

Original Research

A qualitative study of health education experiences and self-management practices among patients with type 2 diabetes at Malamulo Adventist Hospital in Thyolo District, Malawi

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Abstract

Background

The aim of this study was to understand the perceptions and experiences of health education and self-management practices on Malamulo Adventist Hospital type 2 diabetic patients.

Methods

In this qualitative study, key informant interviews (KIIs; n = 4) and focus group discussions (3 FGDs; n = 16) were conducted amongst type 2 diabetes patients who had been treated at Malamulo Adventist Hospital in southern Malawi at least once. Key informant interviews and focus group discussions were audio recorded, transcribed verbatim and translated for analysis. Grounded theory methods were used to identify line-by-line emerging codes and were categorised and examined in Atlas.ti. The data was analysed for emergent themes and supported by critical quotes.

Results

Content analysis revealed participants had a positive regard for the diabetes education classes and had satisfactory health literacy. Participants expressed their ability to integrate diabetes education, such as exercise into their lifestyle. Due to financial constraints subjects experienced trouble maintaining their medication regimen, and had difficulty adopting healthier nutritional alternatives. Although patients expressed efficacy in controlling their blood sugar they subsequently expressed having limited knowledge when dealing with diabetes complications.

Conclusions

Diabetes self-management is comprised of a complex set of processes. Patients with type 2 diabetes at Malamulo Adventist Hospital are deeply impacted by these processes which includes their understanding of the disease process, effects of medication, economic challenges to acquiring health care services and medications, and one's unique life experience. For all patients with type 2 diabetes to successfully manage their condition, support from their family, the medical community, and health policies must be readily available.

Introduction

The incidence and prevalence of Type 2 Diabetes (T2D) is on the rise globally, with increased burden in developing nations especially sub-Saharan Africa.¹ This life-threatening condition can be prevented, managed, and controlled.² However, if not managed appropriately, individuals affected with T2D are more vulnerable to early complications. For Malawians living in low-and-middle income communities the ability to prevent and manage such a condition can be challenging. There is limited data regarding the current diabetes endemic in Malawi. However, in 2009, an assessment of Malawi's burden of T2D was carried out utilising the World Health Organization (WHO) STEPS wise approach to noncommunicable diseases. This study revealed the age-sex-standardised prevalence of T2D was 6.5%, 4.7%, and 5.6% for males, females, and combined male/female adults aged 24 to 64 years respectively.³ In 2014, the International Diabetes Federation Africa (IDFA) reported the number of deaths in Malawi due to T2D to be approximately 12,799.⁴ This burden is expected to increase as urbanisation and sedentary lifestyles rise.⁵

Evidence-based practices have proven that monitoring blood glucose, glycosylated hemoglobin, use of appropriate medication, good nutrition, and exercise are an integral part of care to prevent morbidity and mortality.⁶ Even more essential to T2D care is the incorporation of diabetes education and self-management practices. This practice of increasing knowledge and skills has proven to be a vital social construct that modifies behaviours and produces positive health outcomes.⁷ A 2012 T2D study carried out in Mangochi district, Malawi, discovered that diabetes knowledge among patients was low. This study reveals a gap between transfer of information from health care facilities to their patients, as these patients primarily receive knowledge about their condition from the hospital.⁸ Because of the essentiality of education on T2D care and management, the Malawi Ministry of Health has set it as a priority measure to prevent T2D complications.⁹

In 2012, Malamulo Adventist Hospital (MAH), in Thyolo District integrated diabetes education classes in the hospital's outpatient department. This integration was in effort to

reduce the hospitals T2D morbidity and mortality. To understand what impact the diabetes classes and education at point of care had on persons living with type 2 diabetes' knowledge, attitudes, practices and diabetes control, a 3-phase mix-methods study was carried out. The first phase of the study described in this manuscript is a qualitative assessment of patients' understanding and application of knowledge received in diabetes classes and at point of care as well as their personal experiences with self-management practices. The phase I findings of this study will give more insight of the benefits and barriers in the educational services MAH provides diabetic patients. More so, Phase 2 and III of the study which quantitatively assesses patients and health care provider's knowledge, attitudes and practices in combination with this qualitative assessment will serve as a foundation for future culturally appropriate interventions measures and provide appropriate insight as to where gaps in diabetes education exist to modify and create effective T2D health promotion programmes in Malawi.

Methods

This exploratory research utilised a phenomenology qualitative design. Specifically, researchers utilised key informant interviews (KIIs) and focus group discussions (FGDs) to gain insight on MAH T2D patient's understanding and application of knowledge received as well as their personal experiences with self-management practices. The use of both KIIs and FGDs was used as a triangulation method to validate data. The Health Belief Model was the theoretical framework used to develop the KIIs and FGDs guides. This framework infers that patient's knowledge, attitudes and practices pertaining to T2D constitutes vital constructs (perceived susceptibility, severity, benefits and barriers) affecting their behaviour and self-efficacy toward their condition which ultimately affects their health outcome. The guides captured patients' diabetes history, the treatment they received, the acquisition, the type and the application of the education obtained, self-management practices and related attitudes, complications, barriers/challenges and areas MAH can improve their diabetes education. All guides were written in English then translated Chichewa (a language commonly spoken in Malawi), and then back translated to English for accuracy.

Written permission to conduct this study was first obtained from MAH's research committee and administration. Additionally, the National Health Science Research Committee (NHSRC) through the Republic of Malawi, Ministry of Health, reviewed the study protocols and data collection tools, thereby deeming the study ethical and provided researchers the approval number NHSRC # 16/1/1524. Written informed consent was additionally obtained by all subject participants acknowledging their right to withdraw from the study at any time without consequences to them and the services they were being rendered. All other ethical considerations were fulfilled by maintaining confidentiality.

The inclusion criteria for this study included the following: (1) male or female at least 18 years of age; (2) diagnosis of type 2 diabetes; (3) at least 1 prior treatment from MAH prior to the study. The exclusion criteria included: (1) patients with type I diabetes, (2) individuals with type 2 diabetes having never received treatment at MAH. Utilising purposeful sampling, participants were recruited through the hospital's inpatient and outpatient wards, and within the community

via sensitisation. To verify that each participant had T2D, review of health passports (Mobile medical records) indicating a T2D diagnosis was carried out. All participants were incentivised with 1.5 kg of beans and a bar of soap.

FGDs and KIIs were carried out within MAH, located in Thyolo district until data saturation was met. Trained interviewers conducted 3 FGDs and 4 KIIs between March and May 2016. A total of twenty (20) MAH diabetic patients living in the surrounding areas of Thyolo district participated. All Interviewers were accompanied by 1 or 2 notetakers and the FGDs and KIIs were digitally recorded while being carried out in Chichewa. Confidentiality was protected by assigning each participant with a code number and deidentifying transcripts, notes, and audio recordings. All files are stored in a locked file cabinet in a locked room.

Digital recordings were transcribed verbatim in Chichewa then translated into English. Using field notes and grounded theory, an inductive methodology, emerging line-by-line codes were first developed to create a codebook to all text using Atlas.ti, a qualitative data analysis research software. Thereafter the transcripts were analysed for emergent themes and supported by critical quotes. At the close of the study a dissemination of results was carried out where several stakeholders including study participants were invited. Feedback from the dissemination was essential to guide the credibility of the results.

Results

The investigators carried out 3 FGDs and 4 KIIs. Sixteen subjects participated in the FGDs, 3 men and 13 women. The mean number of years of T2D diagnoses was 2.87 years and 9 participants reported family history of the condition. Four subjects participated in the KIIs, 3 men and 1 woman. The mean number of years of T2D were 3.5 and 3 participants reported a family history of the condition.

Content analysis of the transcripts led to the identification of 9 themes. Each theme was then divided into relevant codes used to organise and analyse participant statements. The themes were organised into a final coding framework

Table 1: Demographic characteristics of focus group participants

16 participants
3 males and 13 females
Mean years since diagnosis of type 2 diabetes: 2.87
Number with family history of diabetes: 9

Table 2: Demographic characteristics of key informant interview participants

4 participants
3 males and 1 female
Mean years since diagnosis of type 2 diabetes: 3.5
Number with family history of diabetes: 3

Table 3: Themes and initial coding framework

Themes (final coding framework)	Initial coding framework
1. Perception of diabetes education	<ul style="list-style-type: none"> • Perception on what diabetes education should entail • Positive regard for diabetes educators • Perceived understanding of diabetes education • Attitudes towards educators' nutritional suggestions
2. Application of education	<ul style="list-style-type: none"> • Integrating diabetes education into lifestyle • Results of heeding to educational instructions • Self-efficacy in control of diabetes • Frequency of attendance to diabetes education classes
3. Nutritional knowledge	<ul style="list-style-type: none"> • Nutritional effects on blood sugar levels • Favorite Foods
4. Knowledge of medication	<ul style="list-style-type: none"> • Alternative medication options • General knowledge of medication effects on the body • Drug prescription instructions knowledge
5. Experiences with medication and practices	<ul style="list-style-type: none"> • Interruptions in medication schedule • Where participants get their medication • Personal experience of how medication affects the body • Daily practices regarding medication • Frequency of refilling prescription
6. Exercise knowledge	<ul style="list-style-type: none"> • Effect of exercise on blood sugar • Exercise options
7. Dealing with complications	<ul style="list-style-type: none"> • Limited knowledge on dealing with complications • Experiences with diabetes complications • Practices when experiencing diabetes complications • Knowing when blood sugar is low
8. Limitations in diabetes care and treatment	<ul style="list-style-type: none"> • Preferences and habits as a barrier to proper nutrition • Limited access to food • Limited access to medication • Exercise challenges
9. Patient Recommendations for increase in diabetes control	<ul style="list-style-type: none"> • Reduced or subsidized medications • Increases in prescription quantity • Increased variety of diabetes education, tools and take away resources

and the codes were used in the initial coding framework to code statements and phrases by the participants.

All excerpts provided were from diabetic patients, living in the rural areas of Thyolo district and were patients of MAH.

Perception of diabetes education

Participants understood what the diabetes classes should entail. When asked, what should be included in diabetes education one participant said,

“They are teaching us to eat foods that diabetics are supposed to eat and how to avoid it.”

Participants had a positive attitude towards education and its importance, as well as positive regard for the health care providers that educated them,

“Education is very important it helps us to be aware.”

Most participants had taken part in the diabetes education classes offered by the hospital. However, for those who had not, they received a form of counseling from pharmacist or other health care providers during treatment.

“This education just adds up to the advice which I get when receiving the medications and which is on the form, so when am free I read these instruction forms to remind myself.”

Application of education

Many participants described daily practices that included the integration of what they learned from Malamulo diabetes classes into their daily practices. One of the most common applications of knowledge was replacing *nsima* with *ngaiwa*, a healthier alternative (Both *nsima* and *ngaiwa* are maize-based staples commonly eaten in Malawi). Many credit this transition as to the recommendation of their diabetes educators,

“...I don't like ngaiwa at all. But my kids encourage me to eat ngaiwa because those are instructions from the hospital. So I try to eat ngaiwa but I am not happy with it.”

Many participants discussed how they had integrated exercise into their daily life based on the diabetes educational class recommendation.

"I also have heard that exercise is good; even if we can't run we have at least to walk and sweat. That helps our bodies to be free. As for my case, I wake up in the morning and run around within my compound; I do 10 rounds."

Some participants felt that after attending diabetes education they experienced a reduction in their common diabetes complications.

"Sugar was getting away. After the education, it was normalising."

Nutritional knowledge

Participants had general knowledge on nutrition related to their blood sugar. The following is a response to a question about blood sugar and its interrelationship with food.

"Yeah, I have heard about it, but what doctors say is that every food contains and bring sugar in the body which is stored somewhere. When it's too much in the body, when you are hungry and drink water, that sugar gets back into the blood."

Some participants believed that food in general would help with blood sugar levels.

"Sometimes you frequently feel hungry so when you eat you find that it has lowered."

Knowledge of medication

When patients were asked about their medication they had general knowledge on how it affects their condition.

"It makes you strong; you are able to carry on with your everyday activities but you become weaker as the drug effect goes low."

The participants referred to alternative sources of medication for their diabetes such as Moringa and other herbs.

"Some say that Moringa lowers blood sugar levels" (MAH diabetes patient)

When asked, what affect the medication specifically had on the body one participant said,

"I just know that the medications reduce the diabetes but it doesn't cure it."

In response to what effect the medications have on the body many did not know. Instead, they knew that they needed to take them daily to generally help with their diabetes. Most reported that they were taught to take their medication every day twice a day.

Experiences with medication practices

Most participants discussed receiving their medication at Malamulo Hospital. If they didn't have access to the medications, they would use herbal alternatives.

"But the good thing is we come here (Malamulo Hospital) and get drugs. If its the case of the other medication, we pluck from trees at home and put in our porridge and then eat."

Throughout the discussions and interviews patients responded that they took their medication daily as prescribed. However, most experienced interruptions in this schedule when they did not have financial ability to purchase medication.

"...It happens that when we are given medicine for a month and we run out of the medicine and we don't have money to buy more, we skip without having medicine because we do not have money to buy"

Exercise knowledge

Many participants had an awareness of what was exercise and its importance as it related to their diabetes condition.

"...I do exercise every morning because of numbness when I sleep. And by running in the morning we increase the blood circulation hence removing the numbness."

Participants believed that exercise could include the traditional exercise, such as walking, running, or playing sports and other physical activities, as well as nontraditional exercise activities such as such as farming or carpentry.

Examples of exercise, "playing ball running, walking"

"There are no problems, because I am a farmer and I walk every day to my farm which is also part of exercise."

"Even working in the field and home lowers blood sugar levels."

Coping with complications

Patients often referred to the complications they experienced. In the following statement a participant speaks of complications in their vision.

"I don't even realise; I just see a figure coming."

Most participants had their own remedies for the complications they experienced. However, they did not always indicate that these remedies were recommended by any health care provider.

"I even stopped putting on my shoes, when I put on shoes, my toes get red."

"When I see that my blood sugar is high, when there are lemons around, I just squeeze and sip and I frequently take water so to normalise the blood sugar."

When asked how they treat numbness in the feet:

"I just walk around like a psychiatric then I feel good."

However, some participants who responded that they did not always feel prepared to deal with their diabetes complications.

"Well I don't know what to do"

Limitations in diabetes care and treatment

Investigators found in the discussions and interviews there were numerous statements on the barriers participants faced in proper management of their diabetes. These barriers at times were personal, but most often included challenges related to insufficient resources for food, and medication. The most mentioned limitation to proper diabetes management was a lack of funds to buy medication or food.

"...one can stay a month without medication or even a single tambala (coins), because there is no help of any kind unless the person has a little something to bring income so that medication can be bought."

The most often discussed barriers to proper nutrition was the recommended switch from Nsima to Ngaiwa. Participants often expressed how they disliked Ngaiwa and were finding it hard to transition.

"...I don't like ngaiwa. But sometimes I eat ngaiwa for like 2 days and switch to ufa owerwa. I can do that for maybe a week and switch back again."

Participants discussed how their greatest barrier to proper nutrition was a need of money.

Facilitator: *"Do you have access to health food that you need?"*

Participants: *"In a hard way."*

Not all participants were actively engaged in daily exercise. A few reported they would like to but the experience caused them pain.

"When I have just started jogging, for the next day not to jog again I experience body pains."

Patient recommendations for improvement in diabetes control

When asked for recommendations for Malamulo Hospital, participants stated a desire for more education and encouragement on the right foods to eat to help control their diabetes.

"... encouraging each other about food. It will encourage someone not to forget about drinking medicine and other important things."

When asked if they had any recommendations for Malamulo Hospital as it relates to diabetes care, all participants suggested subsidies or reduction in prices for medicines and testing.

"If we run out of medicine we just stay, because we don't have enough money to come back to the hospital, some of us we have to get a transport to get here because of legs. So we should think of transportation money, money for medicine and sugar testing. If only the hospital would consider us to if we can have free services for diabetes."

"...if they can reduce the prices of medications and tests for diabetes that can be good."

Some also desired the hospital to give them more education about the food they should eat and better knowledge about their bodies.

"I also would like to understand in relation to what happens in my body I am happy to learn more about it"

Discussion

Malamulo Adventist Hospital's diabetes health educational classes is a good example of integrating evidence based practices to teach self-management skills that will modify behaviours. If these behaviours are consistently, and correctly carried out they will enable patients with type 2 diabetes to successfully manage their condition on their own.⁸ These behaviours include: 1) healthy eating, 2) being physically active, 3) monitoring of blood sugar, 4) compliance with medications, 5) good problem-solving skills, 6) healthy coping skills and 7) risk-reduction behaviours. These essential diabetes self-management behaviours predict good glycemic control, reduction in complications, and improvement in quality of life for patients with type 2 diabetes.^{10,11,12}

However, self-management in diabetes is very complex. It can be described as an evolutionary process of awareness and knowledge development to survive with the complex nature of diabetes in a social context.¹³ Literature reports that adherence to self-management activities has been found to be low, especially when looking at long-term changes.¹⁴ This is particularly true in the context of this study, where financial constraints played a major role in medication non-compliance and poor nutritional choices.

Implications for practice

It is imperative for MAH healthcare providers and educators to evaluate perceived patient barriers to self-management behaviours to work alongside their patients in developing specific and realistic self-management action plans. These action plans should be periodically revisited and altered depending on the patient's response¹⁵. Action plans should be documented in the patients' health passports as it will facilitate provider-patient communication and help in the assessment of compliance. Finally, regular follow-up must be an integral component of its long-term management¹⁶. On a grass-root level, Malawi needs good population-wide

diabetes health education programmes and policies that emphasise lifestyle modification. These programmes should periodically reinforce behaviour change and long-term sustainability.

Malawi can adopt strategies many studies across developed and developing countries have demonstrated. That is, T2D complications can be routinely managed by nurses/health workers/pharmacists in primary care centres in conjunction with a physician through patient education, patient and family counseling, and close monitoring of health outcomes. Key to this success is the development of proper referral systems, increased adherence to practice guidelines, and regular evaluation and auditing of Malawi's national guidelines and management in primary health care.¹⁷⁻²¹

Implications for future research

Malawi should continue to use community based participatory research (CBPR) to address a variety of health issues and social determinants of health. In this study, CBPR allowed investigators to understand the impact diabetes education has on patients' self-management practices and the challenges patients experience that effect their health outcome. Studies which utilise community based participated research should be promoted in developing countries. This ensures the inclusion of patients' perceptions on the effectiveness of their self-care management is understood and appropriate interventions are developed and implemented.

Limitations

The current study has several limitations. The qualitative nature of the study limits characterisation of the strength of the relationships described here. The study describes perceived barriers of self-management and may not always reflect actual barriers. Additionally, the small sample size and the demographic characteristics of the participants may limit generalizability. Also, all participants are patients of MAH and unlike Malawi's government hospital, MAH is a private institution that provides health care services at a low and sometimes subsidised cost. The experiences and perceptions of the study population does create bias as the services provided and the cost associated with it differ from government facilitates which provide care for free.

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Competing interests

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