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Women's experiences and perceptions on the impacts of maternal near miss and related complications in Rwanda: A qualitative study

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Abstract

Maternal morbidity and mortality continue to emerge across the globe especially in lower-income countries. This study aimed at exploring in-depth perceptions of near-miss experiences among Rwandan women and how these experiences can be used to develop strategies for health policy implementation. Using qualitative inductive research based on grounded theory, we analyzed 27 in-depth interviews that were conducted with women with documented records of maternal near-miss events. Women were knowledgeable about pregnancy complications and the benefits of antenatal care. Near-miss events that occurred either before or during hospitalization. Women recognized their own involvement their near-miss events by delaying care seeking. They also mentioned delays due to healthcare providers delaying transfers, misdiagnosing the events, and delaying to intervene even at the time the diagnosis was made. Women acknowledged the life-saving role of outreach programs and community health workers. We believe that pregnancy outcomes would be improved in this population of women with education on pregnancy complications, training of community health workers, and sustained mentorship program. *(Afr J Reprod Health 2022; 26[5]: 63-71).*

Keywords: Maternal near miss, pregnancy complications, subvention system, perception

Résumé

La morbidité et la mortalité maternelles continuent d'émerger à travers le monde, en particulier dans les pays à faible revenu. Cette étude visait à explorer les perceptions approfondies des expériences de quasi-accident parmi les femmes rwandaises et comment ces expériences peuvent être utilisées pour développer des stratégies de mise en œuvre des politiques de santé. À l'aide d'une recherche inductive qualitative basée sur une théorie ancrée, nous avons analysé 27 entretiens approfondis menés avec des femmes ayant des enregistrements documentés d'événements maternels évités de justesse. Les femmes connaissaient les complications de la grossesse et les avantages des soins prénatals. Événements évités de justesse survenus avant ou pendant l'hospitalisation. Les femmes ont reconnu leur propre implication dans leurs événements évités de justesse en retardant la recherche de soins. Ils ont également mentionné les retards dus aux prestataires de soins de santé qui retardent les transferts, diagnostiquent mal les événements et tardent à intervenir même au moment où le diagnostic a été posé. Les femmes ont reconnu le rôle salvateur des programmes de proximité et des agents de santé communautaires. Nous croyons que les résultats de la grossesse seraient améliorés dans cette population de femmes avec une éducation sur les complications de la grossesse, la formation des agents de santé communautaires et un programme de mentorat soutenu. *(Afr J Reprod Health 2022; 26[5]: 63-71).*

Mots-clés: Quasi-accident maternel, complications de la grossesse, système de subventions, perception

Introduction

The concept of maternal near miss (MNM) has evolved to reveal a more complete assessment of quality in maternal health care services. This was proposed as one of the useful strategies to obtain important information on maternal and newborn healthcare[1]. Patients are considered near-miss cases if they survive life-threatening conditions and a maternal near-miss is described as "a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days of termination of pregnancy"[2].

Reducing maternal and neonatal mortality has been a big issue in low-income countries due to many factors including use of unskilled birth attendants and low access to maternal health services. Despite tremendous gains in achieving the millennium development goals, maternal mortality ratio is still high in many African countries. It is and estimated to be between 210 and 320 per 100,000 live births with a neonatal mortality rate at 21 per

1000 births in Rwanda[3-4]. The country has made progress in poverty alleviation as well as in reducing general morbidity, which has resulted in a remarkable decline in maternal mortality[3,5]. However, an estimated 9% of Rwandan pregnant women still deliver at home, a major factor that contributes to the high number of maternal mortality[5-6]. Various programs such as the Training Support Access Model (TSAM) for Maternal, Newborn and Child Health (MNCH) have been implemented by the Rwanda government with the goal of improving maternal, newborn and child health outcomes by working with local partners to improve health service access and delivery. TSAM for MNCH is a project funded by Global Affairs Canada (GAC) through University of Western Ontario.

In Rwanda, quantitative studies have been conducted to investigate various aspects of maternal morbidity and mortality[6-8]. What remains unclear is women's perceptions of near-miss experiences and how these experiences can be used to develop strategies for health policy reform. The aim of this study was to explore in-depth information regarding the near-miss experiences by women in Rwanda.

Methods

A qualitative research was conducted among women who suffered a severe obstetrical complication at district hospital (DH) level that would be otherwise fatal but were saved by the mentorship team and categorized as near misses from March 2017 to June 2019. The selection of provinces (Northern and Southern) was based on TSAM mentorship that only covers the Northern and Southern provinces. Participants were contacted through Community Health Workers (CHW). For each participant, we checked their medical records to identify the exact diagnosis at the time of their complications. The criteria that were used to identify the cases are provided in Table 1.

Face-to-face in-depth interviews were conducted using a checklist of topics including: pregnancy history, knowledge on maternal health services, events leading to near miss, perception on healthcare provided, social support, self-management, perceptions of the TSAM mentorship program that managed the near miss event, and participants perceptions of what could be done for future improvements. All interviews were conducted at chosen location in each participant's home. While a trained reach assistant was interviewing a participant, the principal investigator took notes. All the interviews were conducted in the Kinyarwanda language and were audio-recorded with participants' permission. The audio recordings were transcribed verbatim, translated from Kinyarwanda into English prior to analysis. The analysis was conducted using grounded theory and was guided by themes and constructs related to near miss experiences in the Rwandan context. The transcripts were read several times in order to generate key categories. The researcher and a research assistant independently coded data and the results compared. The coding and analysis of the data was done using "Atlas.ti" software version 7.1.4.

Results

Twenty-seven women were interviewed. The themes that emerged from the analysis were: Maternal knowledge of pregnancy complications, maternal attitude during pregnancy, effect of delays in seeking and receiving care, experience and perception of care received with appreciation of the subvention system, experience sharing and what participants' think could be done to improve near-miss complications in Rwanda. The age, number of pregnancies, and pregnancy complication, are provided at the end of each quotation.

The characteristics of the study sample are summarized in Table 2. These women were young in their thirties (median: 33 years; range: 25 years), and each of them had had 1 to 9 pregnancies and at least one child. Among them, 25 were peasant farmers, 17 were married, and all of them lived in rural areas. Four women indicated they never attended any antenatal clinic during the index pregnancy (the pregnancy that resulted into near miss status). The primary diagnoses on the index pregnancy were uterine rupture, post caesarean infection, hemorrhage, ectopic pregnancy and septic abortion (Table 3).

All participants had community insurance and 26 of them were transfers from health centers to District Hospitals (DH). The life-threatening conditions were developed before or during hospitalization or both. In cases where

Table 1: Near miss criteria

Diagnostic group	Definition	Specific criteria
Hemorrhage	Severe bleeding	- Hysterectomy - Hypovolemic shock - Blood transfusion
Hypertensive disorders	- Ecclampsia -Severe pre-Eclampsia	- Convulsions without history of epilepsy or other medical reason. - BP>140/90mmHg or - BP-increase >30/15mmHg from baseline and - Vasospastic symptoms and/or - HELLP and/or - Proteinuria >1g/24h.
Infection	Infection with clinical signs of sepsis.	- Hypo/hyperthermia and - BP<90/60 mmHg and - HR>120bpm
Obstructed labour	- Uterine rupture - Impending rupture	
Anemia	Severe anaemia without signs of Haemorrhage.	- Hb ≤ 7g/dl and - Clinical signs of anaemia as tachycardia or increased respiratory rate and/or - Blood transfusion

Table 2: Characteristics of study participants

	Variable	Frequency
Age	<25	3
	25-29	5
	30-34	7
	35-39	6
	>39	6
Occupation	Peasant farmers	25
	Housemaid	1
	House wife	1
Marital status	Single	4
	Married	17
	Cohabitate	3
	Separated/widowed	3
Place of ANC	Health center	20
	Hospital	0
	HC and Hospital	3
	None	4
Number of pregnancies	1	4
	2-4	13
	5-7	6
	>7	4

women had severe conditions at home, CHWs played the primary role in transferring them to health centers or even accompanying them to hospitals.

Maternal knowledge of pregnancy complications

The women reported that a pregnancy could be complicated by death, bleeding, miscarriage, preterm labour, getting weak, hypertension, kidney injury, nausea, vomiting and chronic wound because of surgery. Some also highlighted that multiparity increases the risk of pregnancy complications and that "it makes the woman look old faster." The participants also mentioned new-born complications including poor growth, respiratory problems, congenital malformations, frequent sickness, jaundice, inability to breastfeed or cry, infection and death. Most of the women talked about the long-term neonatal complications and death from preventable diseases if a child is not vaccinated.

Maternal attitude during pregnancy

Knowledge about pregnancy complications and home visits by community health workers appeared to influence mothers use of antenatal services. A mother's previous experiences of pregnancy also created a memory of what is to be expected for normal pregnancy and whether complications could occur for both the mother and the new-born. Even though many of them had had at least one prior delivery at home, all of them agreed that they would no longer deliver at home particularly because it is against the government's recommendation. For instance, a participant reported that:

> *"Even though I had delivered at home more than once, my last delivery at home resulted into immediate loss of my baby and I believe that this could have been prevented if I had delivered at an equipped facility, therefore I will not deliver at home anymore"* [30 years old, gravida 5, PPH and transfusion].

Table 3: Status during near miss experience

Responses	Number of mentions
Index pregnancy	
Ectopic	2
Placenta Previa	1
Post-term	1
SVD	6
Abortion	3
uterine rupture	9
Term CS	7
Complication as near miss	
uterine rupture	7
Hemorrhage	26
Peritonitis& sepsis	1
Preeclampsia/eclampsia	2
Management offered	
Hysterectomy	6
Transfusion	25
Bladder injury repair	3
Uterine repair	14
Salpingectomy	3

Among our respondents, those who delivered at home during the indexed pregnancy revealed that they had intended to deliver in the hospital but unexpectedly developed precipitous labour at home. For some others, it was because the health facilities were too far from their homes.

As a mitigation against unexpected high-risk uterine contractions at term, women mentioned that they would go and stay at health facilities [(HC or DH) when they are close to term. In addition, many women mentioned that in their villages, men are always alert to urgently transport women by traditional means (traditional ambulance) until they reach a health facility or reach a road where the modern ambulance can transport the patient. While some were against the use of traditional medicine (TM) because of their perception that traditional medicines can worsen their health condition or lead to abortion or preterm labour, others were still in strong agreement with the use of these TM even when they are in hospital especially when medical personnel have made or communicated a clear diagnosis. Women commented that:

> *"I had bleeding on my pregnancy but I waited for grandmother to give the traditional medicine* [23 years old, primigravida, PPH for retained placenta]

> *"After I was saved from uterine rupture, my lower limbs got swollen and we could not know why but thought it was witchcraft by other women. They [care takers] sampled my saliva so that they take it out to see the cause"* [27 years old, PPH]

Some participants, especially the Christians reported that they cannot use traditional medicines because of their religious beliefs, as they do not believe in other evil forces. Other participants discussed how traditional medicine had not been helpful to them in previous pregnancies.

> *"I only used TM when I had an abortion and they didn't really help much. This time, I decided not to use them but rather go to the health center"* [37 years old, gravida 2, PPH]

Delay in seeking healthcare

The delay in seeking care by some women was influenced by domestic care-work and women's perceptions that they can manage their pregnancy especially for multiparous women. In the comment below, a participant mentioned that:

> *"My husband was asking me to go early to consult, but based on my previous experience, I ignored him. Then I developed uterine rupture at home.* [33 years old, uterine rupture, PPH and transfusion]

Experiences and perceptions of care received at the health facilities

Overall, most of the participants gave positive perceptions of the care they received from the health professionals in the hospital. Participant reported that:

> *"At my second surgery, I went into coma due to cardiac arrest and they resuscitated me. I had chest pain and they told me it was due to chest compressions that they did to me. They [healthcare workers] are people sent from God"* [27 years-old, Gravida 1, PPH)

The CHW appeared to be the best favoured by most participants when they talk about their emotions during their predicament. Mentioned CHWs support included home visits during pregnancy, accompanying women to health facilities; convincing husbands to accompany women during antenatal care, helping them follow medical instructions and vaccination for children. Women

generally appreciated the health professionals but some also reported instances of bad experiences with some health care workers.

> *"…he harassed me that I had AIDS in a discordant couple, but a nice good lady who had advised me to use a three year implant instead of injections every three months, replied to him well and came to comfort me and I decided to start going to a different heath center".* [40 year-old, gravida 6, ectopic pregnancy]

Communication challenges

The findings from this study also showed the negative attitudes toward accessing care are sometimes due to the poor or lack of communication to patients.

> *"I was never told that because of previous multiple caesarean deliveries, that I run the risk of complications such as uterine rupture"* [41 years old, uterine rupture, PPH].

Furthermore, a number of women were given lifesaving hysterectomies but some were still expecting to become pregnant. A participant said:

> *"I didn't know that my uterus was removed. They did not tell me. I am waiting for the return of menses so that I can go for family planning".* [38 years old, grand multiparous, PPH]

Some health care workers at HC also seemed to have been the reason of delay by not giving timely transfers until the woman claims for it or found another HCW. At hospital, also, some women reported to have had their complaint undermined.

> *"…I felt pain during caesarean section and every time I complained about it, they would tell me to shut up. Those doctors were bad people. I did not even know they had removed my uterus".* [37 years old, gravida 3, para 3, PPH]

Lack of skilled personnel

For some women, even when they decide to access health care, the lack of a skilled health care provider to make a lifesaving intervention resulted in their near miss tragedy. Below are some cases reported by our respondents.

> *"I had genital bleeding and pelvic pain and was managed at the HC as outpatient on painkillers but there was no improvement. So I went back to complain and consulted every day for 3 days… I finally requested for a transfer to a hospital. At hospital, I spent four more days without a clear diagnosis. When the TSAM staff came I was diagnosed with a ruptured ectopic pregnancy".* [40 year-old, gravida 6, ectopic pregnancy]

> *"I have been at the hospital waiting for labour induction but when I got reviewed by TSAM specialist, I was found to have twin pregnancy with both foetuses in breech and I had low amniotic fluid level. Hence, I was immediately scheduled for caesarean delivery that saved both babies. I eventually developed postpartum haemorrhage that was managed by TSAM team".* [Gravida 5, PPH]

In some cases even when women on their own initiative make early visit to hospitals, there are always other potential challenges that can influence their access of care. In the comments below a woman reported going to the hospital ahead of time as a precaution to avoid any complications, but still ended with challenges:

> *"…in my situation I had left my family to go stay in hospital because I was worried I would develop contractions at home. I was scheduled to have cesarean delivery on 17th but it was postponed to 18th because my husband was not around to consent on tubal ligation that I had requested for. During that night, I had contractions. They told me that my uterus had ruptured and that I needed emergency surgery to save the child and they removed my uterus. My urinary bladder also got injured in the process so I had to spend 21 days more in hospital with a bladder catheter".* [41 years old, uterine rupture, PPH]

Experiences with family and friends

All women reported their partners to have been supportive even when they do not have legal marriage and have lost the uterus after only one child.

> *"We are not legally married but we live together and have 2 children together. He*

knows that my uterus was removed, he is very supportive and he has never told me anything bad". [28-year-old, gravida 2, placenta praevia, PPH, hysterectomy]

"…my husband and my mother in law know what happened to me. They understood it was the option to save my life and were the first to comfort me". [22 years old, Gravida 1, sepsis/peritonitis post caesarean, hysterectomy]

Given the critical and urgent nature of near-miss experiences, some of the participants indicated that by the time they got to the hospital they were not able to provide or sign consent forms for the various interventions that were planned and this mean some of the women had their caretakers a family member or in in some cases a neighbor had to sign the forms on their behalf. Consequently, many women had their confidential information been transmitted to other people.

Stigma of near miss

Some women did not share their near miss information with anyone, and in some cases not even their husbands. In the comments below, two women who were saved from uterine rupture and ectopic pregnancy respectively said that:

"No one else knows that I had a uterine rupture. Not even my husband". [40 years old, Gravida 9, uterine rupture]

"I keep telling my neighbors that I had surgery for an abdominal mass, but I never really disclosed the diagnosis to other people except my husband". [42-year-old, gravida 5, ectopic pregnancy]

In relation to the underlying sociocultural conceptions of womanhood, some participants reported that their neighbors have stigmatized them after they learned their uteri were taken out:

"After I lost my uterus, my neighbors now consider me as incomplete women or as women who have lost womanhood". [31 years old, Gravida 2, PPH & Hysterectomy]

Social support

For most women the social support they get from their families and friends help them to cope with the effects of their experiences. The types of support they reportedly received from their husbands emotional support, accompanying them to antenatal care service, arranging for transfer of logistics, insuring that they eat balanced diets for quick recovery, paying the hospital bills, cooking and bringing food to them at the hospital and carrying out all the heavy domestic chores while they recuperate from her ill-health. In connection with the support from family and friends, the participants talked at length about what can be done to improve the impact of near miss in Rwanda.

What could be done to improve the impact of maternal near miss?

Overall, the participants discussed the issues they thought could be improved to minimize the impact of near miss in Rwanda. Women reported the use of contraception to prevent unwanted and high-risk pregnancy. Respondents reported that women should go to hospital as soon as pregnancy is suspected, if she has danger signs or when she is exceeding the due date. In the comment below, the participants agreed that all pregnant women should also get health insurance on time to avoid delays when there are complications.

"They [pregnant women] should always have health insurance because you never know what can happen, for example, my complications came at 3 months and yet I had spent nine years without getting pregnant. If I didn't have it (insurance), I would have been in trouble". [33 years old, gravida 5, ectopic pregnancy]

Some of the participants mentioned they would share their pregnancy experience as a tool of providing advice that could share with other couples. Other participants claimed a need for improvements in hospital equipment and technology. For instance, one woman who had twin pregnancy that had been misdiagnosed to as singleton pregnancy commented that:

"If there was an early ultrasound scan, they would have diagnosed the status of my pregnancy. They would have seen that I had twins and not just one foetus" [Gravida 5, PPH]

Overall, the participants talked about the need for improved communication between health care workers and patients. A woman who underwent caesarean hysterectomy said:

> *"Doctors needed to tell me about what future changes I should expect, for instance, I was not told that I will not have menses anymore"* [28 years old, gravida 2, placenta praevia, PPH, hysterectomy]

Other suggestions to improve maternal health in Rwanda included producing more specialists, conducting more frequent mentorship and offering health insurance to all pregnancy women.

Discussion

This study presents findings from women who survived maternal near-miss complications in Rwanda. Women in this study were knowledgeable about pregnancy complications and this appeared to influence their decision on future utilization of maternal health services.

Our findings are consistent with the finding from Souza *et al* showing that the extent to which the women delayed before seeking care were likely due to lack of recognition of the seriousness of the condition, difficulties in accessing care and being overburdened with household chores[9]. Although some of the women understood and recognized the severity of their condition, they were unable to translate this knowledge into prompt action to consult health providers when they experienced danger signs. In the study context, the role of Community Health Workers emerged as an important component of the women healthcare seeking behavior and the utilization of maternal health services in general.

The findings whereby some of the women reported being mistreated in health facilities is of concern. The perceptions of being mistreated in the hospital and deprived of essential information has been documented to influence women confidence and distrust in the health care system and, hence, non-use of maternal health services[10-11].

Consistent with previous research, the inability to become pregnant and give birth can become the central focus of women's lives (Johansson and Berg), and women who had hysterectomies talked of being on an emotional torture due to the permanently lost ability to conceive[12]. Similarly, according to the study by Carvalheira *et al*, for the women whose uteri were removed without their consent, their powerlessness was observed as they generally did not participate in decision-making and were only informed about the medical decisions that were made after the effect[13]. However, despite the loss of their reproductive organ, women have appreciated all effort made to save their lives.

Concomitantly, given that the women were not involved in some decisions, whose husbands and family members were not aware that they have lost their abilities to have a baby through hysterectomies, are left too scared to tell their family members especially where the news will be that 'they loss their womanhood'. This is reinforced by the reports that some women who have had their uteri removed have been stigmatized and made fun of by their neighbors once they became aware they can no longer conceive. Given the trauma of having a severe near-miss and hysterectomy, the pervasive uncertainty and danger can extend into the postpartum period and beyond (Souza *et al.*,). Ayers *et al.* warns, that if such psychological symptoms go unrecognized and if left untreated, they may lead to depression and long-term consequences for women, including, social isolation and alienation from their circle of friends, with potential negative effects on the women's physical health as well[14]. According to Souza *et al.*, under such emotional and stressful circumstances, there is a need to pay attention to helping women post near miss, in order to resolve the trauma they may be going through before this develops into other complications such as post-traumatic stress disorder[9].

Some women discussed anchoring themselves in religious beliefs because they believed that God would give them strength and comfort. In Rwanda, the use of traditional medicines by people in rural areas also should be put in the context of the overall challenges to accessing health care services.

Despite the important findings in this study, there are a number of limitations worth noting. These included potentially incurring reporting bias, because our interviews took a long time after the women experienced near miss. To overcome this bias, the self-reported experiences were validated against hospital medical records. Additionally, inherent in all qualitative in-depth studies, because of the small number of participants that were interviewed for this study, the findings may not be generalizable in all situations, but could provide very useful insights similar contexts.

In conclusion, delays that include the women waiting to seek care, delays in reaching

appropriate health care facilities and delays in receiving adequate care have been recognized in overall patient management, and frequently observed in previous studies in Rwanda[10-11]. Given the experiences of delays especially at HC and DH, interventions to improve the timely seeking of healthcare has to target not only women, but also at the health care workers especially at Health Centers. Furthermore, inappropriate diagnosis or recognition of high risk women, inappropriate treatment and inadequate documentation also call for attention to improve common preventable events. Unfortunately, most of these women were not given the appropriate educational knowledge prior to their hysterectomies. Understandably, as reported by Norhayati *et al*., these mothers have lost their babies and are now being told they cannot have any more babies, hence the compounding adverse psychological impacts[15]. The fact that some of these women are willing to educate their counterparts based on their experiences is noteworthy. In a cultural context where childbirth is regarded as an ultimate desire for women, those who have near miss hysterectomies during their childbearing age may be able to provide support for other women who may be in the same situation. Overall, the findings present a potential causal chain where delays in seeking care and poor diagnoses may lead to inappropriate, inadequate or even the absence of treatment. Subvention systems to enhance efficiency and improve quality of health care are cost-effective as the country strikes to generate specialized health professionals sufficient for constant availability at every hospital. Given the very low number of obstetricians and gynecologists in Rwanda, the findings from this study show a need to reinforce the policy and programming for mentorship in order to trained health care workers that provide timely interventions to women who may experience near miss. The Rwandan government has implemented serval policies on maternal and child health, these should include health promotion policies aimed at educating women from onset of pregnancy on how to access and utilise the different aspects of maternal health programmes.

Ethical considerations

This study was presented to the University of Rwanda ethics board and an ethical approval (Certificate #: 3809/CMHS IRB/2018) was obtained before data collection.

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Conflict of interest

Authors declared they have no conflict of interest

Authors' contributions

All authors have read and approved the manuscript. "PB conceived of the study, conducted analysis and prepared the manuscript. AU and IL supervised the analysis and assisted with the manuscript.".

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