

# 'This disease would suit better those who have money': Insulin-Treated Diabetes Illness Experience in rural Malawi

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## Abstract

### Background

Understanding the illness experience among rural-based insulin-treated diabetic patients has implications for practice and policy. However, there is a lack of in-depth knowledge about insulin-treated diabetic patients' illness experiences in rural Malawi. We explored the experiences of people living with insulin-treated diabetes in rural Malawi.

### Research Designs and Methods

The study used a qualitative narrative inquiry. Participants were identified at Kamuzu Central Hospital Diabetes Clinic. The hospital is a tertiary level health care facility. We purposively selected 10 participants from rural areas attending the clinic. Data were collected through in-depth interviews in the privacy of the homes of the study participants and analysis was done using Riessman approach of thematic narrative analysis.

### Results

The following five themes emerged: (1) diabetes perceived as the illness for the rich; (2) 'everything is on a standstill'; (3) dietary challenges of the diabetes illness experience; (4) drug-related challenges associated with the diabetes illness experience and (5) experiencing physical effects of the diabetes illness.

### Conclusion

Rural-based insulin-treated diabetic patients struggled to live with the illness in the context of low resources. There is a need for multi-factorial approaches at both the community and system levels so as to support people living with diabetes in the rural areas in order to improve their experiences.

**Keywords:** Insulin-treated diabetes, rural areas, illness experience, Narrative inquiry, Malawi

## Introduction

Diabetes is a global public health problem with a worldwide prevalence of 8.8%<sup>1</sup>. The prevalence of diabetes in sub-Saharan Africa (SSA) was at 6% in 2015<sup>1</sup>. In Malawi, studies conducted in the 1960s and 1970s demonstrated that diabetes was not so much an important health problem then; the prevalence of diabetes was estimated at 1% or less<sup>2</sup>. However, in 2017 the prevalence of diabetes was estimated to be 5.6%<sup>3</sup> and was slightly higher in rural than in urban areas among adults aged between 25 and 64 years; 5.4% versus 4.4% respectively<sup>4</sup>. Underlying causes for the increase in the prevalence of diabetes include the altered lifestyle changes leading to a surge of metabolic syndromes<sup>5</sup>. HIV and AIDS has been implicated in Malawi to increase the risk of development of new diabetes or deterioration in glycemic control in existing diabetic patients due to antiretroviral therapy<sup>6</sup>. Additionally, there is evidence that malnutrition causes persistent insulin deficiency, glucose intolerance and insulin resistance thereby increasing the risk of diabetes<sup>7</sup>. Currently, corona virus disease has shown to contribute to the prevalence of diabetes due to induced glycaemic challenges<sup>8</sup>.

The phrase "illness experience" refers to how people define and adjust to perceived interruptions in their health<sup>9</sup>. Diabetes illness experience often encompasses profound life-changing experience that may impact all aspects of a patient's

life; experiencing chronic treatments; experiencing dietary adjustment and regular multidisciplinary health monitoring<sup>10</sup>. However, studies have shown that it is difficult to live with any chronic illness in resource-challenged settings<sup>11,12</sup>. Thus living with insulin-treated diabetes in rural areas may present additional unique challenges but the evidence to confirm this challenge is scanty. This study, therefore, aimed to explore the experiences of people living with insulin-treated diabetes in rural areas.

## Methods

### Research approach and design

This study utilized qualitative narrative inquiry. In this study approach, researchers describe the lives of individuals, collect and tell stories about people's lives, and write narratives of individual experiences<sup>13,14</sup>. This research approach was chosen because it is participant-centred. As argued by Haydon<sup>15</sup>, there is a need to find what is important from the patients' 'point of view' to optimize care. Thus narrative inquiry provided the opportunity for participants to share what was important in their situation.

### Study Setting

Participants were identified from a diabetes clinic at Kamuzu Central Hospital (KCH), a tertiary level health care facility in Malawi.

**Table 1: Characteristics of participants**

Participants	Gender	Age (years)	Distance to the hospital	Marital status	Highest Level of education	Source of income	Duration on insulin(years)
Participant # 1-M-1-05	M	32	35km (Chimbalanga)	Married	Form 2	Subsistence farming	5
Participant # 2-F-3-05	F	56	40km (Mvuwu)	Widow	Standard 8	Working as a temporary worker of selling tap water	20
Participant # 3-M-4-05	M	50	30 km(Dowa Turnoff)	Married	Standard 4	Tailoring	2
Participant # 4-F-4-05	F	45	10km (Njewa)	Divorced	Standard 4	Piece work of washing clothes	10
Participant # 5-F-5-05	F	37	10km(Mtandile)	Married	None	Selling fish fritters	11
Participant # 6-M-6-05	M	22	10km(Mtandile)	Single	Standard 8	Ground labourer	8
Participant # 7-F-6-05	F	35	71km (Kasiya)	Married	Form 2	Subsistence farming	4
Participant # 8-F-7-05	F	63	29km(Mwaganga)	Divorced	Standard 8	Pension as a retired hospital cleaner	2
Participant #9-M-8-05	M	26	35km(Khongo)	Single	Form 4	Ground laborer	4

Tertiary facilities provide specialist health services at the regional level and also offer referral services to district hospitals within the region<sup>14</sup>. Participants from various rural areas in Lilongwe attend the diabetic clinic at KCH. The KCH diabetic clinics are scheduled two times a week (Tuesdays and Fridays), which averages 40 to 60 patients encounters per clinic session. We followed the participants in their respective homes for data collection. As observed by Polit and Beck<sup>15</sup> interviewing participants in their homes help to avoid manipulation of the participants, as they will be free to express themselves within their home setting.

### Sampling

The study population comprised adult insulin-treated diabetic patients from rural areas in Lilongwe; purposive sampling was used. The sample was 10 participants and determined using data saturation. Moule and Goodman<sup>16</sup> support a smaller sample size of 6 to 10 in a qualitative study for rich experiences.

### Ethical considerations

Ethical approval for the study was obtained from the College of Medicine Research and Ethics Committee (COMREC) of the University of Malawi (reference number is P.03/20/2969). In addition, verbal and written consent was obtained from individual participants. Participant identifiers, and not names, were used to promote anonymity.

### Data Collection

Data were collected through face-to-face in-depth interviews using a semi-structured interview guide by EN. The interviews were conducted in Chichewa; a local language used in this area where this study was conducted and were audio-recorded. The interviews took 30 to 45 minutes.

### Data analysis

Data analysis was conducted manually, guided by the five steps of thematic narrative analysis by Riessman<sup>17</sup>. We listened to the recorded interviews and then transcribed verbatim all the interviews. Afterwards, we asked two English secondary school teachers to translate all the interviews into English. The following were the steps involved in thematic narrative analysis: attending to the experience, telling the experience, transcribing the experience, analysis of the experience and reading. During the analysis of the experience, the

transcripts were read several times to familiarize with the data. Afterwards, initial codes were identified. The identified codes were matched with data extracts that demonstrated the particular code. The codes were analyzed further to come up with categories and themes. The themes were then reviewed, after which they were defined and named.

### Study findings

The demographic characteristics of the sample of 10 participants are presented in Table 1 above. The following themes emerged out of the analysis of participants' narratives: (1) diabetes perceived as the illness for the rich; (2) 'everything is on a standstill'; (3) dietary challenges of the diabetes illness experience; (4) drug-related challenges associated with the diabetes illness experience and (5) experiencing physical effects of the diabetes illness.

#### *Diabetes perceived as an illness for the rich*

Some of the participants perceived that it is unusual for diabetes to be diagnosed in people residing in rural areas and they thought that it was a condition for rich people. The following quotes illustrate this:

*Living with this sickness in the village is very unusual. We are still surprised (.)We thought that this disease is found in wealthy communities and not here in the rural' (Participant #3-M-4-05)*

*I thought that diabetes is a condition for the rich people' (Participant #10-M-11-05)*

Most commonly, the participants consider that the disease would be for people who have money to meet the demands for its management and the following voices illustrate this:

*This disease would suit better those who have money to maintain the diet. An individual such as me who lives in the village and has an unreliable source of income wouldn't overcome this disease. ebb, it's really hard(.) My body always needs food' (Participant #4-F-4-05)*

The study findings reflect that because of the challenges of living with diabetes in rural areas, they perceive the illness as torture.

*I have always been wondering about my everyday life the way I feel*

regarding the disease. *Living with diabetes is torture and not a good life (.) I don't have peace of mind at all'* (Participant #2-F-3-05)

### **'Everything is on a standstill'**

Participant's accounts show that living with diabetes was a struggle in rural areas because patients fail to work in the fields due to the illness. Diabetes drains off energy. In their narratives, male participants have fears regarding the future of their families as these excerpts illustrate:

*'Life is more of struggle. The problem is that since I was diagnosed with diabetes, everything came to standstill at home(.) Everything changed for us(.) I don't have energy though (.) I have worries and fears as regards to how I will progress in life without working hard. In a village that I live; farming is the most important source of money'* (Participant #1-M-1-05)

*'this disease drains off my energy. I am like a tree that is being blown by the wind and my body moves to the direction where the wind is blowing. I don't have enough strength'* (Participant #10-M-11-05)

We found that participants depend on others as a result of body weakness. Before the illness, they could do all the household chores on their own as indicated below:

*'Firstly, I feel weak nowadays. I depend on children to assist me with household chores (.) I am not completely independent though (.) Before this disease attacked me, I was independent. I used to do everything myself, but now I'm weak and cannot manage to do work myself'* (Participant #3-M-4-05)

### **Experiencing physical effects of the diabetes illness**

We found that the physical effects of diabetes were a source of concern for the patients. Some of the reported physical effects of diabetes experienced were as follows: sight problem, sexual dysfunction, and effects of low blood sugar and fainting. The common sight problems reported were blurred vision and poor sight. The following quotes illustrate this:

*'I usually experience blurred vision, I see darkness and unable to recognize my own sister'* (Participant #5-F-5-05)

*'I also don't see clearly (.) When the person is close to me, it's like I see 4 people'* (Participant #10-M-11-05)

Sexual dysfunction was the most common disturbing symptoms for male participants. Men reported failure to perform their conjugal role and diminished sexual desire in their sexual lives because of the illness and the following voices illustrates this:

*'I have a problem as regards this disease. Since 2018, I cannot perform my conjugal role as a husband. I informed the doctors about the same. They told me that I would be fine when my blood sugar normalizes'* (Participant #3-M-4-05)

*'I also have challenges to successfully fulfill conjugal activities with my wife. When I complain of this to the doctor, he tells me it is because of diabetes (.) I get worried because my wife is still young'* (Participant #1-M-1-05)

Reports from some of the participants demonstrate that their partners have mixed reactions towards sexual dysfunction. One partner demonstrates understanding about issues related to their sexual relationship whilst another partner registers disappointment. One of the participants expressed the following sentiments:

*'This illness has attacked my private parts; I am unable to perform in bed. However, my wife understands my condition, we do not quarrel, she is faithful to me'* (Participant #3-M-4-05)

On the other hand, the following excerpt shows the partner's negative reaction towards sexual dysfunction:

*'This disease affects my sexual capabilities as a married man (.) Yes, my partner gets disappointed about this development'* (Participant #10-M-11-05)

Some of the participants expressed incidences of losing consciousness as indicated below.

*'I have had incidents of loss of consciousness (.) I was not aware of what was going on until I gained consciousness. I could notice sugar crystals inside my mouth; then my relatives would tell me that I had lost consciousness'* (Participant #5-F-5-05)

### **Dietary challenges of the diabetes illness experience**

When participants became diabetic, food became treatment for the disease. Supporting excerpts included:

*'Food is a treatment for diabetes. When I have not taken food, I always faint'* (Participant #2-F-3-05)

*'The basic medication for the disease is to eat what is recommended for us'* (Participant #3-M-4-05)

Some of the participants perceived that diabetes is challenging because patients are advised to stop eating various food items. One of the participants expressed the following sentiments:

*'The sugar disease is a challenge because I'm restricted to eating a variety of food. I don't find the right food for the diabetic daily. Thus I regard this disease as a challenge'* (Participant #8-F-7-05)

Most commonly, participants reiterated that they know the recommended diet and the schedule. However, it's not easy to follow dietary requirements due to lack of resources as indicated below:

*'I know the recommended diet but cannot manage because I lack resources. I can't eat as per recommendations. Some days can eat 2 or 3 times a day. At times, I take food once or don't eat at all (.) We are advised to eat frequently and take fruits in between meals. However, can't afford it since I'm living in the village; I have an unreliable source of money'* (Participant #4-F-4-05)

We found that food insecurity in the rural areas threatens



**Figure 1: Insulin stored in a cooking pot filled with water**



**Figure 2: Insulin stored in a plastic container with wet sand**



**Figure 3: Insulin stored in a clay pot with wet sand**

insulin adherence as illustrated by the following quotation:

*'Hunger poses a major threat to inject myself insulin. When I'm hungry, I ask myself what would happen if I injected insulin (.). This holds me back from injecting myself insulin since I feel that I may end up killing myself'* (Participant #5-F-5-05)

Improvisation in self-management practices was related to food. One participant described drinking a lot of fluids before going to bed; improvising 'water' as 'food'. This is illustrated in the following voices:

*'If I have slept on an empty stomach, I feel very uncomfortable throughout the night; hence I drink a lot of water until my stomach becomes full. Food is much better than water as it's hard; it stays in the stomach for a long time than water (.). Sometimes, I take a lot of water when there is no food; then I go to bed'* (Participant #9-M-8-05)

### **Drug-related challenges associated with the diabetes illness experience**

Participants expressed positive attitudes toward the use of insulin. They indicated that they are alive because of insulin and they have no plans of stopping taking the drug as these excerpts illustrate:

*'I will be injecting myself daily until I die; this is what the nurses had told me. It's okay with me since insulin keeps me alive; it's fine'* (Participant #5-F-5-05)

*'I can't stop to inject myself or I would ruin my own life'* (Participant #8-F-7-05)

Despite positive view regarding insulin use, some of the participants reported challenges associated with insulin therapy. Participants perceived that insulin is a very strong drug that demands regular intake of food. Representative comments included:

*'Insulin injection is the best treatment for this disease (.). However, it*

*has disadvantages, as I always need to eat. When I was taking oral medications, didn't bother of eating or having food; insulin is a very a strong drug'* (Participant #4-F-4-05)

We found that rural-based diabetic patients experience difficulties regarding the storage of insulin. Insulin was stored in metal pots, clay pot, or plastic basin with wet sand or water (see figure 1, 2 and 3). Participants doubted the potency of the insulin due to the nature of storage facilities that insulin is subjected to. One of the participants gave the following account:

*'Insulin storage is also problematic here in the village. We don't store insulin properly. We doubt if we are using insulin that functions well in our bodies'* (Participant #10-M-11-05)

### **Discussion**

We found that living with insulin-treated diabetes in rural Malawi is a complex and multifaceted experience; often characterized by considerable challenges. The study findings suggest the hassles that rural-based diabetic patients encounter as they live with the illness in the context of limited resources. They struggle to meet daily diabetic dietary demands. Participants reported taking food at least once per day, but none of them took food according to health care provider's recommendations or the American Diabetes Association (ADA) of five meals a day. Angwenyi et al.<sup>20</sup> and Kwanjo Banda et al.<sup>21</sup> also reflect similar findings in a study conducted in Malawi. Angwenyi et al.<sup>20</sup> indicate that participants face challenges in adhering to recommended diet due to food shortages and lack of household income.

We also found that patients resorted to improvisations when faced with a lack of resources for diabetes management. In particular, when food was unavailable, participants improvised 'water' as 'food'. Although, it appears there is less support for this position in literature, but this is one of the significant findings in this study. Arguably, this finding attests to the extent that rural-based diabetic patients would go to self-manage their condition in the context of poverty. Wang<sup>22</sup> indicates that chronic non-communicable diseases carry a relatively high economic burden for the local population, which causes financial stress and aggregates poverty in rural

areas.

Participants perceived insulin to be a very strong drug that demands regular intake of food. Participants resorted to skipping insulin dose when they have inadequate food. Gucciardi et al.<sup>23</sup> observes that health providers should suggest that patients treat days when they have poor access to food as a 'sick or fasting day,' and take less medication that could cause hypoglycemia if food intake will be low. It is indicated that diabetic patients should be allowed to omit doses if meals are missed thereby reducing the risk of hypoglycemia<sup>24</sup>.

We identified non-refrigeration but improvised methods of storing insulin; insulin was stored in metal pots, clay pots, or plastic basin with wet sand or water. This closely relates to research findings elsewhere about insulin storage in sub-Saharan Africa<sup>25,26</sup>. However, Kedogo<sup>25</sup> argues that the effectiveness of these methods is unclear and recommended that the methods should be critically assessed and appraised. In this present study, even participants doubted the potency of the insulin due to the nature of storage facilities it is subjected to. Moreover, the American Diabetic Association (ADA) recommends that insulin 'in use' can be kept at room temperature 15-25 degrees Celsius for 28 days and refrigeration is essential for insulin stored for long periods beyond 28 days<sup>27</sup>. The ADA<sup>27</sup> advises patients to discard the 'in use' insulin kept at room temperature after 28 days as insulin becomes ineffective, unstable and denatured. Arguably, this study reveals that it was impossible for patients to discard insulin due to insufficient resources. Patients use insulin stored at room temperature beyond 28 days. Although without variable evidence, participant's narratives reflect symptoms of poor glycaemic control such as repeatedly feeling dizzy, unwell and powerlessness suggestive of using ineffective and denatured insulin.

Study participants linked diabetes to affluence as reflected in the participant's narratives. The term 'diseases of affluence' is described as an expression sometimes given to selected diseases and other health conditions, which are commonly thought to be a result of increasing wealth in a society<sup>28</sup>. In contrast, the diseases of poverty have tended to be largely infectious diseases resulting from poor living conditions<sup>29</sup>. These include tuberculosis, malaria, and intestinal diseases. There is a positive link between obesity and diabetes. However, a significant number of patients in SSA do not fit this traditional picture of diabetes<sup>30</sup>. WHO recognized malnutrition as a distinct entity and had incorporated Malnutrition Related Diabetes Mellitus (MRDM) as a category in the classification of diabetes in 1985<sup>1</sup>. MRDM is strongly associated with poverty and malnutrition<sup>31,32</sup>. Malnutrition causes persistent insulin deficiency; glucose intolerance and insulin resistance thereby increasing the risk of diabetes<sup>7</sup>. This provides the suggestion that rural-based populations are at risk of malnutrition-related diabetes due to low social-economic status. Thus diabetes is a disease that affects both rich and poor people.

The participant's narratives further reveal that they experienced physical effects of the disease as follows: sight problem, sexual dysfunction, effects of low blood sugar and fainting. Other studies also touch on vision problems due to diabetes<sup>33,34</sup>. The World Health Organization<sup>35</sup> defines the term "sexual dysfunction" as various ways in which an individual is unable to participate in a sexual relationship, as he/she would wish. In this study, men reported total

failure to perform their conjugal role. Diabetes-related sexual dysfunction that was found in this study corresponds to studies on other diabetes populations<sup>36-38</sup>. Literature indicates that diabetes-related sexual dysfunction is caused by hyperglycemia, neurovascular disorders and psychological stress<sup>39</sup>. Studies have shown that sexual dysfunction could be avoided or deferred by effective control of the blood sugar level<sup>37,40</sup>. The study findings illustrate participants had incidences of losing consciousness. Loss of consciousness was one of the prevalent diabetic-related physical effects of the illness. There is evidence that hypoglycemia is a dominant diabetic-related complication in low resource settings which ultimately leads to coma<sup>34</sup>.

## Strengths and limitations

This study is among the limited studies that have reported on the experiences of people living with insulin-treated diabetes within low and medium-income countries. The study findings provide an 'insider view' and significant insights on how diabetes illness is experienced in rural Malawi. However, the main limitation of the study concerns interviewing participants in the local language and translating into English. The translation is also an interpretive act, thus translating data from Malawi local language (Chichewa) to English had the likelihood of losing the meaning of diabetic patients' narratives<sup>41</sup>. To minimize the impact of translation on the integrity of the study findings, the researchers involved two professional translators. However, the researchers were involved in explaining to the translator the intended meaning and its context in the source language regularly. In addition, a language expert of Kamuzu College of Nursing, Basic Studies Department, validated some of the phrases translated.

## Conclusion

We have found that living with insulin-treated diabetes in rural Malawi is a complex and multifaceted experience; often characterized by enormous challenges. There is a need for multi-factorial approaches at both the community and system levels to improve the livelihoods of people living with insulin-treated diabetes in rural areas.

## Conflict of interest statement

The authors declare no conflict of interest.

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