

Barriers to Receiving the Recommended Standard Care During Pregnancy by Illiterate Women in Rural, Northern Tanzania

Dismas Matovelo

Catholic University of Health and Allied Sciences

Pendo Ndaki

Catholic University of Health and Allied Sciences

Victoria Yohani

Catholic University of Health and Allied Sciences

Rose Laisser

Catholic University of Health and Allied Sciences

Respicious Bakalemwa

Catholic University of Health and Allied Sciences

Edgar Ndaboine

Catholic University of Health and Allied Sciences

Zabron Masatu

District Medical Officer, Misungwi District

Magdalena Mwaikambo

Care International

Jennifer L. Brenner

University of Calgary Cumming School of Medicine

Warren M. Wilson (✉ wwilson@ucalgary.ca)

University of Calgary <https://orcid.org/0000-0002-0057-6873>

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Abstract

Background: In 2017, an estimated 540 women in Sub-Saharan Africa died every day from preventable causes related to pregnancy and childbirth. To stem this public-health crisis, the WHO recommends a maternal and neonatal health continuity of patient care, yet most women do not meet this recommendation. Surveys suggest that illiteracy limits uptake of the proposed maternal-newborn package, yet little is known about the association between illiteracy and healthcare seeking, particularly in rural regions of low-income countries. This knowledge gap compromises the ability of public health experts and healthcare providers to provide culturally relevant policy and practice. To begin to address this gap this study explores the experiences related to care-seeking by illiterate, pregnant women in rural Tanzania.

Methods: A qualitative study was conducted in four communities encompassing eight focus group discussions with 81 illiterate women, 13 interviews with illiterate women of reproductive age and seven interviews with members of these communities perceived to have some influence on women's decisions concerning perinatal care services. Themes were coded and their relative importance determined using frequency reports and cross-tabulations.

Findings: Three key themes emerged, illiterate women (1) could not read their healthcare cards or public health messaging; (2) spoke the local language, not Swahili, the language used by healthcare providers, and (3) have endeavored to develop coping strategies to overcome these obstacles. In addition, health service providers are often unaware of who is illiterate.

Recommendations: More health needs of this group could be met, in the short term, by developing a protocol for health service providers to determine who is illiterate, providing translation services for those unable to speak Swahili, and graphic public health messaging that does not require literacy. In the long term, this barrier may be addressed by ensuring that all Tanzanians receive a high-quality, formal education, supporting community health workers, and recruiting healthcare providers from rural areas. A failure of to address the needs of this at-risk group will likely mean that they will continue to experience barriers to achieving the recommended continuity of patient care with detrimental health outcomes for both mothers and newborns.

Background

Globally, the maternal mortality ratio (MMR) dropped 38% between 2000 and 2017. However, maternal deaths still occur too frequently. In 2017, 810 women died every day from pregnancy- or childbirth-related complications; 94% of these deaths occurred in low and lower middle-income countries (LMICs) (1), most commonly in rural areas (2). Sub-Saharan Africa (SSA) has the highest regional MMR at 546/100,000, which is three times higher than the next highest region, South Asia (182/100,000). In 2015, Tanzania's MMR (398/100,000) was the 27th highest among the 46 SSA countries (3). Moreover, adult lifetime risk of maternal death of 1 in 36 in SSA contrasts markedly with 1 in 3300 in high-income countries (3).

Common causes of maternal death in SSA include pre-existing disorders (e.g. HIV, anemia, or malaria) exacerbated by pregnancy (28.6%), haemorrhage (24.5%), hypertension (16.0%), sepsis (10.3%), abortion (9.6%), other direct causes (9.0%), and embolism (2.1%) (4). A pregnant woman is not the only life at risk; globally, in 2015, 2.6 million babies were stillborn (5) and in 2017, 2.6 million children died in their first month of life, of which roughly 2 million (77%) died within the first six days of life (6), most commonly in least developed countries (7). In 2018, Tanzania's neonatal mortality rate (NMR) was 21.1, in comparison to high-income countries where the rate averages three (7). Disparities between least-developed and high-income countries in MMR, adult lifetime risk of maternal death, and NMR rates suggest that many more pregnancy-deaths in least-developed countries could be prevented.

Key to improving maternal and neonatal health, a globally recognized continuity of patient care is recommended. This includes a series of antenatal care (ANC) visits (5), delivery at a health facility by a skilled birth attendant, and postnatal care provided to both a mother her infant (8). ANC enables early screening and recognition of problems and co-morbidities, prevention of complications, micronutrient supplementation, and, crucially, an opportunity to communicate with and support women during a critical period (5, 9, 10). In Tanzania, a woman who attends ANC is twice as likely to deliver in a health facility than a woman with no ANC visits (11). Delivery in a health facility, in turn, reduces stillbirths and deaths from intrapartum-related complications by about 20% (12). Despite recognized, impactful interventions, only about half of pregnant women globally receive even four ANC visits (9). Similarly, in Misungwi District, Tanzania only 47% of mothers surveyed in 2016 had attended four or more ANC visits (13) with their last pregnancy and 61% delivered at a health facility (11).

Variables influencing whether pregnant women receive recommended maternal health interventions have been explored in several studies. In both India (14, 15) and SSA (16–18), researchers identified illiteracy (defined as not knowing how to read or write) as an important risk factor for failure to attend ANC and higher maternal mortality. This is consistent with general linkages between low literacy and worse health outcomes (19) and lower utilization of health services by illiterate women (20). Some studies have identified lower care-seeking due to the stigma associated with illiteracy: some illiterate individuals were hesitant to disclose their illiteracy to healthcare workers, compromising provider support for such individuals (21–23). Studies elsewhere have documented a positive correlation between level of maternal formal education and perinatal healthcare seeking behaviour (11, 24–28).

Relatedly, a 2016 survey in Tanzania's Misungwi District, Tanzania (13) documented that 35% of sampled mothers women were illiterate, versus 26.91% for Tanzanian women overall (29). Amongst illiterate mothers, 41% reported four or more ANC visits and 56% had births attended by a skilled birth attendant, whereas 49% of literate mothers had at least four ANC visits and 67% had births attended by a skilled birth attendant. In the Misungwi District, the association between illiteracy and having fewer than four ANC visits was significant ($2 \times 2 \chi^2$, $p = 0.02$) and, in comparison to the level of formal education received, number of children, and maternal age, illiteracy was the strongest predictor of having fewer than four ANC visits. Likewise, illiteracy in Misungwi District was significantly associated with not having births

attended by a skilled birth attendant (SBA) ($2 \times 2 \chi^2$, $p = 0.0008$) and was the third strongest predictor after number of children and level of formal education received (13).

Hence, illiteracy is a well-established barrier to receiving the recommended antenatal, delivery and postnatal care, yet there is little documented about the lived experiences of illiterate pregnant women and mothers with newborns. Indeed, only one paper (23) providing qualitative data on this topic was found and none were found for rural regions or for LMICs. This is concerning since effective public health policy should be informed by local context (30–32). What is it, for example, that renders illiteracy a risk factor for not receiving the recommended standard care during pregnancy, delivery, and post-delivery? In addition to missing data on lived experiences of illiterate women, specific obstacles to meeting recommended standards of perinatal care are sorely lacking for rural regions of LMICs. This study, consequently, was designed to begin to address this knowledge gap by using qualitative methods to capture the lived experiences related to care-seeking by illiterate pregnant women and mothers in a rural region of an LMIC. It is hoped that this work will inform both health policy and healthcare providers in such regions.

Methods

Study area

This research was conducted in Misungwi District located in Mwanza Region of Tanzania's Lake Zone (Figure 1). Misungwi District is rural, located 45 km from Mwanza city and at last census (2012) had a population of 351,607 (33). Administratively, the district is sub-divided into 4 divisions, 20 wards, and 78 villages. In 2019, 91% of households in Misungwi District were ethnically Sukuma (13). The Sukuma are a patrilineal society in which women are expected to take care of their husbands and children (34). Those individuals included in this study were low-income, living in villages scattered throughout flatland terrain, and subsisting via the cultivation of maize, millet, rice, sweet potatoes and vegetables, cattle grazing on communal lands, and fishing. Most households surveyed in 2019 reported using firewood (83%) or charcoal (14%) for cooking fuel (83%) (13). Sixty-eight percent of households owned livestock and 62% owned agricultural land (13). Thirteen percent of households were connected to electricity, 80% had mobile phones, 57% owned a bicycle, and about 10% owned a mechanized form of transport (13). Piped water, and advanced sanitation facilities are not common. Each of the four villages considered in this study had a primary school and attendance in primary school in Tanzania is compulsory. However, in Tanzania, there exists a lack of a quality, formal education, especially in rural, poor regions where the long distances to schools and insufficiently qualified and motivated teachers, a lack of teaching materials, textbooks and basic technology, and required financial "contributions" (35) are disincentives for some students (36,37). Moreover, Tanzanian girls are more likely to drop out of school than are boys due to their caretaking responsibilities (38). In 2019, Misungwi District had 48 formal health facilities providing delivery services. The district, along with others in the Lake Zone, has amongst the worst maternal, newborn, and child health indicators in the country (11), and is prioritized by government for maternal newborn health programming.

Insert Figure 1 here.

Study sample

The study used Criterion-i (39), purposive sampling (40) to identify two rural divisions in Misungwi District and to select study participants who were knowledgeable or experienced with the phenomena under study (41): barriers to receiving Tanzania's recommended antenatal, delivery and postnatal care services (42). Villages were selected for inclusion by first ranking the four Misungwi District divisions surveyed in 2016 (13) on the basis of accessing antenatal, delivery and postnatal care services, then selecting the two divisions, Mbarika and Inolelwa, with the lowest overall rates of accessing care. Within Mbarika and Inolelwa, cluster randomization (43) was used to identify four wards for study and within each ward, one village was randomly selected, for an overall total of four villages.

A total of 81 illiterate women of reproductive age who were either pregnant or had children and seven influential people, described below, were selected for inclusion in this study. All participants signed informed consent forms, described below. No incentive was provided to the participants, other than refreshments, unless the participant incurred transportation costs to attend the interview(s), in which case transportation costs were refunded.

The illiterate women of reproductive age were recruited by first explaining the purpose and methods of the study to the village leaders and the village-based, volunteer, community health workers (CHWs), then asking them to identify households most likely to have illiterate women of reproductive age. The village leaders and CHWs knew all residents of households in their catchments and had a sense of their literacy status. A second meeting was then held with all members of the village who wished to attend to explain the purpose and methods of the study.

Subsequently, the households of potential illiterate women of reproductive age were visited by field researchers who explained the project. For those pregnant women or mothers of reproductive age who had not completed school beyond the primary level and agreed to continue, literacy was assessed by a standardized protocol (44). Only women who could not read at all were classified as illiterate and eligible to proceed in this study. This process was continued to attain a minimum sample size of 20 illiterate women of reproductive age in each village.

Those perceived to have some influence on women's decisions concerning antenatal, delivery and postnatal care services were also invited to participate, in order to triangulate experiences of the illiterate women of reproductive age (45). These included opportunistically recruited CHWs and other healthcare providers in each of the four villages. CHWs were community members who were selected by their communities, trained using a national curriculum, and expected to voluntarily provide health promotion education and support emergency referral care (e.g. if a CHW identifies an at-risk mother needing health care, the CHW would 'refer' the mother to a health facility) to households in their community, especially to pregnant and newly delivered women. Healthcare providers selected for interviews included nurses and clinical officers providing antenatal, delivery and postnatal services at health facilities. Potential

participants were excluded if they had not been active in their roles in the community for at least the prior six months. A total of two influential individuals were sought in each village. The field researchers met this goal in three of the four villages but was able to recruit only one influential individual in one of the villages.

Data Collection

Data were collected July-September, inclusive, 2018, in focus group discussions (FGD), in-depth interview (IDI) or key-informant interviews (KIIs). Semi-structured facilitator guides were used to maintain consistency across FGDs, IDIs, and KIIs (46). To ensure guiding questions resonated with participants, the facilitator guides were piloted twice in two other, similar villages in the Mbarika and Inolelwa divisions. Questions and probes were refined after the pilots to better reflect the context of the region (47).

The morning after women were selected and confirmed, FGDs were held with illiterate women of reproductive age to gain an understanding of factors influencing the antenatal, delivery and postnatal care-seeking practices of this group (48,49). FGDs were held in a community space chosen by the illiterate women of reproductive age. In FGDs, field researchers took a peripheral role to facilitate a group discussion between participants.

Later that day, IDIs were held with individual, illiterate women and KIIs were held with the CHWs and healthcare providers. In IDIs and KIIs, interviewers engaged in a probing conversation with the interviewee (50,51). Individual IDIs were held with illiterate women of reproductive age to explore topics mentioned in the FGDs in more depth. The illiterate women who participated in the IDIs were selected at random from those who participated in the FGDs. KIIs were held with CHWs and healthcare providers as they generally have a good sense of the needs and practices of pregnant women and those with newborns. IDIs and KIIs were conducted in a private location.

FGDs, KIIs, and IDIs were conducted in the local vernacular, Sukuma. Field researchers, comprised of a moderator, note-taker, and an observer, all fluent in Sukuma, facilitated the interviews. FGDs generally lasted 1-2 hours; IDIs and KIIs were 45-60 minutes long and were audio-recorded. Overall, 8 FGDs, two in each village, composed of 8-10 illiterate women of reproductive age each, were conducted with follow-up IDIs completed with 13 (16%) of these women. Seven 'influencer' KIIs were conducted: 3 with CHWs and 4 with healthcare providers.

Data Analysis

Recorded Sukuma interviews in were transcribed and translated directly and verbatim into Swahili as Swahili was the primary language of the Tanzanian researchers. Transcriptions and translations were checked for accuracy by four of the Tanzanian researchers, fluent in Sukuma and Swahili, who did not conduct the original interviews or transcription/translation. Two additional Sukuma speakers conducted Sukuma source transcripts quality checks. Resulting Swahili transcripts were then translated to English by Tanzanian researchers fluent in English and Swahili.

To provide a systematic account of the observed phenomena and transform interviews into a set of cohesive and meaningful categories, data were coded in four steps using NVivo (v. 12) (52) and, in step five, the importance of themes was determined. In step one, four randomly selected transcripts, including one IDI, one KII and two FGDs, were used to develop a coding template. Here, each of these transcripts was coded individually and the final codes subsequently agreed upon. In step two, four additional transcripts were selected at random and new codes were added if they did not fit with the initial codes. Step two resulted in the final codebook for the study. In step three, 18 additional transcripts were coded for a total of 26 (8 FGDs, 11 KIIs and 7 IDIs) of the 28 transcripts were coded after which it was determined that saturation was reached; that is, new themes or sub-themes were unlikely to emerge from analysis of additional transcripts (53). In step four, thematic analysis was used to collapse the codes into basic themes and subthemes (54). In step five, frequency reports were created and cross-tabulations were used to determine the relative importance of themes in the data and their linkages to one another.

Results

The 81 illiterate women of reproductive age had a mean age of 32 ± 11 years, had a mean of 1.7 ± 0.82 children under the age of 5 (Table 1). None of these respondents had any education, all were subsistence farmers engaged in farming small plots of land, and 84% were married. All of these women spoke Sukuma, but none spoke Swahili.

Insert Table 1 here.

Three content-driven themes related to antenatal care, delivery and postnatal care access by illiterate women of reproductive age emerged from the analysis: 1) a communication gap arising from the these women's inability to read public health messaging documents provided by health facilities, 2) a communication gap arising from healthcare providers not speaking Sukuma dialect, and 3) a dependency of illiterate women of reproductive age on family and neighbors to negotiate their illiteracy. Each of these themes was apparent in transcripts from all participant categories.

Communication gap: illiteracy

Participants in this study generally agreed that illiterate individuals had a poor understanding of health matters and poor adherence to health practices due to failure to understand health information, including appointment dates. As well, illiteracy was perceived to it more difficult for healthcare providers to deliver services.

One illiterate woman of reproductive age explained that, "when we arrive at the health facility, we usually see a poster with medical advice. However, we usually do not understand what it says" (FGD). Another stated, "I usually do not know dates written on the card. I just take my baby to the health care facility for an injection. Then, the health care workers ask me to wait at the clinic. If there are no further vaccines, they tell me to go home. I [then] go back the next month" (IDI).

The CHWs were sensitized to the barriers faced by illiterate women, with one stating that “[illiterate] women are told to go back to the clinic within seven days but fail to return. This is probably due to her not knowing to read the information she was given on her card” (KII). Another pointed out that “You have to sit up and investigate. Often, when mothers come to the hospital and are registered, you can not recognize them all and we do not ask whether or not they can read and write. [As such,] it’s hard to know who is illiterate” (KII).

Communication gap: language

The inability of healthcare providers to speak Sukuma compromises their ability to help illiterate women of reproductive age, who speak only Sukuma. Examples of the difficulties arising from this barrier were provided in the many statements by these women. An oft repeated point made by them is illustrated in this statement: “We are unable to understand what the healthcare provider or CHW is telling us when she speaks Swahili as we do not know Swahili” (FGD). Due to this language barrier, most of the illiterate women expressed anxiety about visiting the clinic. Another common theme is manifested in the words of this illiterate woman of reproductive age: “We are afraid of going to the clinic because we are asked questions by the healthcare providers in Swahili, but we do not know Swahili” (FGD).

‘Influencers’ also identified this barrier. One health provider, for example stated that “illiterate women can’t speak Swahili, so are afraid of going to the hospitals since they are not sure if they will find a healthcare worker who can speak Sukuma” (KII). Another healthcare provider noted that “illiterate women are a real challenge in health education, one day I taught them about the improved Community Health Fund that was free for pregnant women and children under one year of age, but there was one woman who did not know how to read and write and did not understand Swahili. When she left the clinic, she went to tell others that...there is no free treatment for children or pregnant women” (KII). Consistent with these comments, a CHW stated that “the language barrier is a challenge for patients. Women fear going to the large, higher level, hospitals. There they are not sure if they will find a healthcare provider who speaks Sukuma, leaving them unable to explain their condition. So, these are things that may lead to challenges for them during delivery. But when they come to us, we speak Sukuma and just help them. ...The patients really like speaking their native language. Even if she can read Swahili, some will not speak Swahili” (KII). Another CHW pointed out that “literate mothers ask a lot of questions so I can assess their understanding, but illiterate mothers just listen and don’t ask many questions, keeping their lack of understanding hidden from me so that they can just finish the appointment and leave” (KII).

Negotiating illiteracy

The illiterate women in this study sought to negotiate their illiteracy via the assistance of literate neighbors or family members who could help them understand the public health messaging concerning appropriate antenatal, delivery and postnatal care and infant development, or remind them of appointment dates. Without such assistance they sometimes would not attend their recommended and scheduled appointments. As well, some illiterate women tried to keep track of dates via codes they developed. These strategies are apparent in the following statements by an illiterate woman: “We do not

know anything until we get home and the information on our healthcare card is read for us. For example, if I have a child who knows how to read, he will help me to read the card" (FGD). Another illiterate woman added that "if there is a neighbor who is going to the clinic on the same date, she reminds me [and] we go together." (FGD). Another illiterate women noted that "when the date to go to the clinic arrives, family members tell me to go, so I go" (IDI) and "I get the assistance of a neighbor or a student at home to read and understand my healthcare card" (IDI). Many of the illiterate women stated the healthcare providers and CHWs endeavored to assist them. For example, an illiterate woman stated that "if you tell the healthcare providers the truth that you do not know how to write, they will know how to help you or they will tell you to find anyone who can help to read the information. If you do not know somebody to help you read the information, the healthcare provider will help you" (FGD).

The coping strategies of illiterate women were evident to the healthcare providers and CHWs. For example, one healthcare provider stated that "because illiterate women can't read their healthcare card, they just rely on their neighbor's date and only go to the clinic when their neighbors go" (K"what we're doing is just telling them the dates of the return and giving them a healthcare card with the date. If she forgets, we tell her to ask someone who knows how to read to remind her of the date when she should return to the clinic. This may be a child in school or a husband" (KII). Other healthcare providers and CHWs described other practices by illiterate women to ensure that they returned to clinic on the proper date. For instance, a healthcare provider stated that "some of the illiterate women fold pieces of fabric on the weekends to keep track of time. There was one woman here who was folding her fabric every Sunday and when the fourth Sunday had passed, she came to the clinic" (KII).

Discussion

Globally, pregnant, illiterate women and illiterate mothers with newborns are less likely to receive the recommended standard care, with detrimental health sequelae. Indeed, in Misungwi District, in comparison to literate women, illiterate women of reproductive age were significantly less likely to have at least four ANC visits or a delivery by a SBA (13). Why illiteracy was so important was unclear, requiring a deeper consideration of the link between these women's perceptions, behaviors, and socio-cultural environment. Toward that end, this study sought to understand the lived experience of illiterate women of reproductive age in rural Tanzania as it pertains to the recommended standard care during pregnancy and delivery.

That said, the emergent themes were consistent across the FGDs, KIIs, and IDIs with the illiterate women, CHWs, and healthcare providers in this study.

Revisiting a question posed in the introduction - what is it that renders illiteracy a risk factor for not receiving the recommended standard care during pregnancy and delivery? - the emergent themes were consistent across the FGDs, KIIs, and IDIs with the illiterate women, CHWs, and healthcare providers in this study. Illiteracy is associated with two obstacles to receiving the recommended standard care and one coping strategy. First, illiterate women cannot understand written information provided to them by

healthcare providers and CHWs. Clearly, this renders these women's ability to recall appointment dates and read public health messaging a challenge. There is no apparent initiative on the part of healthcare providers or CHWs to determine which women are illiterate and illiterate women may be shy about admitting their illiteracy (21). In the words of one CHW, determining who is illiterate is rendered more difficult by the fact that "illiterate mothers just listen and don't ask many questions, keeping their lack of understanding hidden from me so that they can just finish the appointment and leave" (KII). If the CHW and healthcare provider are not aware of who is illiterate, their ability to address this issue is compromised. If they were aware of the patient's ability to read and write, the CHW and healthcare providers did seek to assist the patient. For example, an illiterate woman noted that if you tell the CHW and healthcare provider that you are illiterate, they "will know how to help you or they will tell you to find anyone who can help to read the information" (FGD). Second, exacerbating their inability to read is the fact that the illiterate in this study received no formal education, so did not learn to speak Swahili. Swahili is the second language of most in Tanzania and is mainly learned at school, especially in rural communities. The illiterate women therefore cannot understand those healthcare providers who do not speak their language, Sukuma. This inability to speak the language of those providing them with healthcare likely mars the experiences of illiterate women with their healthcare providers. As noted above, a key benefit of ANC is the opportunity for healthcare providers to communicate with and support women during a critical period (5, 9, 10). For the illiterate women in this study, this benefit is lost. Even if they do receive the minimum standard of care when pregnant and with a newborn, the language barrier suggests that these illiterate women may benefit little beyond the vaccines their newborns receive. Hence, the problem is larger than whether or not the mother can read or write; rather, illiteracy is a marker of ability to speak the language of healthcare providers. Furthermore, this problem may not be limited to illiterate women, as one CHW pointed out that "even if [a patient] can read Swahili, some will not speak Swahili" (KII).

The CHWs speak both Sukuma and Swahili and could translate for the patient. Indeed, CHWs indicated that they speak Sukuma with women from their community as much as possible, with one noting that "if you speak to them in their language, they can express themselves very well" (KII). However, for two reasons, translating the healthcare providers' Swahili for the IWRA may not be feasible: 1) translation would require a longer appointment which may not be possible, and 2) the use of translators it is often limited by key aspects of care such as diagnosis, consent, and confidentiality. As regards confidentiality, a patient who is already embarrassed about her health issue may be less likely to attend the clinic if she knows she will have to share this information with both the healthcare provider and a translator.

These findings are consistent with the robust body of work noted above that finds a strong association between women's formal education and child health, a finding that holds up when controlling for gender inequality, socioeconomic status, and access to healthcare (55, 56). The current study considers the association between the level of formal education and use of healthcare services more deeply. Here, the driver for not receiving the recommended standard care during pregnancy and delivery is not the lack of formal education, generally, but, specifically, is the resulting inability to understand the language of both healthcare providers and public health messaging.

Contrary to several papers on the topic (21–23), the illiterate women did not report feeling stigma about their inability to read or write. Within social groups, stigma is believed to function to reinforce power inequities, maintain social norms and avoidance of disease (57). As regards norms, stigma is argued to be tightly tied to a society's ideas of how things should be (58) and arises when a phenomenon is perceived as a threat to material goods or symbolic goods such as beliefs values or ideology (59). Thirty-eight percent of the women surveyed in Misungwi District are illiterate (13). As illiteracy is not uncommon in these communities and may have little bearing on a woman's productivity as a subsistence farmer, it may not be perceived as a threat to norms and material and symbolic goods so is unlikely to be stigmatized. That said, the fact that the CHWs and healthcare providers stated that illiterate women did not reveal their illiteracy may indicate that these women do feel stigmatized and, as such, were remiss to admit it in the FGDs or KIs. If so, this would very likely be a barrier to healthcare seeking (58).

The agency of these illiterate women is manifest in their efforts to negotiate their illiteracy via assistance from their relatives or neighbors to help them to understand public health messaging and to remind them of appointment dates written in their healthcare card. While these actions may well serve their purpose for some, being illiterate was the most important risk factor for failure to attend at least four ANC visits (13). As above, even if an illiterate woman's coping strategy gets her to her healthcare appointment on the assigned day, if the healthcare provider speaks only Swahili and there is nobody to translate the Swahili into Sukuma, she may receive little benefit from the appointment.

Interestingly, Tanzania's 2015–2016 Demographic Health Survey (DHS) (11), finds that 67.4% of women aged 15–49 in the Lake Zone reported that they have serious problems accessing health care when they need it. In this DHS, women were asked if the problem accessing health care was due to insufficient money for treatment, distance to health facility, not wanting to go alone, and/or failure to obtain permission to go, and replied in the affirmative 52%, 47%, 30%, and 16% of the time, respectively (11). A communication barrier is not noted in the DHS, likely reflecting the fact that these women were not asked if illiteracy or the ability to speak Swahili was a barrier and suggests that those responsible for the DHS may not have anticipated communication barriers.

Strengths and Limitations

Focus groups and interviews carried out with the protection of anonymity uncovered some of the perceptions of the illiterate women, CHWs and healthcare providers. These perceptions, arising from the informants' socio-cultural situation are critical to healthcare-seeking decisions (30–32). A further advantage of these protocols is that they are resource effective, allowing access to a rich volume of data in a relatively short period of time. Moreover, this study was conducted in the language of the informants, then carefully translated by tri-lingual (Sukuma, Swahili, and English) researchers. It is important to keep in mind, however, that this study likely masks a great deal of complexity. This cohort is not a static, isolated group. Rather, they exist and have agency within multidimensional socio-political networks that are not readily apparent in a cross-sectional study. So, while the generalizability of the sample is not clear, the ability of these protocols to tap into spontaneous views is an advantage.

Conclusion

It has been evident for over 40 years that people are rarely rational actors, especially in uncertain situations (60–62). Decisions arise from a complex and dynamic mix of reason and intuition, informed by one's context, biology, and anticipated outcomes (63, 64). As such, a mountain of evidence from public health experts about the benefits of receiving the recommended standard care during pregnancy and delivery may have no impact on behavior if local perspectives are not considered.

The unacceptably high global MMR and NMR rates could be reduced if pregnant women and mothers with newborns met the recommended standard of care, but at least half of mothers in the region where this study was conducted did not receive this standard and a key risk factor for this was illiteracy. Despite the impact of illiteracy on receiving sufficient care, there exists no qualitative research concerning the use of formal healthcare by this at-risk group. Hence, this study sought to understand the lived experiences that shape the decisions of illiterate women concerning the standard of care. The key finding of this work is that, often, these women can neither understand their attending healthcare providers nor can they read the information provided to them by the clinics. Some of these illiterate women have developed coping strategies to overcome these obstacles, but their success appears to be limited. Notably, this barrier to attaining health care was not documented by Tanzania's 2015-16 DHS in its exploration of problems women faced in accessing health care, generally (11).

Given that there are 126 languages in use in Tanzania, it is probably unrealistic to expect healthcare providers to learn the languages of each community they serve. Hence, in the short term, the needs of this at-risk population may be met by providing a protocol for CHWs and healthcare providers to identify those who are illiterate or can't speak Swahili; a CHW or other local individual with training in confidentiality or a cell-phone application to translate for those unable to speak Swahili; and graphic public health messaging in either a printed format on a health provider's smart phone screen that does not require literacy. In the long term, this barrier may be addressed by ensuring that all Tanzanians have access to an education in which they would learn to read, write, and speak Swahili; continuing to support for CHWs; and recruiting healthcare providers from rural areas who both speak the language of the target population and have insight into local culture. A failure to act on these recommendations would likely ensure that rates of MMR and NMR remain high in this region.

Abbreviations

ANC: ante-natal care

CHW: community-health worker

FGD: focus group discussion

IDI: in-depth interview

KII: key-informant interview

LMIC: low-and-middle-income country

MMR: maternal mortality rate

NMR: neonatal mortality ratio

PNC: post-natal care

SBA: skilled birth attendant

Declarations

Consent for publication: Not applicable.

Availability of data and materials: The data used in this study are available from the corresponding author on reasonable request.

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Authors' contributions:

DM was the co-principal investigator the study, led planning, study monitoring and management and was involved in analysis and review and dissemination of key findings. PN co-authored the research proposal and collected and analyzed data, and played key role in manuscript preparation. VY co-authored the research proposal, oversaw the collection and analysis of the data, and played key role in manuscript preparation. RL participated in data collection, data analysis and drafting the initial manuscript. RB, EN, and MM participated the development of the proposal and data collection. ZM participated in the preparation of the research proposal and provided his Misungwi District Health Management team to assist field researchers with data collection. JLB was the co-principal investigator of this study, led the proposal and project development and planning, review and oversight at stages of the study, articulated key messaging, and played key role in manuscript preparation. WMW co-authored the research proposal, guided data collection, and was the primary author of the manuscript. All authors read and approved the final manuscript.

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Tables

Table 1
 Illiterate Women of Reproductive Age Sample
 Demographics

Characteristics	n	%
Mothers' age [†]		
< 20	11	13.6
20–34	31	38.2
≥ 35	39	48.2
Marital status		
Married	68	84.0
Single	3	3.7
In-relationship	5	6.2
Widow	1	1.2
Divorced	4	4.9

Figures



Figure 1

Misungwi District map This map is our own creation. Note: The designations employed and the presentation of the material on this map do not imply the expression of any opinion whatsoever on the part of Research Square concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. This map has been provided by the authors.