



Ketogenic dietary therapy utilization in Kenya: A qualitative exploration of dietitian's perceptions

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ABSTRACT

This study utilized a qualitative design to explore dietitians' perceptions regarding Ketogenic Diet Therapy (KDT) for patients with drug-resistant epilepsy in Kenya. Dietitians from Kenya were selected and consented. Audio-recorded interviews were conducted, followed by thematic analysis of verbatim transcripts to identify recurring patterns. The study enrolled 18 dietitians, fourteen of whom correctly described their understanding of KDT for managing drug-resistant epilepsy. There was a lack of confidence in their capacity to initiate the KDT with all expressing the need for further training and facilitation. Only one dietitian reported having initiated and maintained KDT. There was an overall positive view regarding KDT and willingness to implement KDT for patients with drug-resistant epilepsy. Dietitians expressed concerns regarding the availability of national policies, inadequate staffing to support families who require KDT, and the cost of implementing this intervention. Dietitians expressed interest in virtual training to enhance their understanding of KDT. Dietitians in Kenya are mostly aware of KDT utilization for the management of drug-resistant epilepsy. However, they cited poor capability and various barriers to implementation. There is a need for policies to facilitate KDT as a treatment option for the benefit of patients with drug-resistant epilepsy.

1. Introduction

Epilepsy is one of the most widespread neurological diseases, affecting approximately 50 million people globally, with the highest incidence recorded in infants and older age groups [1]. Although a wide spectrum of anti-seizure medications is available, they remain ineffective in approximately one third of epilepsy patients [2]. Ketogenic

dietary therapies [KDT] have been successfully utilized for patients with drug-resistant epilepsy, with at least half of the patients reporting a 50 % decrease in seizures [3]. Many studies have demonstrated the effectiveness of KDT for epilepsy particularly in children and some report on increasing utilization over time. However specific information on global trends of application of KDT for epilepsy in various age groups is limited [4,5].

Abbreviations: AKUHN, Aga Khan University Hospital, Nairobi; ASM, Anti-Seizure Medications; IDI, In-depth Interviews; IERC, Institutional Ethics Review Committee; IMAM, Integrated Management of Acute Malnutrition; KDT, Ketogenic Dietary Therapies; KNDI, Kenya Nutritionists' and Dietitians' Institute; LMIC, Low and Middle Income Countries; NACOSTI, National Commission for Science Technology and Innovations.

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Ketogenic dietary therapies are delivered by a multidisciplinary team of healthcare professionals specialized in KDT to manage the complex nature of patients' needs, thereby promoting the safety and efficacy of KDT in patients with epilepsy [6]. The initial step prior to administration of KDT involves screening of patients by the physician and the dietitian for existence of metabolic disorders involving fatty acid oxidation, which could hinder formation of ketone bodies required to attain a state of ketosis [6–8].

The dietitian's role includes conducting nutritional and biological assessments, educating patients, and providing critical support during implementation and on discontinuing the KDT [9–11]. Dietitians, therefore, need to be well-versed in these roles and, in particular, the recognition and management of adverse health outcomes of KDT [12]. Dietitians also provide critical support for patients on KDT under challenging circumstances such as during hospital admissions and transition from paediatric to adult services when increasing independence may interfere with adherence to dietary plans [13,14].

Implementation of KDT in Africa remains challenging due to a myriad of factors, including low awareness among healthcare workers, lack of experienced multidisciplinary teams, cultural aspects, and low levels of adoption of existing implementation guidelines [6,15–18].

A recent study found that access to e-health applications for caregivers of children with epilepsy undertaking KDT enhanced patient engagement better compared to paper-based materials. This study recommended that dietitians utilize e-health applications in the management of KDT [19]. Globally there is minimal data comparing dietitian experience and perceptions on KDT for drug-resistant epilepsy. In one study from the United Kingdom, dietitians indicated that they had insufficient time available to support patients to commence and maintain KDT [9].

In light of this, this study aimed to explore dietitians' perceptions regarding KDT utilization in Kenya to determine gaps and opportunities which, if addressed, would foster improved uptake, thereby reducing the significant epilepsy treatment gap in the country [20]. In addition, we explored dietitians' willingness to engage in virtual training to enhance their capacity to manage KDT.

2. Material and methods

2.1. Study design and participants

This qualitative inquiry aimed to explore dietitians' perceptions regarding utilization of KDT in Kenya. In-depth interviews (IDIs) were utilized to collect the data and were conducted in March 2022. The study population comprised of licensed dietitians in Kenya, who were estimated to be 2,000 in 2021. A total of 18 semi-structured interviews were successfully completed at which point no new themes were documented during analysis, and saturation was observed [21]. Previous studies have shown that minimal additional data is usually obtained by interviewing more than 20 individuals for a specific category of participants [21].

2.2. Recruitment and data collection

The research team comprised of an experienced social scientist and a research assistant who carried out the interviews. A two-day training period was held for the research team and engaged the social scientist and a research assistant who had the required IDI facilitation and notetaking experience and moderated all the interviews. The training focused on the study background, research ethics, the study tool, consent taking and the IDI process. The training was conducted to ensure a standard approach to the data collection process. The study tool comprised open-ended questions, followed by additional probes as relevant, and was utilized at all the interviews. The study tool was developed specifically for this study and piloted to ensure it was comprehensive and appropriate. Pilot data was not included in the data analysis.

The research team began by evaluating the list of dietitians licensed by the Kenya Nutritionists' and Dietitians' Institute (KNDI) practicing in Kenya. One dietitian from each county was identified and invited to participate in the study. Those who indicated an interest in the study were requested to provide a tentative date when they would be available to participate in the interview process. Dietitians were given the option to participate either in person through a visit to the Aga Khan University Hospital, Nairobi (AKUHN), or through a virtual interview using a passcode protected Zoom link on the agreed date. Both in-person and virtual interviews were utilized to promote participation by as many dietitians as possible.

Dietitians who opted for an in-person interview were directed to a quiet and private venue at the Aga Khan University Hospital (AKUHN), which is a private, not-for-profit referral teaching hospital located in Parklands, Nairobi County. This facility provides a neurology service that caters for approximately 4,500 patient visits of varying socioeconomic status each year. A team of six dietitians is available to support the paediatric neurology service, in addition to catering to other patients.

The IDI dialogue centred on dietitian's perception of KDT and its application for drug-resistant epilepsy and included socio-demographic data, professional training details, a description of dietitians' practice, and dietitians' perception of KDT's applicability in Kenya. The interview also served to establish dietitians' opinions on training modalities to enhance dietitians' knowledge regarding KDT for managing drug-resistant epilepsy.

2.3. Ethical considerations

This study was guided by a protocol which was approved by the Aga Khan University Institutional Ethics Review Committee (IERC), reference – 2021/IERC-149(v2) and the National Commission for Science Technology and Innovations (NACOSTI) licence no NACOSTI/P/22/15295. For the virtual interviews, the research assistant emailed the consent form to the study participant, who signed and emailed it back prior to the interview. Those who attended in person signed the consent form prior to the start of the interview. One copy of the signed consent form was returned to the study participant, and the study team stored the second copy in locked cabinets at AKUHN. All respondents provided written consent to participate in the study. Study participants' protection and confidentiality were ensured through data collection sessions in private settings, maintaining the confidentiality of all study materials and information, limiting access to study information to authorized personnel only, and ensuring no identifying information on individual participants was included in the analysis and subsequent reports.

2.4. Data management and analysis

All IDIs were captured through audio recording and field notes. The audio recordings were securely stored in a locked cabinet at AKUHN and were only accessible to the study team. The audio recordings were transcribed verbatim by assistants who were fluent in English. The transcripts were analysed with the use of Nvivo 12 software. Led by two coders, the study employed both inductive and deductive analysis [22,23]. The coders began by using the data collection tool to develop a coding framework for analysis of the transcripts. The data obtained from the transcripts was then coded line by line allowing for identification of themes related to the study objectives (deductive analysis) and novel concepts that may not have been considered prior (inductive analysis). As the coding team identified new codes emanating from subsequent transcriptions, they expanded the code book as necessary. The codes were collated into thematic categories that were then labelled according to specific areas of interest. Lastly, vivid quotes were selected to support the described themes.

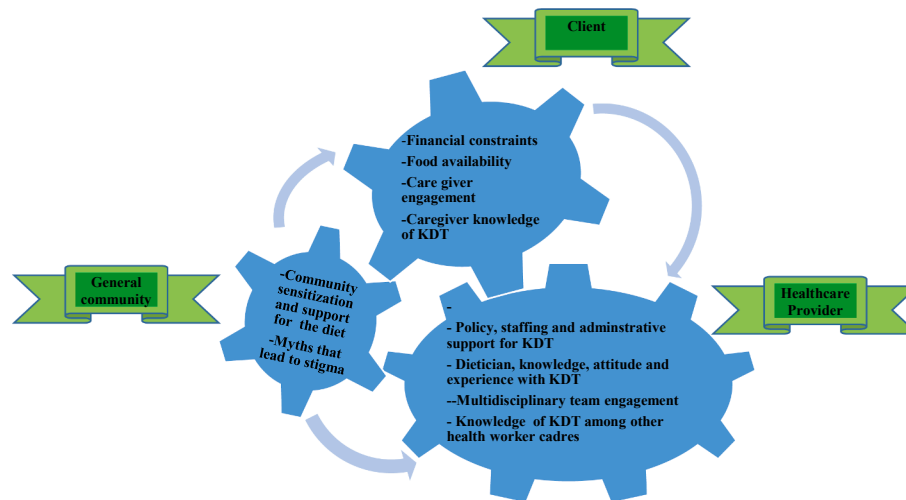


Fig. 1. Dietitians' considerations for KDT.

3. Results

A total of 18 IDIs were conducted and included seven male and eleven female participants. Five in-person interviews were conducted, while the remaining 13 were conducted virtually. Twelve participants were aged between 20 and 30 years, five were between 30 and 40 years, and one was between 40 and 50 years. One dietitian had attained doctoral-level training, three had completed a master's degree in dietetics, one held a bachelor's degree, while the rest (13) had diploma-level training that included dietetics. One dietitian had been actively involved in the provision of KDT for patients with drug-resistant epilepsy.

The majority (14) of dietitians were engaged by hospital-based clinical nutrition departments, with two participants also reporting involvement in concurrent administrative work. Three worked in public health nutrition departments, while one was a research dietitian.

Six participants were clear that KDT has the ability to reduce seizures in children with drug-resistant epilepsy through modulation of brain function. Eight participants thought implementing a ketogenic diet for managing epilepsy in children was advisable because available evidence indicates KDT can reduce seizures and is, therefore, beneficial to patients.

One participant indicated that KDT had three formulations, which meant that KDT implementation required input from neurologists and dietitians who were well-versed in these different variants of the ketogenic diet.

Participants were clear on dietitians' role in implementing KDT, they reported that low staffing levels and lack of multidisciplinary facilitation hindered the implementation of KDT. Participants also communicated the possibility of resistance from other dietitians who are not equipped for changes in management of patients, especially in the face of the existing work overload. The work overload issue was particularly pertinent as KDT was considered a time-consuming intervention. Local dietitians were described as 'stuck in traditional medicine' and would need to be encouraged to embrace new therapies such as KDT if the treatment was to gain traction in the region.

Lack of a guiding policy with resulting poor provision of resources was considered a significant drawback in upscaling the utilization of KDT in the country by two participants. They highlighted that with a dedicated policy in place, the government would sensitize the populace on dietary therapy as part of the primary options of care to be considered for patients with drug-resistant epilepsy and provide the facilitation required to operationalize this intervention.

Five participants thought a lack of experience regarding KDT among dietitians in Kenya would reduce their ability to effectively implement

KDT for managing epilepsy. Eight respondents indicated they lacked the relevant experience required to support families who needed KDT because they had never initiated KDT themselves. They reported reliance on information from other global settings because this was lacking within Kenya. One participant expressed the need to customize KDT-related information to meet clients' needs.

One participant indicated that it was difficult to implement a ketogenic diet appropriately because the patient or patient's family could not obtain the required foods. Consequently, they used foods that clients could access and formulated a diet as close as possible to the recommended therapy plan. Sustainability concerns were raised by two participants who considered the diet too expensive for the average Kenyan family to implement.

Cultural practices and myths were also discussed as barriers that may prevent implementation of KDT in managing drug-resistant epilepsy in Kenya. Lack of an understanding of what KDT entails among patients and a negative attitude towards KDT were also considered potential barriers to uptake in Kenya.

Fourteen participants considered an online training program feasible and effective in enhancing their knowledge of KDT. They felt that virtual training had the potential to expand the reach of proposed training programs. Online programs were also considered as having the possibility to improve patient outcomes and reduce the stigma associated with drug-resistant epilepsy. All 18 dietitians indicated willingness to participate in an online training program because this interaction would not only improve their capability to implement KDT but would also provide an opportunity to collaborate with other dietitians providing the intervention.

Fig. 1 summarizes factors dietitians consider important for successful implementation of KDT in Kenya, while Table 1 summarizes the dietitians' perceptions of the KDT.

4. Discussion

This qualitative inquiry sought to obtain an in-depth understanding of dietitians' perceptions regarding KDT utilization for management of drug-resistant epilepsy and explored dietitians' willingness to engage in virtual training to enhance their capabilities with regards to KDT. The research aimed to better understand barriers to uptake of this treatment modality and opportunities to address these issues in the Kenyan context.

The majority of dietitians who were surveyed displayed some understanding regarding KDT and the potential benefit this intervention holds for patients living with drug-resistant epilepsy. However, only one participant provided details regarding the composition of KDT,

Table 1
Perceptions of dietitians on KDT.

Sub-theme	Quotes
Understanding of KDT composition	<p>“When you look at the average micronutrient distribution range, fat is on the higher side. Then we have the protein, and the lowest micronutrient distribution range is the carbohydrates which is about 5 % of the total energy requirement of the client that you are dealing with...” (KDT-IDI-05)</p> <p>“I remember like there were at least three variations to the ketogenic diet and each needed specific calculations...so you see... you would need the neurologist and the dietitian working together to make it work...” (KDT-IDI-18)</p>
KDT and Seizure Reduction	<p>“Reduced use of carbohydrate consumption uniquely alters the activity of the brain. It reduces excitability of the brain neurons therefore reducing the tendency of generation of the seizures. Yes, that’s my basis of understanding.” (KDT-IDI-11)</p> <p>“Ketogenic diets for epilepsy is something that people have been researching about and studies have shown it is working, so that’s my understanding for now.” (KDT-IDI-13)</p>
Role of the dietitian	<p>“When you are doing a diet plan for a patient, every patient’s diet plan is usually individualized, so it is the role of the dietitian to assess the patient... ensure that the individualized diet plan is prepared and adhered to ... and check the general response of particular patients. (KDT-IDI-04)</p> <p>“They are the ones to spear head the whole process...they are the most professional people to discuss this with the patients - you give details to the patient... The role of the dietitian is to handle the [questions patients] asked about it. They are to introduce the whole idea to the patient.” (KDT-IDI-18)</p>
Client Related Factors	<p>“There are cultural beliefs about a child with epilepsy. Some believe that it is a curse [and] such beliefs can lead to stigma, so children with active seizure may not have opportunity to study and interact with their fellow kids develop social skills and the like” (KDT-IDI-14)</p> <p>“Maybe the diet is expensive. Some of the patients cannot afford to buy a lot of fatty food or protein and now food prices have really gone up. You better eat ugali [corn meal] everyday - not the ketogenic diet.” (KDT-IDI-03)</p>
Dietitians Capacity to Implement KDT	<p>“Another problem we are likely to encounter...you know this will be like adding some work to our dietitians, paediatricians and, to our nurses. We have been complaining of workload...They are likely to say, ‘we need more staff.’ So that is something that might hinder the implementation of this particular program.” (KDT-IDI-04)</p> <p>“Well, I think epilepsy is an emerging problem in children and nutritionists - including myself - don’t have that vast experience on ketogenic dietary therapy.” (KDT-IDI-14)</p>
Policy requirement	<p>“I believe that implementation will also be a problem and there is need to add government policy, so if the government can come up with program to encourage or to promote such activities, otherwise, most people do not consider it as a direct approach, just like I said earlier they will only consider it as the only last option” (KDT-IDI-02)</p> <p>“Okay.... before you implement anything there must be a policy guideline. If we can implement Ketogenic diet for these particular children they are able to respond very well to the ketogenic diet, and I think that it is something we need to initiate as a country” (KDT-IDI-04)</p>
Virtual Training Programs for KDT	<p>“I think it would be a very good idea, given that nutrition is an evolving science and training is one of the things you should be involved in as a practicing dietitian, so an online training program would be such a plus for dietitians who are looking to improve ...the quality of life for these paediatric patients...” (KDT-IDI-06)</p> <p>“Yeah these online and in person trainings will be useful in our country in general because for the longest time epileptic patients have been stigmatized. You know when they are getting these episodes in public or in schools...” (KDT- IDI-05)</p>

indicating that in-depth training and practical experience are likely to improve their ability to support patients initiate and maintain KDT.

Indeed, the majority of the dietitians lacked confidence in their capability to prescribe KDT, with all expressing the need for further training and facilitation. This may have resulted from inadequate foundational education as well as a lack of hands-on experience in the provision of KDT. At present, Ketogenic dietary therapy for epilepsy is included among medical conditions which are managed through dietary interventions in the dietitians’ curriculum in Kenya. However in-depth training on the management of ketogenic dietary therapy is usually acquired through post training courses. Previous studies have shown that inadequate experience could be a limiting factor to the widespread implementation of KDT [24].

Implementing the NICE guidelines led to an increase in the demand for services, which improved the practical experience dietitians have in handling such referrals [25]. Guidelines for paediatrician, neurologists, and dietitians have, over time, been instrumental in fostering uptake of KDT in various settings [7,26]. Lack of adoption of existing guidelines for the implementation of KDT in Kenya contributes to low rates of identification and referral of patients who may benefit from this intervention and, in turn, low levels of dietitian experience with KDT [25,27]. Low staffing levels among healthcare workers are a common problem in low-resource settings that negatively impact the application of newer interventions such as KDT [6,28]. Government policies that support the implementation of KDT in Kenya would facilitate adequate staffing levels required to provide the service.

Currently there are no studies that explore the perception of neurologists practicing in Kenya regarding KDT. Such understanding in future studies could help strengthen referral of patients with drug-resistant epilepsy for evaluation and commencement of KDT which would in turn improve dietitian experience in the delivery of this intervention.

In a previous study; participants estimated that 5000 to 10,000 Kenya shillings (46 – 93USD) was required to provide the modified Atkins diet for children in Kenya[29]. The cost of KDT was expressed as a concern impacting implementation by participants in this study. Further education for dietitians on low-cost, locally available alternatives utilized in similar settings would empower them in this endeavour and overcome expressed concerns for cultural acceptability and sustainability of KDT [15,16]. Local policy formulation that includes educating families and healthcare workers about the efficacy and implementation of KDT would also encourage the uptake of this intervention.

Significant support for an online training program was evident and could be partly because many professionals became familiar with online training during the COVID-19 pandemic, which necessitated distancing and lockdowns for extended periods. Indeed, a survey among dietitians during the pandemic reported that members looked forward to continued use of digital platforms for the management of patients and education even after the pandemic [30]. Courses specifically tailored to improve health worker and patient understanding of KDT, such as the Matthew’s Friends Keto College <https://ketocollege.co.uk/>, are now available and can be harnessed to improve dietitian capacity for KDT.

A similar qualitative study among dietitians utilized telephonic interventions in the survey and reported availability of online resources as enablers in their implementation of KDT for weight loss and follow-up of patients [31]. However, despite the increasing availability of cheap smartphones globally, improving network coverage, and increasing number of data providers, variable access to technology may be a potential hindrance to online training programs and utilization for patient support in low-resource areas [32].

This qualitative study attained saturation of themes therefore, the findings can be considered representative of perceptions of dietitians practicing in Kenya. However, these results may not be generalizable to better-resourced areas where factors such as cultural dietary practices and availability of dietitians would not be challenges to the uptake of KDT. As may occur in other qualitative studies, social desirability bias

for certain aspects, such as dietitian's understanding of KDT, may have influenced some of the responses obtained. Majority of the respondents in this study were diploma holders and this may be a limitation to the generalizability of the results of this study.

5. Conclusion

This study demonstrates the underutilization of dietitians in Kenya for the provision of KDT, leading to poor capability, as demonstrated by low levels of experience and confidence in initiating this intervention despite evident awareness. A national policy that supports KDT as a treatment option would benefit patients living with drug-resistant epilepsy by facilitating referrals, adequate staffing levels, and dietitian training, thereby providing an additional treatment modality for these patients.

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Ethical statement

All subjects gave their informed consent for inclusion before they participated in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Aga Khan University Institutional Ethics Review Committee (IERC), reference – 2021/IERC-149(v2) and the National Commission for Science Technology and Innovations (NACOSTI) licence no NACOSTI/P/22/15295.

CRedit authorship contribution statement

Pauline Samia: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. **Violet Naanyu:** Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Software, Validation, Writing – original draft, Writing – review & editing. **J Helen Cross:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Richard Idro:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Paul Boon:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Jo Wilmshurst:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Stanley Luchters:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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