouraging to note that majority of caregivers considered MADT a feasible option for their child with epilepsy. Availing MADT for younger children was less challenging compared to older children because required dietary changes were easier to implement and the cost of associated dietary changes was lower. Miranda and others have reported the ease with which ketogenic diets have been instituted in younger infants with drug-resistant epilepsy as well as the greater efficacy observed from this intervention in younger children [5,34,35]. These observations have been attributed to the commencement of dietary therapies earlier on in the disease process, better compliance with dietary changes in younger children, and possibly also biological factors including state of metabolism in this age group [34,35].

An interesting enabler highlighted in this study was the fact that required dietary changes were cheaper to implement in rural areas because requisite food items were cheaper in that setting. Caregivers strongly felt that the cost of the diet was location related as food costs are significantly lower in the rural areas. Majority of the Kenyan population still live in the rural areas [36], hence scale-up of MADT in the country is feasible particularly in rural areas where majority of children with epilepsy reside.

Diets in many countries in sub-Saharan Africa are predominantly starch based [37–39], a factor which may cause concern regarding availability of food options required to implement the MADT; hence it was reassuring to note that caregivers attested

to availability of prescribed food options required to implement the MADT in the local Kenyan setting and hence the possibility of widespread adoption of this therapy in the country.

More than half of the caregivers were able to adhere to MADT for extended periods of time. Enabling factors which should be harnessed in future implementation of MADT include; enlisting extended family support and establishment of support groups that include families whose children are on dietary therapies for the management of epilepsy. Parent support groups as key factors in determining the success of MADT implementation have been cited in studies by El Rashidy and Park [22,40].

Poor availability of dietician support was cited as one of the factors that posed a significant challenge for continuation of MADT. Previous studies have demonstrated that dieticians are key for the implementation of Atkins diets for the management of epilepsy [41]. Kossoff et al proposed that dietician support was not mandatory for other forms of ketogenic dietary therapies apart from classic ketogenic diet in low resource areas [19]. Findings from this study suggest otherwise and indeed it appears to be important that future studies examine dietician's attitudes and training as well as their capacity to support families utilize MADT particularly in low resource areas.

Despite the high level of education reported in this cohort of caregivers, this study highlights challenges encountered in following dietician instructions which could have contributed to some of the frustrations they experienced such as weight gain and sub-optimal efficacy of the MADT. This calls for careful counseling at

Table 2
Acceptability of MADT in Kenya.

Theme	Sub theme	Illustrative quote
Acceptability of MADT	Preference over medications	<p>"I would prefer a diet instead of just having some medication. I think if it really worked then I would prefer going that route instead of having a bunch of medications for the baby." (CG 1)</p> <p>"It was like the last beam of hope I would say for our baby for the seizures. So that was the initial motivating factor. And after that, it was because of the improvements that we were seeing with his condition. I think that's the reason why we still do it and we will probably do it for the next two years until something changes." (CG 12)</p> <p>"To me, I think it [MADT] is appropriate. If we can do away with medicine and have a diet that works, the better". (CG5)</p>
	Reduction in seizures with MADT	<p>"As I said, I saw a marked change in the seizure activity. They reduced considerably. That motivated me, it kept me going and I could see it had a positive benefit for her." (CG 13)</p> <p>"Yeah! Actually all my expectations were met. So, we are currently going on 3 months (phone rings) convulsion free. Yeah, so they were all met." (CG 12)</p> <p>"He doesn't get many seizures like before... he used to get up to 10 per day. When he wakes up, when he is walking... they were very many! But right now we have reduced them to waking up seizures. But with the diet it is really helping. I am like 90% satisfied. The 10% challenge is during visits. Like when you go for safaris and holidays, you can't easily get all that you need. Everything is coated with wheat, at home you can ensure that you don't use wheat in coating your food..." (CG 8)</p>
	Child's acceptance of MADT	<p>"At first it was difficult, but I said, as I continued doing it over and over, he adjusted but it took about three months. But I would tell that he was not comfortable adjusting." (CG 3)</p> <p>"And how did you feel about the change in diet? - I felt good, yeah! Yes, the diet was not hard. Yeah, let me tell you this. Seizures they don't come. They don't come even at all! Yeah, I am happy off course. The only thing I get that's disappointing me, is that I get headaches and stomach aches. And then I go and vomit (Adolescent 1)</p> <p>"It can help people... I stopped taking drugs for my seizures." (Adolescent 2)</p> <p>"Yes I was happy with the diet apart from the coconut oil" (Adolescent 3)</p>

the inception of MADT, easy availability of dieticians for consultation during implementation, and simplification of instructions using apparatus and charts as has been done in other settings [21].

4.2. Acceptability of MADT

Majority of the participants in this study considered the MADT a safe and acceptable form of treatment for their child. Greater satisfaction with MADT was more likely to be reported by caregivers who experienced reduction in seizures in their child. The possibility for reduction or cessation of anti-seizure medication use was a major motivating factor as caregivers perceived MADT to be a safer option compared to medications, despite complications of MADT that were experienced, including weight loss, weight gain, and constipation. Satisfaction with Atkins diets has been found to vary according to food preferences of children, culture, and facilitation

[22,24,42]. In this study, satisfaction with the MADT was closely related to how effective the intervention was in reduction of seizures. Probably due to the cosmopolitan nature of diets engaged in by the study group, cultural factors and food preferences were not a hindrance to the uptake of MADT for this cohort of participants.

Consciously planning services to allow for appropriate levels of dietician support is a surmountable barrier which could further improve feasibility and acceptability of MADT in Kenya. This can be achieved by ensuring appropriate training in ketogenic dietary therapies in dietician curricula, refresher education of dieticians post training to improve confidence in application, and also lobbying for government and institutional support to avail dieticians familiar with MADT at centers where patients with complex epilepsy are referred.

4.3. Limitations of the study

Some of the limitations of this study were that it was performed in a setting where caregivers were well educated and also better resourced than majority of Kenyans, and hence the findings may not be easily generalizable. There were no cultural barriers to the implementation of MADT elicited in this setting, a factor which has been cited in several other studies and may be a limiting factor on large-scale implementation of MADT.

5. Conclusions

Implementation of MADT in Kenya is feasible particularly for younger children living in rural areas where food items required for MADT intervention are cheaper. Both caregivers and adolescents found MADT to be an appropriate and acceptable intervention for management of epilepsy. Dietician, family and social support, availability of food items required for MADT, and a child's acceptance of new foods were important for the successful implementation of MADT. Cultural factors did not influence feasibility or acceptability of MADT in this study.

Declaration of competing interest

The authors declare they have no competing interests in relation to this work.

Acknowledgements

We thank the study respondents for warmly welcoming our research team and taking time to share their experiences and knowledge. We are grateful for the support received from the Aga Khan University Hospital Nairobi (AKUH-N) staff and authorities as we conducted this study.

Funding statement

Funding for this study was provided through a seed grant from Aga Khan University. The Aga Khan University was not directly involved in the conceptualization and conduct of this study.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2021.108362>.

References

- [1] Dalic L, Cook MJ. Managing drug-resistant epilepsy: challenges and solutions. *Neuropsychiatr Dis Treat* 2016;12:2605–16. <https://doi.org/10.2147/NDT.S84852>.
- [2] Kwan P, Arzimanoglou A, Berg AT, Brodie MJ, Hauser WA, Mathern G, et al. Definition of drug resistant epilepsy: consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies. *Epilepsia* 2010;51(6):1069–77. <https://doi.org/10.1111/j.1528-1167.2009.02397.x>.
- [3] Téllez-Zenteno JF, Hernández-Ronquillo L, Buckley S, Zahagun R, Rizvi S. A validation of the new definition of drug-resistant epilepsy by the International League Against Epilepsy. *Epilepsia* 2014;55(6):829–34. <https://doi.org/10.1111/epi.12633>.
- [4] Lee PR, Kossoff EH. Dietary treatments for epilepsy: management guidelines for the general practitioner. *Epilepsy Behav* 2011;21(2):115–21. <https://doi.org/10.1016/j.yebeh.2011.03.008>.
- [5] Miranda MJ, Mortensen M, Povlsen JH, Nielsen H, Beniczky S. Danish study of a Modified Atkins diet for medically intractable epilepsy in children: Can we achieve the same results as with the classical Atkins diet? *Seizure* 2011;20(2):151–5. <https://doi.org/10.1016/j.seizure.2010.11.010>.
- [6] Cervenka MC, Patton K, Eloyan A, Henry B, Kossoff EH. The impact of the modified Atkins diet on lipid profiles in adults with epilepsy. *Nutr Neurosci* 2016;19(3):131–7. <https://doi.org/10.1179/1476830514Y.0000000162>.
- [7] Amari A, Turner Z, Rubenstein JE, Miller JR, Kossoff EH. Exploring the relationship between preferences for high fat foods and efficacy of the ketogenic and modified Atkins diets among children with seizure disorders. *Seizure* 2015;25:173–7. <https://doi.org/10.1016/j.seizure.2014.11.001>.
- [8] Sharma S, Jain P. The modified atkins diet in refractory epilepsy. *Epilepsy Res Treat* 2014;2014:1–6. <https://doi.org/10.1155/2014/404202>.
- [9] Satte A, Kossoff EH, Belghiti M, Zerhouni A, Ouhabi H, Guerinech H, et al. Why should modified Atkins diet be encouraged for treating epilepsy in emerging countries? *Afr Health Sci* 2017;17(2):556. <https://doi.org/10.4314/ahs.v17i2.32>.
- [10] Wilmshurst JM, Berg AT, Lagae L, Newton CR, Cross JH. The challenges and innovations for therapy in children with epilepsy. *Nat Rev Neurol* 2014;10(5):249–60. <https://doi.org/10.1038/nrneurol.2014.58>.
- [11] Thurman DJ, Begley CE, Carpio A, Helmers S, Hesdorffer DC, Mu J, et al. The primary prevention of epilepsy: A report of the Prevention Task Force of the International League Against Epilepsy. *Epilepsia* 2018;59(5):905–14. <https://doi.org/10.1111/epi.14068>.
- [12] Singh G, Sander JW. The global burden of epilepsy report: Implications for low- and middle-income countries. *Epilepsy Behav* 2020;105:106949. <https://doi.org/10.1016/j.yebeh.2020.106949>.
- [13] Mung'ala-Odera V, White S, Meehan R, Otieno GO, Njuguna P, Mhuri N, et al. Prevalence, incidence and risk factors of epilepsy in older children in rural Kenya. *Seizure* 2008;17(5):396–404. <https://doi.org/10.1016/j.seizure.2007.11.028>.
- [14] Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach: Estimation of the Burden of Epilepsy. *Epilepsia* 2010;51(5):883–90. <https://doi.org/10.1111/j.1528-1167.2009.02481.x>.
- [15] Kind CJ, Newton CRJC, Kariuki SM. The Neurodevelopment Disorders study group. Prevalence, risk factors, and neurobehavioral comorbidities of epilepsy in Kenyan children. *Epilepsia Open* 2017;2(4):388–99. <https://doi.org/10.1002/epi4.12069>.
- [16] Ngugi AK, Bottomley C, Fegan G, Chengo E, Odhiambo R, Bauni E, et al. Premature mortality in active convulsive epilepsy in rural Kenya: causes and associated factors. *Neurology* 2014;82(7):582–9. <https://doi.org/10.1212/WNL.000000000000123>.
- [17] Carter JA, Molyneux CS, Mbuba CK, Jenkins J, Newton CRJC, Hartley SD. The reasons for the epilepsy treatment gap in Kilifi, Kenya: using formative research to identify interventions to improve adherence to antiepileptic drugs. *Epilepsy Behav* 2012;25(4):614–21. <https://doi.org/10.1016/j.yebeh.2012.07.009>.
- [18] Kariuki SM, Matuja W, Akpalu A, Kakooza-Mwesige A, Chabi M, Wagner RG, et al. Clinical features, proximate causes, and consequences of active convulsive epilepsy in Africa. *Epilepsia* 2014;55(1):76–85. <https://doi.org/10.1111/epi.12392>.
- [19] Kossoff EH, Al-Macki N, Cervenka MC, Kim HD, Liao J, Megaw K, et al. What are the minimum requirements for ketogenic diet services in resource-limited regions? Recommendations from the International League Against Epilepsy Task Force for Dietary Therapy. *Epilepsia* 2015;56(9):1337–42. <https://doi.org/10.1111/epi.13039>.
- [20] Kossoff EH, Dorward JL. The modified Atkins diet. *Epilepsia* 2008;49:37–41. <https://doi.org/10.1111/j.1528-1167.2008.01831.x>.
- [21] Sharma S, Goel S, Jain P, Agarwala A, Aneja S. Evaluation of a simplified modified Atkins diet for use by parents with low levels of literacy in children with refractory epilepsy: a randomized controlled trial. *Epilepsy Res* 2016;127:152–9. <https://doi.org/10.1016/j.epilepsyres.2016.09.002>.
- [22] El Rashidy OF, Nassar MF, El Gendy YG, Deifalla SM, Gaballa S. Experience with MAD on children with epilepsy in Egypt after classic KD failure. *Acta Neurol Scand* 2018;137(2):195–8. <https://doi.org/10.1111/ane.12856>.
- [23] Gauthier A, Simic N, Jones KC, Ramachandran Nair R. Modified Atkins Diet with slow reduction of carbohydrate. *Epilepsy Behav Rep* 2020;13:100353. <https://doi.org/10.1016/j.ebr.2019.100353>.
- [24] Seo JH, Kim HD. Cultural challenges in using the ketogenic diet in Asian countries. *Epilepsia* 2008;49:50–2. <https://doi.org/10.1111/j.1528-1167.2008.01834.x>.
- [25] Kossoff EH, Zupec-Kania BA, Auvin S, Ballaban Gil KR, Bergqvist AGC, Blackford R, et al. Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International ketogenic Diet Study Group. *Epilepsia Open* 2018;3(2):175–92. <https://doi.org/10.1002/epi4.12225>.
- [26] Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. *Qual Health Res* 2019;29(10):1483–96. <https://doi.org/10.1177/1049732318821692>.
- [27] Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Method* 2018;18(1):148. <https://doi.org/10.1186/s12874-018-0594-7>.
- [28] Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study: qualitative descriptive study. *Nurs Health Sci* 2013;15(3):398–405. <https://doi.org/10.1111/nhs.12048>.
- [29] Wijnen BFM, van Mastrigt GAPG, Evers SMAA, Gershuni O, Lambrechts DAJE, Majoie MHJM, et al. A systematic review of economic evaluations of treatments for patients with epilepsy. *Epilepsia* 2017;58(5):706–26. <https://doi.org/10.1111/epi.13655>.
- [30] Kossoff EH. Nonpharmacological approaches. In: *Handbook of clinical neurology*. Elsevier; 2013. p. 803–8. <https://doi.org/10.1016/B978-0-444-52891-9.00083-X>.
- [31] Kossoff EH, Dorward JL, Molinero MR, Holden KR. The modified Atkins diet: a potential treatment for developing countries. *Epilepsia* 2008;49(9):1646–7. <https://doi.org/10.1111/j.1528-1167.2008.01580.6.x>.
- [32] Kossoff EH, Zupec-Kania BA, Amark PE, Ballaban Gil KR, Bergqvist AGC, Blackford R, et al. Optimal clinical management of children receiving the ketogenic diet: Recommendations of the International ketogenic Diet Study Group. *Epilepsia* 2009;50(2):304–17. <https://doi.org/10.1111/j.1528-1167.2008.01765.x>.
- [33] Alsfook BA, Alsfook AA, Chen Z, Kwan P, Brodie MJ. Pharmacological outcomes in teenagers with newly diagnosed epilepsy: A 30-year cohort study. *Epilepsia*. Published online May 21, 2019;epi.15664. doi:10.1111/epi.15664.
- [34] Lyons L, Schoeler NE, Langan D, Cross JH. Use of ketogenic diet therapy in infants with epilepsy: a systematic review and meta-analysis. *Epilepsia* 2020;61(6):1261–81. <https://doi.org/10.1111/epi.16543>.
- [35] Kim JA, Yoon J-R, Lee EJ, Lee JS, Kim JT, Kim HD, et al. Efficacy of the classic Ketogenic and the modified Atkins diets in refractory childhood epilepsy. *Epilepsia* 2016;57(1):51–8. <https://doi.org/10.1111/epi.13256>.
- [36] Joseph NK, Macharia PM, Ouma PO, Mumo J, Jalang'o R, Wagacha PW, et al. Spatial access inequities and childhood immunisation uptake in Kenya. *BMC Public Health* 2020;20(1). <https://doi.org/10.1186/s12889-020-09486-8>.
- [37] Feyisa BB, Tefera GM, Endris BS, Asayehu TT, Gebreyesus SH. Feeding practice, energy, and nutrient intake adequacy among children aged 6–23 months in Southern Ethiopia: a community based cross-sectional study. *Food Sci Nutr* 2020;8(12):6680–90. <https://doi.org/10.1002/fsn3.1962>.
- [38] Gewa CA, Murphy SP, Weiss RE, Neumann CG. Determining minimum food intake amounts for diet diversity scores to maximize associations with nutrient adequacy: an analysis of schoolchildren's diets in rural Kenya. *Public Health Nutr* 2014;17(12):2667–73. <https://doi.org/10.1017/S1368890014000469>.
- [39] Lovelace S, Rabiee-Khan F. Food choices made by low-income households when feeding their pre-school children: a qualitative study: influences on food choices. *Matern Child Nutr* 2015;11(4):870–81. <https://doi.org/10.1111/mcn.12028>.
- [40] Park EG, Lee J, Lee J. Use of the modified Atkins diet in intractable pediatric epilepsy. *J Epilepsy Res* 2018;8(1):20–6. <https://doi.org/10.14581/jer.18004>.
- [41] Roehi K, Sewak SL. Practice paper of the Academy of Nutrition and Dietetics: classic and modified ketogenic diets for treatment of epilepsy. *J Acad Nutr Dietetics* 2017;117(8):1279–92. <https://doi.org/10.1016/j.jand.2017.06.006>.
- [42] Amari A, Dahlquist L, Kossoff EH, Vining EPG, Trescher WH, Slifer KJ. Children with seizures exhibit preferences for foods compatible with the ketogenic diet. *Epilepsy Behav* 2007;11(1):98–104. <https://doi.org/10.1016/j.yebeh.2007.04.005>.