

# Perceptions of diabetes in rural areas of Eastern Uganda

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**Background:** People diagnosed with diabetes mellitus are increasing in sub-Saharan Africa and prompt care seeking depends on perceptions of the illness.

**Objective:** The objective was to explore perceptions of diabetes in rural areas.

**Method:** We conducted a qualitative, explorative and descriptive study in rural eastern Uganda. Eight focus group discussions with community members were conducted. Community members were presented with a story about a person with diabetes symptoms and their perceptions of the diagnosis and treatment elicited. Four focus group discussions with people with diabetes and seven key informant interviews with health workers were conducted. Respondents were asked how the community interpreted symptoms of diabetes, its causes and whether it was curable. Manifest content analysis was used.

**Results:** Some respondents thought people with diabetes symptoms had HIV or were bewitched. Causes of diabetes mentioned included consuming too much fatty food. Some respondents thought diabetes is transmitted through air, sharing utensils with or sitting close to people with diabetes. Some respondents thought that diabetes could heal fast whilst others thought it was incurable.

**Conclusion:** Misdiagnosis may cause delay in seeking proper care. Preventive programmes could build on people's thinking that too much fatty food causes diabetes to promote diets with less fat. The perception of diabetes as a contagious disease leads to stigmatisation and affects treatment seeking. Seeing diabetes as curable could create patient expectations that may not be fulfilled in the management of diabetes. Rural communities would benefit from campaigns creating awareness of prevention, symptoms, diagnosis and management of diabetes.

## Introduction and background

Diabetes mellitus is a growing public health problem in Africa (Hall *et al.* 2011). Uganda, one of the countries in sub-Saharan Africa, is experiencing an upsurge of diabetes (Government of Uganda 2005). In 1972, Uganda had 254 people with diabetes recorded but by 2006 about 560 000 people with diabetes had been registered (Wasswa 2006). Since treatment seeking for diabetes depends on perceptions of the illness and symptom interpretation (Ryan & Zerwic 2003; White *et al.* 1998), it is important that community perceptions of diabetes and diabetic symptom interpretation be explored.

Previous studies have demonstrated that knowledge of diabetes in the general population is generally inadequate (Al Shafae *et al.* 2008; Wilson *et al.* 2012). Many communities may know of diabetes but would indicate that it is an issue they do not understand very well (Yeoh & Furler 2010).

In sub-Saharan Africa, a number of studies have been conducted amongst people with diabetes attending clinics in urban areas (Baumann *et al.* 2010; Danquah *et al.* 2012; Glover *et al.* 2012; Hjelm & Nambozi 2008; Matsha *et al.* 2012). However, few studies have been conducted amongst people who do not have diabetes and even fewer amongst people from rural areas. The latter is an important issue as diabetes mellitus is increasing not only in urban areas but in rural areas as well (Reeve & Falkner 1986).

## Problem statement

There is not much literature on perceptions of diabetes mellitus amongst people living in rural areas of sub-Saharan Africa and in Uganda in particular. Yet, some of the people with diabetes come from this group and their perceptions determine the promptness with which they seek appropriate treatment. With the increase in the number of people living with diabetes mellitus,

it is critical that perceptions of rural community members be explored to inform interventions for early diagnosis and appropriate treatment.

### Research purpose

The research purpose was to explore and describe community members' perceptions of diabetes mellitus in rural areas of eastern Uganda.

### Research objective

The study objective was to elicit perceptions of the symptoms and causes of diabetes amongst community members in rural areas of eastern Uganda, and establish whether they consider diabetes curable.

### Definition of key concepts

**Perception:** This is a way of seeing, understanding or interpreting something (Hornby 1995).

**Rural areas:** This is a locality of, in or suggesting the countryside with the predominance of work being agriculture (Siegel & Swanson 2008).

### Significance of the study

The significance of this study lies in understanding how communities in rural areas perceive diabetes. Understanding perceptions in rural communities would assist health educators in designing appropriate communication messages regarding the diagnosis and treatment of diabetes.

## Research method and design

### Design

The study followed a qualitative, exploratory and descriptive design. Qualitative research engages with the complexity of social interaction and is grounded in lived experiences of the participants (Marshall & Rossman 1999). It elicits contextualised experience and interpretation (Rice & Ezzy 1999). This study investigated the social interaction, experience and interpretation of symptoms of diabetes in rural communities. An exploratory study is used when investigators are trying to understand little known phenomena (Marshall & Rossman 1999). Perceptions of people living in rural communities of diabetes mellitus have not been well documented. The interaction between the participants was used to explore their views about diabetes in this particular context (Dahlgren, Emmelin & Winkvist 2004).

### Population and sample

Data were collected from community members selected from villages from different sub-counties from the districts of Iganga and Bugiri in eastern Uganda. The participants were between 30 and 75 years old. They were selected because as people advance in age, their risk of getting diabetes increases. Within each village, a local council leader assisted in mobilising the group. Both Iganga and Bugiri districts have general hospitals where between 300 and 450 people

with diabetes receive treatment every month. The hospitals are located in the town centres of the districts and serve people from the two districts and the neighbouring districts.

Discussions were also held with people with diabetes to highlight how they were treated by their family and community members when they had sought care before being diagnosed with diabetes. People were mobilised by nurses working in the diabetic clinics. They were selected purposively as they came to the health facility for treatment. Their age ranged between 15 and 70 years.

Health workers were interviewed because people often first seek treatment from them. Four nurses, two clinical officers and one medical officer were interviewed. Two health workers came from government facilities whilst five were from private clinics and drug shops. Only one respondent was picked from a health unit so as to have variation in places of work. Seven facilities were selected. These were health facilities which were within 5 km from Iganga or Bugiri towns, facilities that were known to refer patients to the general hospitals. A researcher entered the health facility and asked for a health worker who sees patients on a regular basis and that health worker was the one interviewed. Health workers were taken to be informed about perceptions of patients who come for treatment but do not yet know that they have diabetes and hence were expected to give an overall view on these perceptions (Marshall & Rossman 2006).

### Data collection methods

Data were collected by three social scientists with undergraduate degrees. Each had at least seven years' working experience in qualitative research and all were fluent in both Lusoga (the indigenous language) and English. They underwent two days' training during which the researchers discussed the study objectives with them. The social scientists were also instructed on how to conduct key informant interviews and focus group discussions. The social scientists did role plays for the key informant interviews and pilot tested the tools amongst community members and health workers who were not in the study areas.

Eight focus group discussions (FGDs) were conducted in the rural villages: four with adult female respondents and four with adult male respondents. Three female and three male FGDs had ten members each whilst the other female FGD had nine and the other male FGD had eight participants. Focus group discussions were used because they describe perceptions, interpretations and beliefs of a particular, select population. The researcher gains understanding of a particular issue from the perspective of the group's participants (Khan & Manderson 1992). The interaction between the participants is used to explore people's views about the issue being discussed in a certain context (Dahlgren *et al.* 2004). The participants were presented with a descriptive story (vignette) about a person with symptoms of diabetes mellitus. The female FGDs were presented with a female subject whilst the male FGDs were presented with a male

subject. This was to enable participants to easily identify with the subject. The person's symptoms in the story included: frequent passing of urine six or seven times a night, excessive thirst, wanting to eat more often than previously, weight loss, poor vision, general body weakness and excessive sweating. Respondents were asked to name the disease, its causes and whether it could be cured with treatment.

Four FGDs were conducted with patients with diabetes at Iganga and Bugiri hospitals; each hospital had one FGD with female patients and another with male patients. One FGD at each hospital was done to get variations of perceptions across the two hospitals. Each patient FGD had eight participants. Separate FGDs were conducted with men and women in order to allow free expression amongst participants. FGDs provide an opportunity for those who have little chance of expressing their opinions to do so (Rice & Ezzy 1999). In patient FGDs, participants were asked how they got to know that they had diabetes, how community members interpreted their symptoms, and what their family members thought caused their illness. FGDs were conducted in Lusoga by an interviewer supported by a note taker in a venue identified as convenient by the participants.

Seven key informant interviews (KIIs) were conducted with health workers. These interviews were conducted with the health workers because they attend to patients with diabetes. Health workers were asked questions related to how patients who had not been diagnosed with diabetes interpreted diabetes symptoms, what they considered as causes of diabetes and whether they considered diabetes mellitus curable or not. The KIIs were conducted in English at the offices of the health workers by an interviewer who also took notes. Each session was between 30 min and 50 min long.

## Data analysis

Both the FGDs and KIIs were tape recorded to ensure that the details were not lost. Data were transcribed and typed in English whilst retaining the Lusoga concepts as far as possible. FGDs were translated at transcription but the translation was crosschecked by the first author to see whether it corresponded to the audio recording. Manifest content analysis was used (Graneheim & Lundman 2004).

The unit of analysis for the FGD was the FGD text whilst the unit of analysis for the KII was the interview text. Meaning units were generated from the text and condensed into codes, which were shared amongst the investigators. These codes were discussed, the investigators went back to code again using the agreed upon codes and these were condensed into themes. An example of how meaningful units were coded and then condensed into themes is given in Table 1.

## Context of the study

The study was performed in the adjoining districts of Iganga and Bugiri in eastern Uganda. Iganga town is about 115 km east of the capital Kampala whilst Bugiri town is 38 km east of Iganga. Bugiri district was originally part of Iganga district. The population in these two districts is predominantly Basoga and they speak and understand Lusoga, which is the local language. Data was collected between July 2011 and December 2011.

## Ethical considerations

Qualitative studies involve obtaining ethical approval from organisations with jurisdiction over the research project (Rice & Ezzy 1999). The study was approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council of Science and Technology (Ref. SS 2729). Permission to conduct the study in the study villages was requested and received from the local council leaders. The medical directors of the hospitals gave permission to conduct the study within the hospitals. During the study, the rights, privacy and welfare of the participants need to be safeguarded. Informed consent, anonymity and confidentiality of the participants should be ensured (Berg 2001). Each participant received an explanation of the study and its objectives and could withdraw participation any time within the course of the interview or FGD. Participants gave verbal consent before data was collected. During the interviews or FGDs, respondents were free to respond to questions they wanted to respond to and were not coerced to answer any question they did not want to answer. Anonymity was guaranteed because no names were written on the transcripts. Confidentiality was maintained as only the researchers had access to the information provided by

**TABLE 1:** Perception that diabetes is contagious.

Code	Meaningful unit
Diabetes is transmitted in the community through air from a person with diabetes to another who does not have the disease	'For me I think diabetes is an air borne disease because there are people who don't take sugar but still they develop diabetes, so diabetes can be got through air. If someone with diabetes coughs and spits anyhow where other people pass, they can get diabetes from this person.' (FGD men from the community)
Diabetes can spread from one person to another if people with diabetes come into contact with those who do not have it	'Personally I think those diseases come because we are treated in the same area with those affected. I think the virus that causes diabetes can easily spread from one person to another especially if one person has it and the other is free.' (FGD men from the community)  'I always see people trying as much as possible not to be near those that have such illnesses. They say that when you sit near a diabetic person, you will get it also. So they try as much as possible to avoid it.' (FGD men from the community)
Diabetes can spread from one family member to another by using the same utensils	'Some family members get worried if a member gets diabetes because they say that it's contagious so they always want you to use utensils separate from theirs lest they get diabetic.' (FGD women from the community)  'The family members try to avoid you in fear that you will spread the disease to them. They say let's separate the cups and plates and the patient should eat and sleep in isolation. They say that when they mingle freely with you, you spread the disease to them.' (FGD women from the community)

FGD, focus group discussion.

the respondents and the researchers did not disclose it to anyone outside the research team. The data collected was entered on computers whose access was protected with a secure password; this data would be destroyed after the mandatory five years of keeping data as stipulated by the Uganda National Council for Science and Technology has passed. Respondents did not receive any remuneration as incentives to participate in the study.

## Trustworthiness

Trustworthiness was ensured through respondent validation, transferability, dependability and fairness (Bryman 2001). In respondent validation, researchers during the FGDs and KIIs would summarise what they had understood from the discussion for the respondents to confirm or correct. Transferability was ensured through a purposive selection of the participants, a detailed description of the respondents and a dense description of the results with direct quotes to support the discussion. Dependability was ensured through peer review of the entire process of data collection, management, analysis and report writing. Tape records were kept of all FGDs and KIIs. After initial analysis and coding, the investigators shared and synthesised what they had coded and came up with common codes; then they reanalysed the data using the agreed upon codes. To ensure fairness, different views were represented in the data even if they were minority views.

## Discussion

Several themes emerged during data analysis. It was found that members of the community in rural areas associated symptoms of diabetes mellitus with witchcraft and HIV. Some thought diabetes mellitus was caused by excessive sugar consumption or changes in diet. Many thought that diabetes could be transmitted through air, using the same utensils or coming into close contact with patients with diabetes at the hospital. There was no agreement as to whether diabetes was curable; some said diabetes was an acute illness that can be cured whilst others said it was incurable.

### Theme one: Diabetes symptoms mistaken for witchcraft

Some community members ascribed passing urine frequently and numbness of the feet to having diabetes mellitus whilst others ascribed these symptoms to witchcraft. One person with diabetes said:

‘In 2000 when I started feeling sick, my friends told me that I was bewitched. I went to traditional healers; I spent a lot of money there. Later I went to a doctor and I was tested for diabetes. It had taken me one year. I was then told that I had diabetes.’ (FGD men with diabetes)

On the other hand, some family members directed people to hospitals where investigations could be done:

‘I felt a lot of itching in my private parts and scratched myself a lot. Eventually I started feeling thirsty and started taking a lot of water, and at the same time urinating frequently. I sometimes wetted my bed at night. I started feeling paralysed in the legs and

hands; I was told that I was bewitched. I went to witchdoctors but I was not helped. Later I told my mother-in-law; she told me that it was not witchcraft but that I was suffering from diabetes and that I had to go to hospital. I came here for medical check-up and I was told that my blood sugar was very high.’ (FGD women with diabetes)

When health workers were asked about patients’ perceptions of diabetes symptoms, most indicated that patients sometimes thought that they had been bewitched:

‘As you also know the community members, if somebody gets such an illness whose cause is not known, they can think that it is witchcraft. It’s really hard for community members to accept that so and so has complications of diabetes.’ (KII health worker)

Interpreting diabetes symptoms as witchcraft corresponds with findings from a Zimbabwean study (Hjelm & Mufunda 2010) in which people with diabetes suspected that they were bewitched when they started experiencing diabetes symptoms. People who suspected that they had been bewitched would seek treatment from traditional healers – this is similar to findings from a South African study (Shai-Mahoko 1996). Cultural beliefs manifest in the way people interpret illnesses, especially when they do not have an adequate explanation for the symptoms. Sustained community health education can enlighten the population to seek appropriate care at health facilities when experiencing diabetes symptoms. This is the case with malaria – after decades of sensitisation, caretakers of children now seek modern treatment first instead of going to traditional healers (De Savigny *et al.* 2004).

### Theme two: Diabetes symptoms mistaken for having HIV

It was mentioned in all the focus group discussions that people with symptoms of diabetes mellitus are thought to be infected with HIV:

‘People don’t differentiate between an HIV positive person and a patient with diabetes. This is because a patient with diabetes loses weight and we all know that it is AIDS that does this. So people cannot separate the two diseases.’ (FGD men from the community)

‘One starts with losing weight and AIDS also makes somebody lose weight. When you walk in town, everyone says that you have AIDS; it feels bad. But when you go for check up and you are diagnosed as having diabetes, then the stress reduces and you do not get people saying you have AIDS.’ (FGD men with diabetes)

People with diabetes gave personal testimonies of having taken a number of HIV tests before taking a test for diabetes. One woman narrated her experience thus:

‘My husband also said I was suffering from AIDS; I could not even eat food. I went for HIV testing and I tested HIV negative. After three weeks I went back for check up and repeated the HIV test and I was found HIV negative. My friend then told me to come here to this hospital; I came and after the investigations were done, I was found to have diabetes and I started on treatment.’ (FGD women with diabetes)

Health workers indicated that confusion over the symptoms of diabetes and those of AIDS kept people away and that



they would only come for treatment when the disease was in an advanced stage:

'People always think that when someone loses weight, then that person has AIDS. The patient takes time to seek treatment fearing the stigma people put on AIDS. Anxiety comes in since the person has lost a lot of weight. You actually find that some people seek treatment when it is too late and the disease is in its advanced stage.' (KII health worker)

The study findings indicate that the majority of rural participants interpreted diabetes symptoms as symptoms of AIDS because people lose weight. People with diabetes seemed to fear AIDS more than diabetes and were relieved when laboratory tests confirmed that they had diabetes and not AIDS. This is similar to how people with both comorbidities rated AIDS as a worse pathology than diabetes and had better control of HIV infection than diabetes (Henry *et al.* 2011). This demonstrates the strong stigma attached to AIDS – unfortunately, this stigma sometimes leads to delayed treatment seeking as people fear to be labelled HIV positive. Sensitisation of communities is needed so that losing weight is not ascribed to AIDS alone but also to the possibility that one could have diabetes. Health workers should also be highly suspicious of diabetes in those patients who present with wasting and not focus only on testing for HIV infection.

### Theme three: Perception that consuming too much sugar or fatty food causes diabetes

Most of the participants suggested that diabetes mellitus was caused by consuming sweet foods and drinks in large quantities. Most people with diabetes strongly agreed that community members thought that diabetes was caused by consuming too much sugar:

'For me when I was staying with my grandparents, I used to pick jackfruits and sometimes I would eat a big jackfruit alone. On top of jackfruits, I used to eat sugarcanes, sweet bananas and take a lot of sugar in my tea. So after some time, I was diagnosed with diabetes and people said that I used to eat a lot of sugary things, so those might be the things that brought about this disease.' (FGD men with diabetes)

Members from the community also thought that diabetes was caused by poor eating habits, eating fatty food or food cooked with oil.

'Diabetes is brought [on] by things that we [did] not ... use long ago. Foods like cooking oil were not common among the poor people. The poor people [ate] greens and this played a very important role in reducing diabetes among them.' (FGD men from the community)

Although the majority of the participants thought that diabetes is caused by consuming too much sugar, others attributed it to dietary transition from consuming less fatty foods to consuming more fatty foods. Community members were of the opinion that consuming fatty foods is a practice of the rich which was now being taken up by the poor as well. Other studies also attribute the increase in diabetes to communities' transition from a less refined diet to a more westernised refined diet (Hu 2011). A less fatty diet has been shown in a series of studies to be useful in the prevention and control of diabetes (Esposito *et al.* 2010). Community

perceptions of the usefulness of consuming a less fatty diet in the prevention of diabetes could be a good starting point for interventions for diabetes prevention.

### Theme four: Perception that diabetes is contagious

The majority of participants thought that diabetes could be passed from one person to another through air, especially by coughing:

'I think diabetes is an air-borne disease because there are people who don't take sugar but still they develop diabetes, so diabetes can be got through air. If someone with diabetes coughs and spits anyhow where other people pass, they can get diabetes from this person.' (FGD men from the community)

Many participants thought that diabetes mellitus could be transmitted by sharing utensils:

'If I use a cup that a patient with diabetes used before washing it, I will get diabetes but if I wash it first, I won't get it.' (FGD women from the community)

There was only one person in all the focus group discussions who said that diabetes cannot be spread by sharing a cup or plate. This was an isolated case because she did not receive support from other group members:

'In my opinion, someone can't get diabetes as a result of sharing a cup or a plate with someone who is diabetic. Diseases that can spread through sharing utensils are like TB but no one can get diabetes as a result of sharing a plate or cup.' (FGD women from the community)

Many participants thought that coming in close contact with people with diabetes in health facilities could spread the disease to those who do not have it:

'Personally I think diabetes comes because we are treated in the same area with those affected. I think the virus that causes diabetes can easily spread from one person to another especially if one person has it and the other is free. All those that have diabetes meet in the same place with those that do not have it. Those that are diabetic can easily spread this disease to those that don't have it.' (FGD men from the community)

A common perception amongst community members was that diabetes was contagious. Participants thought that diabetes was caused by a virus that could be transmitted. Many studies have demonstrated a significant interaction between diabetes and infectious diseases such as Tuberculosis (TB) and HIV in sub-Saharan Africa (Hall *et al.* 2011). Skin infections have also been indicated as one of the manifestations of diabetes (Farshchian *et al.* 2010). In this instance, however, the rural people still think of diabetes as infectious. The unfortunate thing is that patients may be shunned by other patients at health facilities thinking that they may contract diabetes by sitting next to them. This increases the stigma and could lead to a delay in testing for diabetes. Health education on how people acquire diabetes mellitus is needed so that diabetes is not seen as contagious.

### Theme five: Perceptions of whether diabetes is curable or not

Although most participants thought that diabetes mellitus was incurable, a couple of participants indicated that it could

be cured. According to most respondents, medicines only kept people with diabetes alive for some time:

‘According to me, this disease is incurable. I had an aunt who had diabetes. We tried all that we could but at the end of the day, she died of that same illness.’ (FGD men from the community)

‘The medicines don’t heal the illness but keep the patient alive for some time. I have never seen a patient with diabetes getting fully recovered.’ (FGD women from the community)

The community’s perception of diabetes as a chronic illness was supported by health workers:

‘In the community people always say that diabetes doesn’t heal; in other words that it is a chronic illness. People say that so and so has diabetes and his condition isn’t getting better.’ (KII health worker)

However, there were some people in one FGD who thought that diabetes was curable. According to them, if one followed the instructions of the doctor or sought treatment early, one would be cured:

‘Diabetes is curable but I think my colleague is saying that it is incurable because the patients with diabetes delay to go to the hospital for the necessary investigations and confirm the illness. The patients with diabetes go to hospital when the levels of sugar are high and when the disease is in its advanced stage.’ (FGD men from the community)

According to health workers, people who thought that diabetes was an acute illness that can be cured also took traditional medicine:

‘The patient will end up using both the biomedical medicine and the traditional medicine hoping that this will bring healing faster.’ (KII health worker)

Some participants thought that diabetes mellitus was curable whilst others thought it was not. There have been various studies highlighting the treatment of diabetes using bariatric surgery and lifestyle interventions (Kashyap, Louis & Kirwan 2011; Maffi *et al.* 2011). However, this is not the perspective of the community members; they looked to herbs as the cure for diabetes. Similar to findings from Zimbabwe (Helm & Mufunda 2010), there seems to be some limitations in the way communities perceive diabetes as a curable or non-curable disease. There is great need to conduct health education in communities on the nature and prognosis of diabetes so that people can appreciate that diabetes is not an acute illness that can be cured by taking herbs.

## Limitations of the study

Triangulation across the respondents, male and female, community members, patients with diabetes and health workers, as well as the use of KIIs and FGDs was useful in checking for consistency and contradictions within and amongst groups (Berg 2001; Flick 1992). The participants were purposively selected and the research findings cannot be generalised to the general population. Further studies on how these perceptions affect preventative and care seeking practices at the general population level are necessary.

## Conclusion

This study has highlighted that there are several misconceptions about diabetes mellitus. Notably people with

diabetes symptoms are commonly labelled by members of the community as being bewitched or being infected with HIV. The rural communities correctly ascribe diabetes to consuming too much fatty food. The common belief that diabetes is a contagious disease causes stigmatisation of people and may affect treatment seeking and disclosure. There is a belief that the disease is curable if the person is diagnosed early and adheres to treatment.

## Recommendations

The perception that consuming too much fatty food is associated with diabetes provides an opportunity for a preventative community programme. There is need for health education in the communities on the symptoms of diabetes so that members of the community see weight loss as having other causes too, not only HIV infection. Health education talks should incorporate information about diabetes not being a contagious disease. Awareness campaigns could be conducted in rural areas explaining the chronic nature of diabetes mellitus so that people with diabetes do not keep looking for a quick cure. With the increase in the number of people with diabetes in sub-Saharan Africa, it is critical that messages regarding the prevention and treatment of diabetes are taken outside the hospitals to rural communities.

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## Competing interests

The authors declare that they have no financial or personal relationship(s) which may have inappropriately influenced them in writing this article.

## Authors’ contributions

E.R. (Makerere University School of Public Health), S.K.K. (Makerere University School of Public Health), S.N.G. (African Field Epidemiology Network), A.D.M. (Makerere University School of Medicine) and L.A. (Makerere University School of Public Health) were responsible for designing the study, developing tools, conducting field work and writing the manuscript. E.R., S.K.K. and L.A. performed the analysis. All authors approved the final manuscript.

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