Perceptions on preeclampsia and eclampsia among older women in rural southwestern Uganda

Harriet Nabulo (✉ hnabulo@must.ac.ug)

Mbarara University of Science and Technology Faculty of Medicine <https://orcid.org/0000-0002-4568-4421>

Gad Ruzaaza

Mbarara University of Science and Technology

Francis Mugabi

Mbarara National Referral Hospital

Francis Bajunirwe

Mbarara University of Science and Technology

Research

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Abstract

Background: Eclampsia is among the leading causes of maternal mortality. It is a serious hypertensive (HT) complication of pregnancy and increases the risk of cardiovascular disease (CVD) in later life. Pregnancy-related HT complications predispose to chronic hypertension and premature heart attacks. A significant proportion of women with preeclampsia/eclampsia does not reach the formal healthcare system or arrive too late because of certain traditional or cultural beliefs about the condition. The older senior women in the community are knowledgeable and play a significant role in decision making regarding where mothers should seek maternal health care. Therefore, the purpose of this study was to explore the perceptions of older women regarding the manifestation of, risk factors and possible causes of preeclampsia/eclampsia.

Methods: We conducted a qualitative study in a rural area in southwestern Uganda. The key informants were older women including community elders, village health team members and traditional birth attendants who were believed to hold local knowledge and influence on birth and delivery. We purposively selected key informants (KI) and data were collected till we reached saturation point. We analyzed data using a combined inductive and deductive approach to identify themes. Analysis was completed using N-Vivo version 12.

Results: We interviewed 20 key informants. Four themes emerged namely: local name, causes and risk factors, remedies, and effects of preeclampsia/eclampsia. There was no identifiable local name from the interviews. Women carried several myths regarding the cause and these included little blood, witchcraft, stress from relations including marital tension and ghost attacks. The remedies identified included corrective nutrition, herbal treatment and prayers. Women were generally aware of the outcomes of eclampsia; mainly that it kills.

Conclusion: Eclampsia is associated with significant myths and misconceptions in this rural community. We recommend interventions to increase awareness and dispel the myths and misconceptions regarding eclampsia, increase access to antenatal preeclampsia surveillance, and facilitate timely referral for basic maternity care as means for early detection and management of preeclampsia.

Plain English Summary

Preeclampsia is a pregnancy complication characterized by high blood pressure (hypertension) and signs of damage to organ systems most often the liver and kidneys. Eclampsia is a severe complication of preeclampsia where high blood pressure results in seizures during pregnancy and is life threatening. It is the 3rd contributor to maternal death in Sub-Saharan Africa. Survivors have an increased risk of suffering cardiovascular diseases like stroke. Its manifestation may not be well understood leading to late health - care seeking where women report with complications. Older women influence care –seeking behavior for younger women owing to their life experiences and are custodians of cultural beliefs that may affect

health. We explored the perceptions of older women regarding the manifestation of, risk factors and possible causes of preeclampsia/eclampsia in rural south western Uganda.

Participants were asked to name a disease that presents with blurred vision, severe headache, right upper quadrant abdominal pain, fitting ,what causes such symptoms, how one can know that a pregnant woman has high blood pressure, what increases one's risk of developing the disease, suggested remedies and effects on pregnant women.

In-depth interviews were conducted among 20 key informants, who were mainly aged between 45 and 49, married, from the Bakiga tribe, were either village health team members (VHTs) or traditional birth attendants (TBAs) with no formal education.

No clear identifiable local name emerged from the interviews. The cause was associated with little blood, witchcraft, strained relationships including marital tension and ghost attacks; remedies identified included corrective nutrition, herbal treatment and prayers. Women were generally aware that eclampsia kills.

Knowledge about preeclampsia/eclampsia in this community is marred with misconceptions. Interventions to increase awareness about the condition, increase access to antenatal preeclampsia surveillance and facilitate timely referral as a means for early detection and management of preeclampsia are recommended.

Introduction

Preeclampsia is a pregnancy complication characterized by high blood pressure and signs of damage to organ systems most often the liver and kidneys. Eclampsia is a severe complication of preeclampsia where high blood pressure results in seizures during pregnancy and is life threatening. Both preeclampsia and eclampsia are pregnancy-specific conditions resulting in hypertension and multi-organ dysfunction. [1, 2] Hypertension and other forms of cardiovascular disease (CVD) are a leading cause of death and in sub Saharan Africa and women are more likely to die of heart disease compared to men. [3, 4] Overall, incidence of heart disease and other non-communicable diseases are on the rise in resource limited settings. [5]

Prior history of preeclampsia or eclampsia increases risk of cardiovascular disease [2, 6, 7] and diabetes [8] later in life. Preeclampsia is associated with a 4-fold increase in future incidence of heart failure and a 2-fold increase in the risk of coronary heart disease, stroke, and death from a cardiovascular disease related event. [1, 2, 9-12]. Hypertensive disorders complicate 5% to 10% of pregnancies.[13]

Uganda's maternal mortality ratio is estimated at 368 deaths per 100,000 live births, and approximately 15 pregnant women dying every day due to direct causes like hemorrhage and hypertensive disorders. [14] Almost 15% of maternal mortality in southwestern Uganda is attributable to hypertensive disorders in pregnancy mainly eclampsia from women admitted in critical condition. [15, 16] Preeclampsia and

eclampsia are among the top three causes of maternal mortality worldwide [17] and the incidence remains high in resource limited settings, although it has reduced in resource rich countries. [18] Between 2003 and 2009, hemorrhage, hypertensive disorders, and sepsis were responsible for more than half of maternal deaths worldwide with hypertensive disorders contributing 14.0% to direct maternal mortality. [19] Headache disorders were also highly prevalent among females. [20] In sub-Saharan Africa, about one third of the mothers with eclampsia will experience a still birth and eclampsia is responsible for almost 20% of maternal mortality and disability. [21] Maternal mortality may be higher in rural areas due to difficulty in access to services as shown in a recent study in south western Uganda where most of the maternal deaths were related to late referrals. [15] Rural women often experience delays to make a decision to seek care, delay to reach place of care and delay in receiving appropriate and adequate care. [22, 23] The decision to take up referral and deliver at a higher level facility may be influenced by community perceptions regarding the conditions for which the patient is referred.

Perceptions towards a health condition are influenced by several facets such as culture, personal beliefs, experiences and knowledge. [24] Studies conducted in Asia and West Africa suggest there is a variety of community perceptions that may be barriers for women with pre-eclampsia to seek care and eventually deliver at a health facility. [25-27] The clinical presentation of preeclampsia and eclampsia may not be well understood by some of the communities, and is often confused with other conditions and some communities believe local home remedies may cure them. [25] Some communities associate preeclampsia/eclampsia with witchcraft. [28] These alternative explanations may lead to late care seeking for mothers with preeclampsia and this is often further compounded by weaknesses in the existing health system that prevail in low resource settings. [29]

Older women in the communities and families play a significant role and decision on where mothers will deliver. [30, 31] The perceptions they carry about certain health conditions may influence pregnant women's decision to seek care or deliver in health facilities. [32] There is limited data on studies to explore the perceptions of older women on preeclampsia/eclampsia in resource limited settings with poor access to health care. Therefore, the purpose of this study was to explore the perceptions of older women regarding manifestation, risk factors and possible causes of preeclampsia/eclampsia in rural southwestern Uganda. We hypothesize that these perceptions may be driven by cultural beliefs, myths and misconceptions which may contribute to staying away or delay in seeking care by women with preeclampsia in rural south Western Uganda.

Methods

Study design

This was a cross-sectional qualitative study conducted using key informant interviews. We interviewed older women and documented their perceptions on preeclampsia and eclampsia .

Study setting

The study was conducted in Kabuyanda subcounty, in Isingiro district of southwestern Uganda, a rural remote location. The terrain in this district is very hilly, making transportation very challenging. The sub-county is served by two health center IIs (parish level health facilities), namely Rwakakwenda and Rwamwijuka. The two health facilities do not offer antenatal care services. Most women in this sub-county are referred to Kabuyanda HC IV (county level health facility) which is relatively far away, approximately 30minute to 1-hour journey on a motorcycle taxi. Kabuyanda HC IV refers cases they are not able to handle, to the Mbarara Regional Referral Hospital, a journey that takes well over 1 hour. By the time women from this community arrive at the biggest regional referral Hospital for basic and comprehensive emergency services, they are often very ill with complications. The village is the smallest administrative unit in the local government of Uganda. A village usually consists of between 50 and 70 households and may be home to between 250 and 1,000 people. A collection of 6 or 7 villages makes a parish. About five to seven parishes make up a sub-county and three or four sub-counties make county, an area represented by a member of parliament.

The health care system is decentralized and at village level, the village health team serves as a satellite site with no definite physical structure for services such as outreach for immunization and health education. A health center II serves a parish and offers preventive, promotive, outpatient curative health services, and outreach care to a population of about 5000 people. A health center III serves at sub-county level with a reach of about 20,000 people and offers preventive, promotive, outpatient curative, maternity and inpatient health services and laboratory services. A health center IVs serves at county level, with a population of about 100,000 and offers preventive, promotive and outpatient curative, maternity, inpatient health services, emergency surgery, blood transfusion and laboratory services and referral services.

According to Uganda's health care delivery system, a HC II does not provide ANC and birthing services. Pregnant women in our study setting may be at a relatively higher risk of developing undiagnosed pre-eclampsia due to difficulty in accessing antenatal blood pressure check- ups. This study area was chosen because Mbarara Regional referral hospital receives a significant proportion of mothers from this region, often referred very late with eclampsia.

Study population and sampling

The key informants were older women aged 45 years or above. The participants interviewed were aged between 45 and 79. Teenage pregnancies and marriages are highly prevalent in this community and therefore women at 45 years of age are considered older, knowledgeable about reproductive health issues and elders in their communities. These were chosen because they influence health care seeking behavior, as they are believed to be the custodians of traditional beliefs and practices that may affect health seeking behavior. The older women are usually of higher parity and their experience with numerous births offers them more experience with complications of pregnant, either for themselves or persons they know. They consisted of traditional birth attendants (TBAs), village health team (VHT) members and older women of higher parity; outside reproductive age. Traditional birth attendants are usually older women who have learned to deliver babies, usually from an older woman and run maternity services for the

community from their homes. Some of them have received some formal training through workshops on how to perform safe deliveries and referrals. Village health team consists of lay persons usually 3 or 4 per village, nominated in each village and tasked with overseeing and mobilizing for health-related activities in the village. The study was conducted in the 5 parishes of the sub-county and for each parish, we selected 4 key informant interviews. Data were collected till saturation point was reached.

We used purposive sampling to identify the study participants. In this approach, we sought out for the eligible women and interviewed them. We used this approach because they are a smaller proportion of the community where the study was conducted and random sampling would not be feasible.

Data collection tools

We designed an interview guide to collect data. The interview guide had sections on demographic characteristics of the participants. We asked participants their age, occupation and level of education, classified as primary or secondary. The education system in Uganda requires 7 years of primary education. Lower primary education level is from primary one to four and upper primary is from primary 5 to primary seven. The secondary education lasts 6 years, with 4 years of lower and 2 years of upper secondary school.

Questions were designed based on the literature reviewed and included open-ended questions. We described preeclampsia and eclampsia as they present in pregnancy and asked participants to mention the local name for disease, what they thought was the cause and risk factors and how the condition should be managed. Participants were asked to name a disease that presents with blurred vision, severe headache, right upper quadrant abdominal pain, fitting, what causes such symptoms, how one can know that a pregnant woman has high blood pressure, what increases one's risk of developing the disease, suggested remedies and effects on pregnant women. We used open ended questions to obtain this information and also what the participants thought were the short term and long-term effects of eclampsia on pregnant women.

We recruited three experienced research assistants (RAs) and trained them to administer the interview guide. One of the co-authors (HN) worked with the RAs during the training and conducted role plays with the tools to ensure there was clear understanding of the questions. The research assistants were exposed to the study tools to get acquainted with them in the two-day training. We conducted pilot interviews with 4 older women in a contiguous parish, not the study parish, to test the tool in a similar setting to ensure the questions were valid. We made a few adjustments following the pilot.

Data collection and analysis

Data were collected over a 2-week period in April 2018. The RAs collected data with the supervision of one of the co-authors (HN). We obtained an introductory letter from the Assistant District Health Officer and presented this to the parish mobilisers as our port of community entry. Parish mobilisers are

volunteer community members who mobilize for health campaigns and activities in their locality such as mass mosquito net distribution, vitamin A supplementation and mass immunization campaigns among others. The parish mobilisers are very familiar with their local communities, are well known and trusted persons and serve as a resource in mobilizing for health programs and community-based exercises.

These mobilizers assisted in identification of the eligible participants and the RAs approached them for their participation. All participants approached accepted to be interviewed. The interviews were conducted in the local language, *Runyankore-rukiga*, and in private rooms at the parish headquarters. Data collection was stopped when the point of saturation was reached. Interviews lasted between 30-45 minutes and were audio recorded. The interview time was deemed adequate for the interview when further probing yielded no new responses. At the end of each day, two co-authors (HN and GR) listened to the audios. The RAs transcribed the audio material after a day's work.

The transcripts were translated into English by a native *Runyankore-rukiga* speaker. Two co-authors (HN and FM) are fluent in the local language and listened to all the audios to ensure they corresponded with the transcriptions. The corresponding author read and re-read the transcripts to ensure they were complete. We used a combined inductive and deductive thematic approach to the data analysis. Data analysis was done in three phases: preparation, organization and results' reporting as described elsewhere. [33-35] The teams read through and examined the data, identified coding units, analyzed data by applying the coding units and made a tally of the number of times a coding unit had appeared [36] . The unit of analysis was a key informant interview. We reviewed existing studies to inform the potential emerging themes but also kept the analysis open to allow new themes driven by the data to emerge. Data were coded by two teams separately (HN and GR, FM and FB) and the teams reviewed the emerging themes to reconcile any differences. We used NVivo software version 12 to analyze the data.

Ethical considerations

We obtained ethical approval from the Mbarara University of Science and Technology Research Ethics Committee and the final approval was issued by the Uganda National Council for Science and Technology. Administrative clearance was granted by the Assistant District Health Officer (ADHO) of Isingiro district, the study location. The ADHO provided introductory letters to the local authorities permitting data collection in the villages of the county. We explained the details of the study procedures to the participants, and once they understood and agreed to participate, we obtained written informed consent. For the participants that could not write, we asked them to append their right thumb prints in place of the signature. The identity of the participants was kept anonymous. Data were accessible to only the study team.

Results

We enrolled 20 participants and reached data saturation. The largest proportion were aged between 45 and 49 years, were married, belonged to the Bakiga tribe and the details of the socio-demographic

characteristics are shown in Table 1 below. Most of the women were either members of the village health team or traditional birth attendants. The largest proportion of them did not have a formal education.

Table 1: Demographic characteristics for participants n=20 older women in Kabuyanda, Isingiro district, southwestern Uganda

Variable	n =20
Age	
65 and over	2
60-64	4
55-59	4
50-54	3
45-49	7
Marital status	
Married	18
Widow	2
Tribe	
Mukiga	19
Nyankore	1
Parity	
1-5	9
6-10	9
>10	2
Education level	
None	12
Lower primary	6
Lower secondary	2
Occupation*	
Traditional Birth Attendant	8
Village Health Team	9
Peasant farmer	2
Chairperson for women committee	1

*Occupation categories are not exclusive. * lower primary is from primary 1 to 4 and upper primary from primary 5 to primary 7.

Emerging themes

Four themes emerged from our analysis namely; local name, causes and risk factors, remedies, and effects of preeclampsia/eclampsia and these are presented in Table 2 below. The theme local name emerged from the subthemes of no identifiable local name and a couple of other conditions namely meningitis and epilepsy which were mistakenly confused for pre-eclampsia. Causes and risk factors emerged from multiple pregnancy, 'little' blood, witchcraft, strained relationships like marital tension, ghost attack, drinking alcohol, having a big baby, poor feeding and a disease of the well-to-do cited as potential causes. The remedies emerged from the consistent mention of herbal treatment, prayers and counseling, corrective nutrition, appeasing the dead, 'good treatment' by spouse and seek medical help as potential solutions cited by the majority. The effects theme emerged from the mention of premature delivery, caesarian section delivery and death as potential consequences.

Table 2: Emerging themes on perceptions of pre-eclampsia among older women in Isingiro, south-western Uganda

Codes	Sub-themes	Themes
No local name <i>Obuzimba bw'enda y'abarongo</i> <i>Omuraramo, ensimbo</i>	No clear identifiable local name	Local name
Marital tension Nagging co-wives Ghost attack Poverty Alcohol intake Food insecurity Lack of craved foods Big baby Poor feeding Multiple pregnancy <i>Puresha</i> (high blood pressure) A disease of the well-to-do	'Little' blood Strained relationships. Witchcraft High blood pressure Ghost attack	Causes and risk factors
Herbal treatment Prayers and Counseling Corrective nutrition Appease the dead "Good treatment" by spouse Seek medical help at the hospital	Counseling Herbal treatment Corrective nutrition Appease the dead Seek medical help	Remedies
Premature delivery Still birth Caesarian section delivery Death	Premature delivery Difficult birth Death	Effects of preeclampsia/eclampsia

Local name

The *Baganda* tribe in central Uganda and *Banyakitara* tribes in southwestern Uganda call pre-eclampsia '*amakilo* and *amakiro*' respectively but none of these KIs we interviewed seemed to know this name.

'I am really not sure of the name for a disease that presents that way; besides I have never had those symptoms in combination but I see women with twin pregnancies having swollen feet' 47-year VHT Member, mother of 4.

Instead, some KI seemed to have coined other names such as "*Obuzimba bwe'enda y'abarongo*" translated as 'swelling of the body due to twin pregnancy'. The KIs seemed to suggest that the body swelling in preeclampsia was due to weight gain that happens when a woman is carrying a twin pregnancy.

"You can tell that a woman has multiple pregnancy if you see her body swollen up. But usually in the morning, the swelling has reduced but because the babies she is carrying are heavy, then her body swells up again, the swelling is there all the time but more pronounced during the day when it is difficult for her

legs to carry her pregnancy and do chores as well. So I think this disease that presents this way together with body swelling is Obuzimba bw'enda y'abarongo , 73-year old widow , mother of 7.

Ensimbo, translated as 'epilepsy' was confused with pre-eclampsia by some of the women. Participants said that fits/convulsions in pregnancy are due to epilepsy especially if it has been pre-existing before the woman got pregnant.

'Fitting in pregnancy is caused by [ensimbo]. It's a bad omen to suffer from epilepsy. When someone is convulsing because of epilepsy, we run away from them because should they pass flatus when one is near them, he catches it too. It's terrible, you don't want your relative to have epilepsy of all diseases.' 48-year-old, peasant, mother of 6.

'Omuraramo, translated as 'meningitis' was considered to have symptoms equivalent to those of pre-eclampsia by some women. The fits/convulsions that manifest in eclampsia were perceived as meningitis by the participants.

'When I was growing up there was an outbreak of omuraramo and sometimes patients would fit. It was a killer disease and they would remove fluid from their back. Your patient would never make it after this extraction of fluid from the back. I think a pregnant woman fitting has caught omuraramo [meningitis] and is destined to die with her pregnancy' 73-year old, TBA widow, mother of 7.

Causes and risk factors

Participants thought that the convulsions that occur in this disease can be caused by *omuraramo* or *ensimbo* literally meaning meningitis and epilepsy respectively in the local Runyankore-rukiga dialect.

'Those symptoms could be caused by omuraramo [meningitis] and ensimbo [epilepsy] but now you see the confusion is that even men can have it and can fit.' 44-year-old TBA, mother of 3.

The respondents associated the oedema or body swelling seen in preeclampsia and eclampsia patients with having anemia or 'little blood' in the pregnant woman's body. Respondents mentioned that a poor diet dominated by *matooke* [steamed bananas] and no beans or greens or even millet porridge was to blame for the 'little blood' in women.

'When you eat poorly, especially when you can't find foods that give blood, then your whole body will swell.' 57years TBA, mother of 5.

Respondents mentioned that poor feeding resulting from a pregnant woman not being able to find foods rich in nutrients such as iron, not having enough to eat in general due to lack of money to buy the necessary food stuffs was seen as a cause of 'little blood' and body swelling in pregnant women.

'I think the person is weak in this case and does not have enough blood because of poor feeding, you know village life where people don't have money to buy foods rich in iron like the health worker tells us of meat and fish, so this may be the cause for the swelling in pregnant women, then the stress will bring

about headache. As you know, our poor way of living in the village may have brought about this,' 45-year-old VHT member, mother of 6.

This was echoed by other participants who thought not taking the right foods is solely responsible for body swellings in pregnant women.

'I thought the pregnancy was big and also the woman was not having a balanced diet. At times the pregnancy restricts one and they have no appetite. A woman may end up eating matooke with no salt, they don't want beans or other times they depend on only drinking water. Such a person may lack blood and end up getting swollen.' 56 years, women's leader, mother of 5.

'The challenge is that some pregnant women are not feeding well or have other diseases that are left untreated and can swell up or even fit and so they will blame pregnancy when it isn't the case' 45-year-old VHT, mother of 4.

There was a common belief in spirits and ghosts. Some respondents thought the fits were linked to a ghost attack from recent demise of a close relative especially if the pregnant woman was not at peace or was liked too much by the deceased.

'Some relatives don't die completely. If at the time of demise, you had a misunderstanding or they loved you too much and are not resting in peace, they may strangle you so that you die too.' 73-year old widow, mother of 7.

Some participants thought that life stressors like strained relationships, abusive spouses can cause stress resulting in a headache. Respondents mentioned that some women are in polygamous relationships with nagging co-wives, and poverty where they are unable to have enough nutritious foods such as those rich in iron. They believed that all these factors may cause a rise in one's blood pressure especially when pregnant.

'For us we always think that she has a lot of thoughts like when the woman is unstable at home, like the man doesn't bring for her home necessities and when she encounters such problems , they can cause a headache and 'puresha' [high blood pressure].', 48 year old , Peasant, mother of 6,

Several respondents believe the illness may be a result of witchcraft especially from persons that do not wish the pregnant woman well.

"Not everyone is happy for you when you get pregnant, for some reason, someone can bewitch you and you fit, a co-wife for example could wish you dead. When you are pregnant, she is already imagining that your child will compete for property with her children" 45-year-old VHT, mother of 5.

Multiple pregnancies are associated with a certain level of prestige but seemed to be associated with complications such as body swelling and anemia.

'They are not many though I usually see some women with swollen hands, face and legs and I always think it is because one is expecting twins and at times, we joke about it.' 45 -year old, VHT member, mother of 6.

Respondents believed that body swelling was predictive of the size of the baby the mother was carrying, and some respondents seemed to suggest that the more the swelling, the bigger the baby would be.

'We say that a woman swelling during pregnancy means that she has a big baby who is demanding a lot of blood hence the swelling.' 56-year-old, women's leader, mother of 5

Majority of the respondents seemed to correctly relate having high blood pressure with symptoms of pre-eclampsia and eclampsia as evidenced in the narrative from a VHT member.

'The signs that she has, the woman who has [high blood] pressure, she has severe headache, she tells you that the heart pumps a lot like it is about to fly out of the chest, and those are the only ones. I don't do much with such a woman, I just give her a referral letter to hospital immediately. There is nothing more I can do really because am not empowered to help her'. 45 year, VHT coordinator, mother of 4.

Remedies

Participants had different views on how a client with preeclampsia /eclampsia should be managed. The recommendations ranged from herbal medical treatment to referral to the formal health care facilities.

Some of the participants said that when getting medical treatment from the hospital is difficult, they resort to some herbal concoctions. The respondents believed that these had the ability to raise their blood levels and therefore the swelling would reduce.

'The woman goes to a health facility and gets some tablets but these may not be very helpful most of the time. At times they go to Kabuyanda [county level] health center and are not helped so they are advised to seek further medical treatment in a hospital. But they do not go because they have no money. So, they resort to using herbs. ...they can use a red herbal concoction that increases their blood levels' a 45-year-old VHT member, Para 6+2.

Some respondents thought convulsions in a pregnant woman are linked to a ghost attack from recent loss of a close relative. They mentioned that the traditional healer would appease the dead by performing certain rituals.

'The services of a traditional healer should be sought to appease the dead. I don't know what the traditional healer does but I know that he should be performing some rituals to appease the dead' 73-year old widow, retired TBA, mother of 7

Some respondents believed in spiritual healing as a remedy for eclampsia. Although this was not common, the few respondents that suggested so were very passionate about the potential effectiveness of the remedy.

'Seeing a counselor can help her to be peaceful since they have troubles. She can join a prayer group and pray for peace in her home to save her the stresses of daily life.' 60-year-old farmer, mother of 7.

Respondents alluded to a balanced diet for the participants as being essential, although their understanding of a balanced diet meant eating beans, green vegetables, sweet potatoes, and millet porridge to correct the anemia. They believe that this type of diet will correct the dizziness and body swelling and prevent the convulsions.

'At times the pregnancy is very demanding on the woman to carry but also lack of enough blood. When they are swollen up, they are encouraged to feed well so that they can get enough blood like feeding on liver can bring back the blood and the body swelling will slowly go away. They say they get swollen and when they visit the hospital, they are advised on how to feed. Enough blood prevents them from fitting as well.' 65 years VHT, mother of 6.

Some respondents believed that symptoms related to eclampsia were because the woman was being mistreated by her husband. They believed that if the husband treated her better and took good care of her, these symptoms would resolve or would not appear in the first place.

'Loving each other and getting due attention from husband when a woman feels any pain , helps a lot. Also, a husband who treats his wife well saves her stress that can cause her [high blood] pressure.' 65 years, VHT member, mother of 6.

Although some respondents were proponents of local herbal remedies, some strongly discouraged and recommended visiting the health facility.

'Long time ago herbs used to help in every illness of our forefathers but nowadays they tell you they take but the herbs are of no help. So, they are better off going to hospital for treatment because herbs these days no longer help.' 45-year-old VHT, mother of 4.

Effects of preeclampsia and eclampsia

Participants were aware of the potential consequences of the symptoms of eclampsia. They mentioned that the condition could lead to death of the baby in utero or even the mother. These potential adverse outcomes were mentioned by the majority of respondents.

'The person may die if not referred to hospital. If the woman does not die, her baby will die in the womb. How can the baby survive with a mother that has no blood?' 45 year, VHT coordinator, mother of 4.

Most of the participants linked the signs and symptoms of preeclampsia to little blood that causes body swelling. They said that such women can have premature deliveries.

'Maybe the baby can become very weak or some women get swollen legs, little blood and this can sometimes lead to premature births. That is how we see them.' 60-year old farmer, mother of 7

Participants thought that a woman with symptoms of preeclampsia/eclampsia becomes very weak and may get difficult deliveries. They mentioned that such women are likely to be surgically operated to remove the baby.

'No, it's not that they get all that well, they remain weak and at the time of giving birth they may still be weak, they may fail to push the baby and are delivered by caesarian section.' 45-year-old VHT member, mother of 6.

Participants acknowledged that preeclampsia/eclampsia is a serious illness and life threatening. They agreed that if not attended to, the disease had some grave consequences including the potential to cause death.

'I think such a person should get help from a health facility but because we are in village at times when a woman is in such a condition and you tell her to go to hospital, their husbands, don't mind so they don't care, in such a situation, the woman remains in that poor state of health and at times she dies.' 57 year old TBA, Mother of 7.

Discussion

Our data from rural southwestern Uganda shows that majority of the women understood that eclampsia was related to high blood pressure and is also potentially fatal. Although, a distinct local name did not emerge, respondents related the condition to other medical conditions namely epilepsy and meningitis due to a shared symptom of convulsions. The women described various factors that they believe may be causes and remedies for the condition, most of which had no direct relation with eclampsia. The same older women of influence that we engaged in the interviews hold significant myths and misconceptions about eclampsia.

The descriptions women gave were made in reference to other diseases namely, meningitis and epilepsy. Anecdotal evidence from midwives practicing in central and other places in southwestern Uganda where the *Bakiga*, the predominant tribe in our study area live, refer to eclampsia as '*amakilo*' and '*amakiro*' in central and southwestern Uganda respectively. We were surprised that a clear local name for eclampsia did not emerge for this community that is also largely comprised of the same *Bakiga* tribe. It is not clear whether migration could have caused the loss of the disease name. A disease with a local name and an identifiable set of symptoms becomes a clear target for interventions. A local name attached to preeclampsia and eclampsia is desirable as this gives the condition a local identity and enhances uptake of interventions.

However, data from a study in rural Nigeria [26] and Pakistan [37] support our finding that a local name may not necessarily exist. In the Nigerian study done among the *Yoruba* tribe, respondents described the condition as the epilepsy of pregnancy, similar to what participants in our study did.

Our data show that when women were asked about causes and risk factors for eclampsia, they revealed a high level of misconception regarding the condition. The women suggested several potential causes for eclampsia and these included anemia or having little blood, carrying a very big baby, poor feeding, witchcraft and even marital stress. It is clear the misconceptions are common face in sub Saharan Africa. In a qualitative study in Nigeria [26], women also suggested that marital conflict, abusive husbands and strained relationships were responsible for eclampsia.

In a similar study in Mozambique designed to examine community knowledge about preeclampsia, women also believed that it is caused by stress, worry and mistreatment from in-laws. [28] In this Mozambican study, extreme suggestions such as snakes living inside the woman's body were fronted as possible explanations. Witchcraft was mentioned as a possible cause in our study and the Mozambican one. Despite these prevailing misconceptions, some respondents correctly associated eclampsia with high blood pressure.

There were several misconceptions regarding the remedies for preeclampsia. The one most participants easily turned to was herbal remedies. Herbal remedies are common throughout sub Saharan Africa as a first mode of treatment. The concern is these remedies provide false hope and may cause delay in seeking treatment. One study in Nigeria [38] found that use of herbs was associated with severe eclampsia and preeclampsia. Women also suggested prayer as a potential remedy. While there are strong religious beliefs in sub Saharan Africa, these may contribute to the delay in seeking care or the first delay. [39, 40]

Most of the respondents were aware of the dangers of eclampsia and expressed fear for maternal deaths as the ultimate consequence of eclampsia. This awareness of the dangers of eclampsia provides a window of opportunity for interventions to target even the wider challenge of the misconceptions. The health belief model has been used to explain poor health care seeking behaviors in Nigeria owing to misconceptions. [41] The perceived susceptibility to still birth and death among mothers with eclampsia as reported by these older influential women in our study and the acknowledgement by some that medical attention should be sought could provide a valid basis for interventions. Community health workers provide a potential first line of intervention as they have been shown to have sufficient knowledge and ability to identify women with preeclampsia and administer initial treatment. [42-44] Future programs will need to develop interventions that focus on demystifying the prevalent myths and promote a more scientific understanding of the condition and eventually this knowledge could serve as cues for action.

Our study has important strengths. Although several studies have been conducted on this subject, our study focuses on the older senior women who play a significant role in the health care seeking behavior of pregnant women. Second, our study is community- based in a rural population. The data collected provides a strong grip for interventions to improve outcomes of mothers with eclampsia. These respondents are the custodians of local knowledge and the power to influence belief and practice of younger women and eventually their health seeking behavior. Third, our study reveals some unique myths

and misconceptions that should be explored in other communities as well. There are some limitations to our study. We used only key informant interviews to collect data. A combination of focus group discussions (FGDs) and KIs could have enabled us to obtain richer data. Secondly, we were only able to enroll a handful of participants above 60 years of age.

In conclusion, our study in rural southwestern Uganda has shown that women were generally aware of the potential danger of pre-eclampsia. However, there is no identifiable local name for preeclampsia that can be easily tagged to the condition. The community holds a lot of myths that surround the possible causes and risk factors for preeclampsia and these may negatively influence health care seeking behavior. There is a great necessity to create campaigns to raise awareness/knowledge about preeclampsia and dispel the myths surrounding it, increase access to antenatal preeclampsia surveillance, and facilitate timely referral for basic maternity care as means for early detection and management of preeclampsia.

List Of Abbreviations

ADHO	Assistant District Health Officer
ANC	Antenatal Clinic/care
HC	Health Centre
MRRH	Mbarara Regional Referral Hospital
MURTI	Mbarara University Research Training Initiative
REC	Research Ethics Committee
TBA	Traditional Birth Attendant
UNCST	Uganda National Council for Science and Technology
VHT	Village Health Team

Declarations

Ethical approval and consent to participate

The study was approved by the Mbarara University of Science and Technology Research Ethics Committee and the Uganda National Council for Science and Technology (UNCST-Ref No. SS 4611). The district health office and parish authorities gave administrative permission to collect data, individual written consent was obtained from the participants.

Consent to publish: Not applicable

Availability of data and materials: These are available from corresponding author upon reasonable request and with approval from the Research Ethics committee.

Competing interests

The authors declare that they have no competing interests.

Author contributions

HN, GR and FB conceived and designed the study. HN supervised the data collection. HN, DR and FM participated in data collection. All authors participated in reading the transcripts and data analysis and verification. HN made the first draft of the manuscript. All authors read, revised and approved the final version of the manuscript. **Author information**

Harriet Nabulo, corresponding author is a Lecturer in Midwifery at Mbarara University of Science and Technology, Department of Nursing, Mbarara, Uganda.

Gad Ruzaaza, heads the Community Based Medical Education Program in the Department of Community Health at Mbarara University of Science and Technology, Mbarara Uganda.

Francis Mugabi is Director of the Community Health Program, Mbarara Regional Referral Hospital, Mbarara, Uganda

Francis Bajunirwe, is a Senior Lecturer in the Department of Community Health, Mbarara University of Science and Technology, P.O.BOX 1410, Mbarara, Uganda

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Appendix 1

INTERVIEW GUIDE FOR KEY INFORMANTS: PERCEPTIONS ON PREECLAMPSIA/ECLAMPSIA AMONG OLDER WOMEN IN RURAL SOUTH WESTERN UGANDA

Participant Code, age, Parish, Sub-County, Initials of the interviewer.....

Date interviewed:

1	Demographic characteristics of the participant Age, Religion, Tribe, Level of Education, Marital Status, Parity, Occupation.
2	Questions If a pregnant woman presented with the following signs, occurring at the same time, <ul style="list-style-type: none"> • Severe headache, • Blurring of vision • Palpitations • Difficulty in breathing • Swelling of the whole body • Difficulty in breathing • Right upper quadrant abdominal pain/epigastric pain, • And sometimes a fit; what would you think she is suffering from?
	What is the local name that can be used to refer to a disease that presents this way in pregnant women?
	What would you think is the cause of the above symptoms I have listed in a pregnant woman?
	Probes: <ul style="list-style-type: none"> • If a pregnant woman presented with severe headache that does not respond to the common painkillers sold over the counter, that are always used like Panadol; what would you suspect the woman to be suffering from? • If a pregnant woman started fitting/convulsing, what would you think she is suffering from? • What do you think can cause such a symptom like fitting in a pregnant woman? • How can you tell that a pregnant woman could be having a high blood pressure? • What can cause body swelling in a pregnant woman? What can make the woman's body swell when she also has a high blood pressure?
	1. - What increases a pregnant woman's risk of developing the disease you have named above or presents this way with the symptoms I have talked about?
	1. - If a woman presented with the above symptoms, what do you think should be done to her?
	1. - What do you think are the short-term consequences of a pregnant woman suffering from such a disease that presents with the symptoms I have talked about above?

	1. - What do you think are the long-term effects if a pregnant woman suffered the above disease that presents with all the symptoms I have talked about above? (repeat list of symptoms to participant as appropriate)
	1. - In your child bearing journey, what treatment was given to you (if you ever suffered this disease) or someone you could have encountered with such symptoms/disease?
	1. - Please tell me anything else that can be done to help a pregnant woman with such a disease/symptoms.
Thank you for participating in our study.	