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‘They say she is bewitched’: A qualitative study of community and health provider perspectives regarding pre-eclampsia and eclampsia in rural Tanzania

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Karen Yeates^{1*}, Sidonie Chard², Alexa Eberle³, Alexandra Lucchese⁴, Melinda Chelva⁵, Sanchit Kaushal⁶, Zacharia Mtema⁷, Prisca Dominic Marandu⁸, Graeme Smith⁹, Erica Erwin¹⁰, Anna Nswilla¹¹, Robert Philemon Tillya¹²

Department of Medicine, Queen’s University, Kingston, Ontario, Canada¹; Department of Public Health Sciences, Queen’s University²; Center for Clinical Epidemiology, Lady Davis Institute, McGill University, Montreal, QC, Canada³; Queen’s University, Kingston, Ontario, Canada⁴; Department of Medicine, Queen’s University, Kingston, Ontario, Canada⁵; Faculty of Health Sciences, Queen’s University, Kingston, Ontario, Canada⁶; B.A.C.D, Ifakara Health Institute, Tanzania⁷; Pamoja Tunaweza Women’s Centre, Kilimanjaro, Moshi, Tanzania⁸; Department of Obstetrics and Gynecology, Queen’s University⁹; BORN Ontario/Obstetrics and Maternal Newborn Investigations, Ottawa, Ontario, Canada¹⁰; Ministry of Health, Department of Policy and Planning, Tanzania¹¹; Department of Health Systems, Impact Evaluation and Policy Ifakara Health Institute, Tanzania¹²

*For Correspondence: Email: tmzethy@gmail.com; Phone: +268 76590655

Abstract

The objective of this qualitative study was to understand community and health provider perspectives regarding pre-eclampsia and eclampsia in rural Tanzania. Key informant interviews and focus group discussions with health workers and community members were conducted in the Geita and Singida districts. An interview guide, focusing on individual or community-based factors affecting women’s access to reproductive and maternal health services, was developed. Data was collected during December 2017 and May 2018 and analyzed using a thematic approach. Three themes emerged regarding perceptions about pre-eclampsia and eclampsia: 1) insufficient knowledge regarding signs, symptoms and risks, 2) misconceptions regarding the causes, due to beliefs and attitudes, and 3) variable patterns of health-seeking behavior among pregnant women who have signs and symptoms. While health providers had a good understanding about causes and management of pre-eclampsia and eclampsia, a much larger proportion of community members held misconceptions regarding the causes and recommended management. Community-based educational programs to improve community knowledge about the causes, risks and requirement of pre-eclampsia and eclampsia by trained health providers has the potential to improve maternal outcomes in rural Tanzania. (*Afr J Reprod Health 2021; 25[3s]: 92-104*).

Keywords: Preeclampsia, eclampsia, knowledge, attitudes, beliefs, practices, qualitative study

Résumé

L’objectif de cette étude qualitative était de comprendre les perspectives de la communauté et des prestataires de santé concernant la pré-éclampsie et l’éclampsie en Tanzanie rurale. Des entretiens avec des informateurs clés et des discussions de groupe avec des agents de santé et des membres de la communauté ont été menés dans les districts de Geita et de Singida. Un guide d’entretien, axé sur les facteurs individuels ou communautaires affectant l’accès des femmes aux services de santé reproductive et maternelle, a été élaboré. Les données ont été collectées en décembre 2017 et mai 2018 et analysées selon une approche thématique. Trois thèmes ont émergé concernant les perceptions concernant la pré-éclampsie et l’éclampsie : 1) connaissances insuffisantes concernant les signes, les symptômes et les risques, 2) idées fausses concernant les causes, dues aux croyances et aux attitudes, et 3) modèles variables de comportement de recherche de santé chez les femmes enceintes qui ont des signes et des symptômes. Alors que les prestataires de santé avaient une bonne compréhension des causes et de la gestion de la pré-éclampsie et de l’éclampsie, une proportion beaucoup plus importante de membres de la communauté avait des idées fausses concernant les causes et la gestion recommandée. Les programmes éducatifs communautaires visant à améliorer les connaissances de la communauté sur les causes, les risques et les besoins de la pré-éclampsie et de l’éclampsie par des prestataires de santé qualifiés ont le potentiel d’améliorer les résultats maternels en Tanzanie rurale. (*Afr J Reprod Health 2021; 25[3s]: 92-104*).

Mots-clés: Prééclampsie, éclampsie, connaissances, attitudes, croyances, pratiques, étude qualitative

Introduction

Maternal mortality remains a challenge in sub-Saharan Africa, which accounted for roughly two-thirds of all global maternal deaths in 2017¹. In 2017, Tanzania had an estimated maternal mortality ratio (MMR) of 524 per 100,000 live births², which was 2.5 times greater than the global estimate (211/100,000 live births), and almost 50 times greater than the MMR estimate in high-income countries (11/100,000 live births)¹.

Most maternal deaths in Tanzania are caused by factors relating to failure to visit medical clinics during pregnancy and childbirth, low awareness of signs and symptoms of obstetric complications, poor access to reproductive health services, and a weak health system³. Current estimates indicate that 25% of all maternal deaths occur during the antenatal period, most of which are caused by eclampsia and antepartum hemorrhage that would otherwise be manageable if pregnant women obtained antenatal care (ANC) in a timely manner⁴. In Tanzania, ANC guidelines include evidence-based processes of care that can detect and guide follow-up and treatment for pre-eclampsia, thus preventing the development of eclampsia but only 51% of pregnant women meet the recommended number of four ANC visits, with only 24% starting within the first trimester⁵.

Tanzanian women fail to seek timely ANC due to many factors including traditional gender roles and cultural beliefs, health system barriers, and economic or geographic constraints⁶. There exists little published evidence surrounding the knowledge and beliefs about pre-eclampsia and eclampsia among Tanzanian women, their health providers and community knowledge of the disease, beliefs and practices, and their influences on women seeking ANC. However, a 2016 study conducted in Dodoma, the capital city of Tanzania, showed that knowledge of pre-eclampsia/eclampsia among women in this community was low (41% provided correct answers), and signs and symptoms of pre-eclampsia were the least well-known of all sub-topics⁷. Increased awareness and education in Tanzania with respect to signs, symptoms, and treatment of pre-eclampsia/eclampsia could increase ANC attendance and quality of care, thus preventing the development of eclampsia and the associated maternal morbidity and mortality.

This qualitative study was part of a mixed-methods study on the effectiveness of a smartphone-based intervention used by health providers and community health workers (CHWs) to improve recognition, diagnosis and management of pre-eclampsia and eclampsia while also strengthening guideline-based processes of antenatal and post-natal care in health centres and hospitals in 4 districts in Tanzania. At the time of the development and implementation of the implementation plan, limited published evidence existed as to the knowledge, beliefs and attitudes of women, community and health providers regarding pre-eclampsia and eclampsia in Tanzania.

Therefore, to develop our mHealth intervention we first sought to explore and examine the knowledge, attitudes, beliefs and practices regarding pre-eclampsia and eclampsia among health providers, women, men, community health workers, and traditional birth attendants in the communities where our intervention was being implemented. This allowed us to gain a better understanding regarding awareness of and seeking health care services for pre-eclampsia and eclampsia in several diverse rural districts in Tanzania.

Methods

Study setting and study design

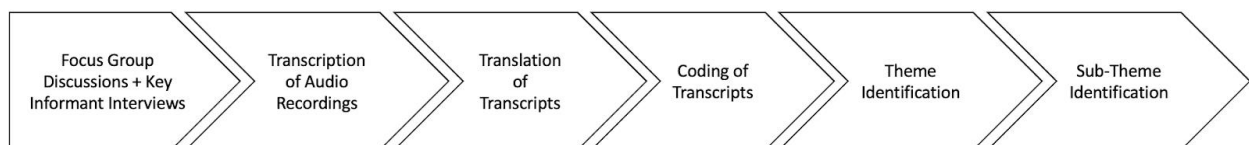
The study was conducted in Geita, Nyang`hwale, Singida and Singida DC districts of Tanzania. Focus group discussions (FGDs) and key informant interviews (KIIs) were conducted in the Geita and Singida districts. These districts are considered rural. These study areas were purposely selected because they were the study areas for a mixed-methods implementation research program that also included a cluster-randomized controlled trial of health facilities and communities that were the study sites for a health facility-based and community-based health provider targeted mobile health intervention with a focus on improving detection and management of pre-eclampsia and eclampsia⁸. Table 1 describes the most recently available key population statistics and demographics and maternal health related statistics for the entire country of Tanzania and, where available, for some of the study districts.

Table 1: Key population demographics and maternal health statistics for Tanzania

Indicator	Statistic	Data Source
Total Population	44.9 million	National Bureau of Statistics (2012) ⁱ
Life expectancy at birth (in years)	62	National Bureau of Statistics (2012 Census) ⁱⁱ
Adult mortality rate (per 1,000)	4.6 (Women) 4.3 (Men)	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Maternal mortality rate (per 1,000 woman-years of exposure)	0.94 (Age 15-49)	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Maternal mortality ratio	556 deaths per 100,000 live births	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Neonatal Mortality Rate (per 1,000 live births)	25	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Infant Mortality Rate (per 1,000 live births)	43	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Under 5 Mortality Rate (per 1,000 live births)	67	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Crude Birth Rate	37.2 per 1,000	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Crude Death Rate	9.3	National Bureau of Statistics (2012) ⁱ
Total Fertility Rate (Children per woman)	5.2 (Tanzania) 5.8-6.7 (Geita Region) 5.2-5.7 (Singida Region) *Women in lowest wealth quintile have 4.4 more children than women in the highest wealth quintile *TFR 3.8 in Urban Regions and 6.0 in Rural Regions	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Antenatal Care Components:	70.2 (Tanzania Mainland)	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016
Blood pressure measured (% with selected service)	42.5 (Geita Region) 68.7 (Singida Region)	Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016

Tanzania Demographic and Health Survey and Malaria Indicator Survey 2015-2016 (2015-16 TDHS-MIS) (<https://www.dhsprogram.com/pubs/pdf/FR321/FR321.pdf>)⁵

I. National Bureau of Statistics (NBS) [Tanzania], Ministry of Finance (MOF), Office of Chief Government Statistician (OCGS), Ministry of State, President's Office and State House and Good Governance. 2015: Population and Housing Census 2012. immortality and Health. Dar es Salaam, Tanzania: NBS, MOF, OCGS, Ministry of State, President's Office and State House and Good Governance. (<https://www.nbs.go.tz/index.php/en/census-surveys/population-and-housing-census>)

**Figure 1:** Description of study procedures and processes

The FGD participants had to be a resident in the local community and all participants had to provide informed consent to participate in the research, including consent for the recording of the FGDs. They were also told during the informed consent

process that they should feel comfortable in openly discussing their experiences, beliefs, and opinions in a confidential group setting as all inputs would remain completely confidential and that no identifying information about them would be

recorded beyond the information collected in the informed consent process.

The research team developed a FGD interview guide that included questions aimed at leading the discussion with the overall research objective focused on individual and community-based factors that were experienced by women that were considered barriers or enablers to women accessing reproductive and maternal health services including contraception, antenatal care (ANC) and postnatal (PNC) services. A description of study procedures and processes is illustrated in Figure 1.

We utilized an exploratory study design. The use of exploratory design was based on its ability to offer an opportunity to explore people's experiences in their own settings. For the community-based data collection, FGDs were chosen rather than also using KIIs as group dynamics and interaction in FGDs were thought to create better anonymity and spontaneity. The combined effect of the group produced a wider range of information, insight and ideas than the number of individuals' responses⁸. We chose to use both KIIs and FGDs among health providers so that we could collect both individual health provider and group perspectives to enrich the qualitative inquiry and the data^{9,10}.

Participant sampling and recruitment

KIIs and FGDs were conducted among health providers and facility and health district leadership in the districts where the study health facilities were located. FGDs were conducted within communities in the catchment area of the study health facilities. The FGDs were pre-set at 8-10 participants in the communities and 4-8 participants in the health facilities. Selection of participants was made in consultation with local health and village/community leaders who were affiliated with the community health management team who then identified and invited community members to participate based on participant criteria set by the researchers. The facility-based KIIs and FGDs included ANC clinic nurses, community health workers, midwives, social workers, and district nursing officers (DNO) (Table 2). The community based KIIs and FGDs included unmarried women with and without children, married women with children, single men, married men, traditional birth attendants, traditional healers, and other community

leaders involved in community-based maternal health decision making (Table 3).

Data collection

First, an interview topic guide was developed to facilitate the conduct of the FGDs and KIIs. The guide was developed in English with thematic topics linked to leading questions to be used for KIIs and FGDs. The interview guide was then translated to the Kiswahili language and translated back to English to verify face-validity of the questions. Data collection was done during the months of December 2017 and May 2018. FGDs were conducted in a quiet location and privacy was ensured to enable discussants to freely express their opinions. In the community setting, the FGDs were conducted for women and men separately and with no facility-based health providers in the groups. The health provider discussions were conducted with a mixture of health providers and allied health staff recruited from rural health facilities in study sites. The facility-based, health provider data collection included both KIIs and FGDs with antenatal care clinic nurses, midwives, social workers, and district nursing officers (DNO). Besides taking field notes during the KIIs and FGDs, all interviews and FGD sessions were audio taped. The interviews took approximately 45 minutes to one hour and the FGD sessions took about one and a half hours on average.

The KIIs and the FGDs were conducted by skilled moderators who had training and experience in leading FGDs in similar contexts in rural Tanzania. The female team member of investigators and a female research assistant conducted the FGDs for women and a male team member of investigators and a male research assistant conducted the FGDs for men.

Data analysis

Tape-recorded data were transcribed in Kiswahili and then transcribed to English for any outstanding questions, clarifications and confirmation of findings from the initial transcription and coding phases were discussed among the research team (SC, AL, AE) until consensus was reached. Thematic analysis based on initial inductive and deductive coding was used to identify emergent themes and triangulate¹¹ the information collected, and this was facilitated by NVivo for Mac v11.4.0

Table 2: Provides a description of the participants that were recruited from the health facilities in the study areas

Focus Group Discussion and Key Informant Interview Participants (Health Facility Based)					
Title	Location	No. Interviewed	Median Age	No. Females	No. Males
ANC Nurse	Geita	2	30	1	1
Community Health Worker	Singida	1	32	1	0
	Geita	2	33	-	2
	Singida	2	37	1	1
District Nursing Officer	Geita	0	-	-	-
	Singida	1	50	1	-

Table 3: Provides a description of the participants that were recruited from the communities in the study areas

Focus Group Discussion and Key Informant Interview Participants (Community Based)					
Title	Location	No. Interviewed	Median Age	No. Females	No. Males
Unmarried Women	Geita	6	24	6	-
Married Women	Singida	7	23	7	-
	Geita	7	27	7	-
	Singida	7	31	7	-
Men (Single and Married)	Geita	8	38	-	8
	Singida	6	36	-	6
Traditional Healer	Geita	1	42	-	1
	Singida	0	-	-	-
Traditional Birth Attendant	Geita	1	38	1	-
	Singida	1	37	1	-

(QSR International, Melbourne, Australia). This analytic approach allowed for establishing links between research objectives and findings from raw data and developed deeper understanding of the underlying experiences and processes evident in emergent themes. Data coding continued until theoretical saturation was reached and no new concepts were emerging from the data¹². The completed code structure was applied to develop and report themes and reach consensus among the research team. All themes and sub-themes identified in the coding were collated into a thematic chart organized in line with Attride-Stirling's thematic network analysis framework¹³. Verbatim quotations from the transcripts were frequently used to illustrate the responses of the respondents on important issues and sub themes.

Results

A total of 15 FGD sessions were conducted and 12 KIIs. Three themes emerged in the analysis regarding pre-eclampsia and eclampsia. These were:

1. Insufficient knowledge regarding signs and symptoms and risks associated with pre-eclampsia and eclampsia.

2. Misconceptions regarding the causes of pre-eclampsia and eclampsia due to individual or community-based beliefs and attitudes
3. Variable patterns of health-seeking behavior among pregnant women who have signs and symptoms of pre-eclampsia and eclampsia due to lack of knowledge, beliefs or other factors.

There were a number of sub-themes that emerged from the analyses and these are described further and discussed below.

Theme 1: Insufficient knowledge regarding signs and symptoms and risks associated with pre-eclampsia and eclampsia

Overall, knowledge of maternal health among community members in the rural areas studied was insufficient. The amount of knowledge surrounding the severe conditions of pre-eclampsia and eclampsia was no exception. In many of the FGDs,

members of the community attributed this lack of knowledge to a lack of education regarding maternal conditions that put pregnant women at risk. Subthemes that emerged under this theme

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were the distinction between the clinical presentation of pre-eclampsia versus eclampsia and the associated risk and knowledge of the diagnosis and management of this obstetrical complication.

“You know it's hard to talk about something you don't know, it's hard to say because the high percentages here, I say 95% of us living here don't know about eclampsia. When someone knows what the problem is, they can explain it.” (Man)

While knowledge about pre-eclampsia and eclampsia was insufficient, participants from the community-based FGDs were aware of the existence of pre-eclampsia and eclampsia and had some relevant knowledge related to its clinical presentation but not that it was necessarily associated with high blood pressure or that pre-eclampsia was a condition of pregnancy that could lead to eclampsia. Headache, lower leg edema and generalized edema were the most consistent presenting symptoms that the community associated with pre-eclampsia. One married woman who experienced body swelling said:

“My legs were swollen, and I couldn't even put my shoes on, but I gave birth safely. Now if you get swollen feet, people are worried, they say you must go to the hospital.”

Another offered a similar explanation:

“I know what eclampsia is like. You swell, your legs and all your body swell, and your heart rate goes up, and it causes eclampsia.” (Married Woman)

A few community participants demonstrated their knowledge of the woman with pre-eclampsia/eclampsia being hypertensive, however this was infrequent.

“A person with eclampsia if she is pregnant, she swells all over her body, and her blood pressure rises, and then the disease comes back when she is in labor pain.” (Unmarried Woman)

A male participant also discussed how he had never heard of eclampsia, but he did recall attending a funeral of a woman with similar signs and symptoms that could have been eclampsia:

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“I really have never heard of eclampsia. And I have never seen a person with eclampsia in this area, and even if they have been found it is very rare. There was a time I attended a funeral at Geita town, one pregnant woman fell, so may I ask was that eclampsia or was high blood pressure or what is it perhaps? Since she was pregnant?”

a) Distinction between pre-eclampsia and eclampsia and the associated risks

In the FGDs, the distinction between preeclampsia and eclampsia emerged as a prominent sub-theme. Members of the community demonstrated a clear understanding of pre-eclampsia being a condition of pregnancy that can lead to eclampsia, and they associated eclampsia with loss of consciousness, fainting, convulsions, seizures and what is perceived as epilepsy during pregnancy. Furthermore, some members of the community clearly and accurately recognized the severity of eclampsia and were aware that it is a cause of maternal deaths. One man in a male FGD said:

“As I mentioned earlier, in this society when a woman gives birth and has lost consciousness, there are very few who will receive the knowledge that she has eclampsia. Now she will be wondering what was the cause of eclampsia. As far as I understand it comes from a pregnant woman giving birth and losing consciousness.” (Man)

And another male FGD participant said:

“For what I know, eclampsia is when a woman gives birth and then loses consciousness, that is what I know, maybe if there is another point.”

b) Knowledge regarding diagnosis and management of pre-eclampsia and eclampsia

Nurses in the health facilities were knowledgeable regarding the requirement for measuring blood pressure and testing for the presence of protein in the urine during antenatal care to detect pre-eclampsia, however the lack of resources and inadequate services at the antenatal clinics were a barrier to the detection of pre-eclampsia.

“[in response to “Do you measure blood pressure?”]Yes, we do. That of going to the lab is a cycle, because the lab is serving the out-patient

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department cases also. so, when she goes (the pregnant woman), she has to start over (in the line), she has to collect the card again and sit in the queue. So, a pregnant woman spends most of her time waiting for service, if she comes in one hour, she can leave the clinic after five or more hours. But if all things are done there within the ANC clinic it would be much better” (ANC Nurse)

Although the intrapartum management in stabilizing pre-eclampsia and eclampsia in a pregnant woman was never explicitly stated by healthcare providers, they appeared to be aware that the definitive treatment in preventing disease progression is the delivery of the fetus.

“Many of them come in already fit (seizing), like someone has come here recently has fits (seizures), but fortunately we gave her management and pushed the baby (out), right now she is doing well.” (ANC Nurse)

One female participant also alluded to the idea that health providers may not recognize signs and symptoms of eclampsia when women present to health facilities:

“The woman who got the madness was scratching herself and hurting herself a lot. Until she reached the point of death the nurses did not take any action.” (Married Woman)

Other than healthcare providers, members of the community did not demonstrate a complete understanding of the diagnosis or management of pre-eclampsia/eclampsia.

“I don’t know it well, I heard they say a person has eclampsia, why do they say they have eclampsia? she is in agony, after giving birth she fainted, but it is caused by what I do not know, and her treatment really I do not know.” (Married Woman)

Traditional healers did not demonstrate a deep understanding of eclampsia, but they did recognize that it is different from epilepsy. One traditional healer stated:

“Ah, it must be different [from treating a man or woman with epilepsy], this one has another creature in the womb, now if you insist on treating her you can even harm the organism that is in the womb.”

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Another traditional healer also stated:

“Now this problem of eclampsia in the community, since the community has not had any alternative education, they assume that this person is suffering from a normal epilepsy. This one is suffering from epilepsy, they don't know the difference between eclampsia and epilepsy, they assume, this one already has epilepsy, and it ends there.”

Theme 2: Misconceptions regarding the causes of pre-eclampsia and eclampsia due to individual or community-based beliefs and attitudes

This theme also had several sub-themes that strongly emerged which further delineated the topic areas where misconceptions were evident. These sub-themes were: 1) Individual and community-based misconceptions and cultural beliefs regarding the causes of pre-eclampsia and eclampsia and 2) Stigmatization of pregnant women related to signs and symptoms of pre-eclampsia and eclampsia.

The understanding of pre-eclampsia and eclampsia in rural communities of Tanzania is powered by cultural beliefs and superstitions. The beliefs that the community shares regarding the cause of eclampsia leads to its stigmatization. Members of the community believe that eclampsia is caused by a supernatural force that makes a pregnant woman “crazy” and therefore eclampsia is stigmatized as “craziness”, and not recognized as a life-threatening medical condition of pregnancy.

[In response to the question-Have you heard of the eclampsia?] “Yes, it's craziness” (Married Woman)

a) Individual and community-based misconceptions and cultural beliefs regarding the causes of pre-eclampsia and eclampsia

The majority of the community was either unaware of the cause of preeclampsia/eclampsia or believed that it is due to supernatural powers, such as witchcraft. They attributed their symptoms to evil worms and rather than a dangerous medical condition. Due to this belief, women with eclampsia were sent to traditional healers instead of receiving appropriate medical care.

“They [pregnant women] know it is witchcraft, because eclampsia symptoms are that a person feels

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like the face is swollen, the legs are swollen, maybe the head is aching, they themselves know it is worms. In Swahili they call (it) safura, like evil worms, so they do not care that it is a dangerous symptom. Now they give them traditional medicines so that her feet shrink, by the end of the day they come here on that stage, she has gotten fit. They said our sister is bewitched." (ANC Nurse)

A number of participants related the signs of eclampsia, presumably seizures to the belief in the community that a woman who develops this complication could be 'bewitched' which in Tanzanian culture typically refers to her having had some form of voodoo, black magic or 'jujuu' placed on her and may be related to punishment for something she has done. There was also the belief that a woman who is perceived as 'bewitched' would be taken to a traditional healer instead of a hospital because traditional healers can perform practices that can remove the bad elements that are bewitching the woman.

"They say she is bewitched. If there is someone who knows eclampsia, they should take her to a hospital. Some of the uninitiated will take her to a traditional healer, or they will begin to pour water on her there. For many ignorant people will believe that it is a superstitious force, because they will know that a person who was not sick has become like this again, they will begin to accuse only of superstitious things." (Unmarried Woman)

Some people in the community were aware that eclampsia is a medical condition of pregnancy and has a medical cause. However, in the FGDs, incorrect medical conditions such as anemia, were stated as a cause instead.

"Because of lack of knowledge, some might base the issue of superstition, those who are educated might say this woman has anemia and maybe the pregnancy is the cause of epilepsy." (Man)

Although some members of the community were aware of the potential danger associated with excessive edema or its association with pre-eclampsia and eclampsia, others attributed the cause of edema to superstitious beliefs or inaccurate medical causes.

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[In response to the question: "What does society say about a pregnant woman's swollen feet?"] Some find that they are too lazy to exercise regularly. Some think that it is an illness or that she is bewitched." (Unmarried Woman)

b) Stigmatization of pregnant women related to signs and symptoms of pre-eclampsia and eclampsia

The stigmatization of pre-eclampsia and eclampsia is intrinsically related to the community beliefs of its cause. Eclampsia is known as a demonic disease and is associated with witchcraft, evil worms, and madness. Women with this disease are stigmatized and society refers to them as lunatics and mentally retarded. Some people even believe eclampsia to be infectious and avoid contact with affected women.

"We sat down with pregnant women and talked about it, and asked them how they understood eclampsia, they thought it was a demonic disease. Until you properly educate them, they understand you, but most of them when they get eclampsia they go to traditional healers, that's why they are delayed in getting the dose. Pregnant women here while they see legs swelling, the danger signs, which are eclampsia symptoms, they feel like they are demons." (ANC Nurse)

One community health worker also brought forward the idea that some community members will stay away from a woman who has clinical signs of pre-eclampsia or eclampsia [swelling or seizures] because they fear that her condition is contagious:

"When a person gets that problem there are some who are very scared, some people even won't get near her they believe they will get infected."

Similarly, another participant also described the signs and symptoms of a seizure caused by eclampsia as if the pregnant woman was developmentally challenged or had a mental health disorder:

"I know eclampsia. When a pregnant woman is like a certain lunatic, she is like she doesn't understand she is mentally retarded. She is blowing bubbles in her mouth, losing consciousness. And if you ask her

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if she fell, she doesn't know what happened.”
(Unmarried Woman)

Theme 3: Variable patterns of health-seeking behavior among pregnant women who have signs and symptoms of pre-eclampsia and eclampsia due to lack of knowledge, beliefs or other factors

The health-seeking behavior of pre-eclampsia and eclampsia is divided in the community. Healthcare providers recognize the severity of eclampsia and the need for medical treatment. However, in general, members of the community believe in traditional medicine as a treatment for pre-eclampsia and eclampsia.

“They rush to the traditional healers because they think they have been bewitched. And we work hard to advise them to go to a health centers for care, and if we see someone go to a local healer, we visit her to advise her and go to the health center for tests.” (CHW)

Two strong sub-themes in relation to this theme were evident through the analysis of the data. These were related to health seeking behavior and were focused on a. Recognition (or lack thereof) of the need for urgent obstetrical medical care and b. Seeking care from traditional healers.

a) Recognition of the need for urgent obstetrical medical care

Despite the community's cultural beliefs surrounding the cause of eclampsia and its stigmatization, healthcare providers are wary that this obstetrical complication requires immediate attention, with skilled medical care at hospitals and referral to physicians. Traditional healers also recognize that eclampsia needs special medical attention, and that traditional medicine does not help this condition.

“Another [common disease of pregnant women] is eclampsia, but this is occurring in the ward, because when we first find out at the antenatal clinic, we referred them to doctors to be admitted.”
(ANC Nurse)

One traditional birth attendant implied that there are no 'traditional' forms of healing for pre-eclampsia or eclampsia and that the pregnant woman needs to

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be taken to hospital even if she cannot afford the health care expenses.

[Answer to the question-For those who suffer from eclampsia and cannot afford medical costs, what alternatives are they using to get treatment?]
“There is no other treatment, if it happens a person is very sick and taken to hospital immediately, if she is helped or failed.”

A traditional healer also stated that there are no natural remedies for pre-eclampsia or eclampsia and that if they saw a woman in this condition they would encourage her to seek health care:

“About the side of natural remedies there we still haven't reached that treatment, because when they come in such a way, we push them to go for health care. The reason we have not had the knowledge to say that if you see her this way, she needs this treatment.”

b) Seeking care from traditional healers

Although the data as presented in the sub-theme above do support that community healthcare providers such as traditional birth attendants and traditional healers are aware of the severity of the disease and the necessity of seeking proper medical care, health facility-based health providers shared their belief that women continue to seek help from traditional healers during pregnancy. They believed that this leads to the delayed treatment of pre-eclampsia and its progression to eclampsia.

“Now they give them traditional medicines so that her feet shrink, by the end of the day they come here at the stage where she has gotten fits (seizures).” (ANC Nurse)

Similarly, a district nursing officer also stated that health care is delayed for women with pre-eclampsia and eclampsia when they seek care from traditional healers:

“She is taken to a traditional healer, the healer tells her it is only swollen feet and will help you, but it is later that she has a seizure and is unable to find the car they bring to the hospital too late.”

The belief that delays in care were occurring due to lack of community-level knowledge regarding eclampsia was also shared by a community health worker:

“In a society many are unaware, have no understanding of eclampsia, and when the community is exposed to such problems, they usually refer them to traditional healers. Because they say this is not treatable at the hospital, which is a misconception.”.

Discussion

Pre-eclampsia is a leading cause of maternal mortality in developing countries and in sub-Saharan Africa, hypertensive disorders of pregnancy account for 16% of maternal deaths^{14,15}. To understand the high prevalence and case-fatality of this obstetrical complication, it is critical to understand community and healthcare provider perspectives of this condition. The aim of this study was to explore and better understand the knowledge, attitudes, beliefs and practices regarding pre-eclampsia and eclampsia among healthcare providers and women and men living in rural communities in Tanzania. Our results demonstrate that there is a lack of knowledge related to the presentation, as well as the diagnosis and management of pre-eclampsia and eclampsia in these communities. Furthermore, our data also suggests that cultural beliefs, misconceptions, and stigmatization may be a factor that is driving the high rate of undetected and untreated cases of pre-eclampsia and eclampsia in rural Tanzania.

Knowledge of the signs and symptoms of the community and healthcare providers was consistent but limited. Common signs and symptoms of pre-eclampsia, other than those required for the establishment of the diagnosis, include headache, visual disturbances, right upper quadrant or epigastric pain and edema¹⁶⁻¹⁹(3-6). Out of these symptoms, only edema and headache were reported in the FGDs. Loss of consciousness and fainting were also consistently reported, however the link with these signs being a manifestation of a seizure was often not apparent. In many FGDs, it was noted that death could occur in severe and untreated cases. This highlighted that there was some knowledge that the condition is severe and could be associated with a poor outcome for the pregnant woman. Although edema is a common sign of both pregnancy and pre-eclampsia, it is often associated with cultural taboos and superstitions. Society believes that lower leg edema is due to the woman being pregnant with twins, malnutrition, laziness and bewitchment of the

pregnant woman. The limited knowledge of women and other members of their communities to the presentation of pre-eclampsia in our study is similar to that of other countries in Africa. In a cross-sectional study performed in Ghana, the prevalence of inadequate knowledge of pre-eclampsia among pregnant women was 88.6 percent. In the same study, nearly half of pregnant women were not aware of the severity of the disease²⁰. In a study performed in Makole Ward, Tanzania to assess knowledge levels of women with respect to pre-eclampsia, the sub-topic of signs and symptoms were the least well known⁷. In Mozambique, the community were aware of similar warning signs as in our study such as headache, weakness, dizziness, fainting and swollen feet²¹.

In the FGDs, knowledge of the diagnosis of pre-eclampsia is never explicitly stated. Pre-eclampsia is diagnosed by gestational hypertension accompanied by proteinuria and/or maternal organ dysfunction^{16,18}. A few members of the community were aware of the association with hypertension, but it was not common knowledge. Several healthcare providers stated that urine dipstick and blood pressure measurement during antenatal care is a challenge because it is time-consuming for the pregnant women to go from the clinic to wait again at the health facility laboratory to have the urine dipstick test completed.

With regards to the management of pre-eclampsia and eclampsia, healthcare providers are aware that its severity necessitates treatment at a hospital, medical referral and delivery of the fetus. However, within the community, some people believe that women with eclampsia need to go to the hospital immediately, while others believe that women need to go to traditional healers first.

A qualitative study in rural India demonstrated that most people resort to traditional home remedies, such as providing the smell of onion, placing an iron object in the hands or squeezing the fingers and toes, to treat eclampsia prior to accessing a health center²². Similarly, in Nigeria, traditional home remedies are used for seizures²³. A study in Mozambique that assessed community health worker knowledge and management of pre-eclampsia demonstrated that most CHWs immediately refer women with eclampsia and that the vast majority could neither measure blood pressure nor proteinuria²⁴. A study in the Democratic Republic of Congo also

demonstrated poor knowledge of the prevention and management of pre-eclampsia of healthcare providers²⁵.

In the community, the cause of pre-eclampsia is either unknown or attributed to non-medical or supernatural forces such as witchcraft, magic, or evil worms. Knowledge of the existence of eclampsia and association with pregnancy in the FGDs varied, however one member of the community stated “[...], I say 95% of us living here we don't know about eclampsia”, indicating that overall, most people are unaware of what eclampsia is. Even among CHWs the cause is not clear; although they understand that it's cause is medical, in one of the focused groups they attributed it to anemia and not hypertension. Many studies that identified community beliefs of causes of pre-eclampsia in low-income countries also demonstrated misconceptions of the causes of eclampsia. In a qualitative study on health worker knowledge and practice to pre-eclampsia in Nigeria, it was demonstrated that the most consistently stated cause of pre-eclampsia by participants was psychological with the majority pointing to depressive thoughts due to marital conflict or financial worries, while eclampsia is due to prolonged exposure from the cold²⁶. The beliefs of the cause of pre-eclampsia and eclampsia in the community are what lead to its stigmatization. Eclampsia is referred to as “craziness”, “madness caused by pregnancy”, and “demonic disease”. In one FGD, it is mentioned that “When a person gets that problem there are some who are very scared, some people even won't get near her they believe they will get infected”. Since members of the community see a woman with eclampsia as “bewitched” and not affected by a dangerous medical condition, women are sent to traditional healers. In the previous study we cited from Dodoma, Tanzania where traditional beliefs are held by some but not most of the population, half of the participants believed that evil spirits and exposure to fire were causative agents for pre-eclampsia⁷.

A strength of this study is its exploratory and qualitative nature. The participants of the FGDs were made aware that their inputs were completely confidential, and that no identifying information would be recorded. The researchers conducting the FGDs and KIIs were experienced and well trained

and understood the exploratory purpose of the research so that they could allow for exploration of new information and concepts brought forth by the participants. Furthermore, interview questions were initially open ended and then redirected at times to gain more understanding of certain themes. These conditions allowed for free expression of the participants. In addition, the FGDs were separated by gender and by community and facilities to allow for more interactive discussion and avoid hierarchies by education, age, marriage and gender. Another strength of this study is the systematic way that themes were identified. All FGDs were qualitatively coded by three people using NVivo 12.0 software. Discussions had to reach a consensus on the most important themes and subthemes to include in the research manuscript. This process ensured maximal accuracy and reliability of our results, providing our study with optimal internal validity. One of the limitations of our study is that the questions asked in the FGDs did not go in depth as to the knowledge of the management of pre-eclampsia and eclampsia, which includes antihypertensives and magnesium sulfate for seizure prophylaxis^{16,17,19}. Although healthcare providers demonstrated their knowledge of the severity of this condition and the need to go to the hospital for treatment and the need for medical referral, they did not express knowledge on how to stabilize this condition, other than delivery of the baby. Another limitation of our study is that we obtained qualitative data from rural communities and health facilities in four largely rural districts of Tanzania. Therefore, it is unclear if these results can be generalized to the country as a whole, or even to other low-income countries.

Ethical considerations

Ethical clearance was obtained from Institutional Review Boards of Ifakara Health Institute, Queen's University and the National Institute for Medical Research in Tanzania (NIMR) Institutional Review Board. Consent at the community and individual levels was obtained in both verbal and written formats. Each participant was given a copy of the transcriptions. Information regarding age, sex, marital and occupational status was collected by the research assistant, and remained with the data.

Conclusion

In conclusion, our study demonstrates that there is a wide gap between the medical knowledge of pre-eclampsia and eclampsia between the community and healthcare providers in rural communities of Tanzania. The cultural beliefs and attitudes toward this obstetrical complication in the communities of Tanzania has led to its stigmatization. Consequently, the severe nature of pre-eclampsia remains undetected and/or untreated and progresses to eclampsia. Understanding the discrepancies in knowledge of pre-eclampsia and eclampsia is a stepping stone in decreasing the maternal morbidity and mortality of this condition, which is highly prevalent in sub-Saharan Africa²⁷. Future research should aim to explore community-based interventions to promote and establish evidence-based and optimal knowledge among women, their partners and within community health leadership structures. In addition, this study highlights that further research is needed on interventions and education programs to increase evidence-based knowledge and obstetrical emergency management skills among frontline health providers to better identify and provide optimal management and safety for women with pre-eclampsia and eclampsia in low-resource countries and health systems such as Tanzania.

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