BJOG: an International Journal of Obstetrics and Gynaecology
September 2005, Vol. 112, pp. 1302–1307
DOI: 10.1111/j.1471-0528.2005.00703.x

Personal accounts of 'near-miss' maternal mortalities in Kampala, Uganda

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Objective To explore the socio-economic determinants of maternal mortality in Uganda through interviews with women who had 'near-misses'.

Design Observational study using qualitative research methods.

Setting The postnatal and gynaecology wards of a large government hospital in Kampala, Uganda.

Sample Thirty women who had narrowly avoided maternal deaths with diagnoses of obstructed labour (7), severe pre-eclampsia/eclampsia (3), post caesarean infection (6), haemorrhage (5), ectopic pregnancy (5) and septic abortion (4).

Methods The semi-structured interviews were conducted in the local language by a woman unconnected to the hospital, and were recorded before being translated and transcribed. Analysis was conducted in duplicate using commercial software.

Results The predominant theme was powerlessness, which occurred both within and outside the hospital. It was evident in the women's attempts to get both practical and financial help from those around them as well as in their failure to gain rapid access to care. Financial barriers and problems with transport primarily governed health-seeking behaviour. Medical mistakes and delays in referral were evident in many interviews, especially in rural health centres. Women were appreciative of the care they received from the central government hospital, although there were reports of overcrowding, long delays, shortages and inhumane care. There were no reports of bribery.

Conclusions Women with near-miss maternal mortalities experience institutional and social powerlessness: these factors may be a major contributor to maternal mortality.

INTRODUCTION

The maternal mortality rate in Uganda has remained static at around 500/100,000 for the last six years, with the number of women using the health services for antenatal and labour care remaining low.[1] Although there are some whose access to health services is restricted by finance or transport, there are many others who choose to have their care provided by traditional birth attendants or family members, despite a knowledge of the risks of pregnancy and childbirth.[2]

If we are to understand the difficulties that women experience in obtaining health care and their reasons for electing to have their births away from hospital, it is necessary to look at their experiences of care. In attempting to understand maternal mortality, it is especially important to listen to those who have shown themselves to be at highest risk of death. Although it is impossible to interview directly those who have died, women who have suffered 'near-misses' may provide adequate substitutes.[3]

This study sets out to record the experiences of women who have experienced a 'near-miss' maternal mortality (NMMM), in a major government teaching hospital in Kampala, Uganda.

METHODS

This was an observational study using semi-structured interviews.[4] Thirty women who had experienced NMMMs were interviewed during their recovery in Mulago Hospital. For the purposes of this study, a NMMM was defined as a disease of pregnancy that would probably have resulted in a maternal death within 24 hours had action not been taken. The women were selected by purposeful sampling, attempting to interview women with a variety of life-threatening complications of pregnancy. The sample size was chosen to ensure an adequate mix of problems within the budgetary and time constraints.

Each woman was interviewed on her own in a side room of the main hospital wards by a single trained interviewer (EN) who was a traditional birth attendant working outside

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the hospital setting. After obtaining written consent, semi-structured interviews were conducted in the local language, Luganda, using open-ended questions. The local experience of three of the authors (AW, EN, FM) gave the interview schedule content validity. The interviews lasted for around 30 minutes and the recordings were translated and transcribed into English by a translator and AW. Pseudonyms were used throughout. The transcripts were entered into winMAX Pro qualitative analysis software and analysed independently by two researchers (AW and TL) to identify themes. The analysis was compared and resolved through discussion.

Permission to conduct the study was obtained from the Mulago Hospital Department of Obstetrics and Gynaecology and from the Mulago Hospital Ethics Committee.

RESULTS

Thirty women were interviewed. The primary diagnoses were obstructed labour/uterine rupture (7), severe pre-eclampsia/eclampsia (3), post caesarean infection (6), haemorrhage (5), ectopic pregnancy (5) and septic abortion (4, Table 1).

There were a number of overall themes that ran throughout the interviews: the women's powerlessness, satisfaction with the medical care obtained at Mulago, the lack of resources within the health setting, the delays in obtaining quality care and the poor attitude of some health workers.

The most striking feature is the women's descriptions of their powerlessness, which was seen in all aspects of their lives. For some, it caused the medical problems—through rape, through the refusal of their partners to use contraception or through forced illegal abortions. For others, it affected access to care when complications arose—through the inability to afford health care or transport to reach it. It was also seen in aspects of their everyday living—a lack of food while in hospital, an inability to access information about their condition or verbal abuse by health care workers.

Juliet, a schoolgirl who had a hysterectomy and bowel resection following a botched abortion with sticks by a traditional healer, describes how she became pregnant:

> The man, who made me pregnant, had tried to befriend me and I refused . . . he wanted to have sex with me and I refused. He locked the door and I told him to use a condom and he refused. Then we had unprotected sex.

Table 1. Demographics of interviewees. SB = stillbirth; CS = caesarean section; PPH = postpartum haemorrhage; APH = antepartum haemorrhage; PP = placenta praevia.

Case no.	Pseudonym	Age	Parity*	Condition	Place of complication
1	Joan	18	1 + 0	Uterine rupture	Mulago Hospital
2	Margaret	20	0 + 0	Eclampsia	Health Centre/Mulago Hospital
3	Alice	†	4 + 0	Septic abortion	Private clinic
4	Elizabeth	19	0 + 0	Septic abortion	Private clinic
5	Florence	27	6 + 1	Septic abortion	Health centre
6	Justine	18	0 + 0	APH	Mulago Hospital
7	Cissy	20	0 + 0	Obstructed labour/cord prolapse + SB	Mulago Hospital
8	Dorothy	30	2 + 0	Obstructed labour	Health Centre
9	Rose	25	1 + 0	Ectopic pregnancy	Home
10	Betty	19	0 + 1	Ectopic pregnancy	Home
11	Jane	29	6 + 0	Ectopic pregnancy	Home
12	Veronica	26	2 + 0	APH, PP	Home
13	Harriet	29	5 + 0	Ectopic pregnancy	Home
14	Enid	39	5 + 0	Ruptured uterus	Mulago Hospital
15	Patricia	†	2 + 0	Ectopic pregnancy	Home
16	Prossy	23	2 + 0	Ruptured uterus	Private clinic
17	Akuma	17	0 + 0	Severe pre-eclampsia	Mulago Hospital
18	Rose	20	2 + 0	Ruptured uterus	Private clinic
19	Solome	24	2 + 0	Post CS sepsis	Mulago Hospital
20	Christine	20	1 + 0	APH, PP	Home
21	Jane	24	3 + 2	APH	Home
22	Harriet	19	1 + 0	Post CS sepsis	Mulago Hospital
23	Mary	21	0 + 0	Abruption, SB, PPH	Mulago Hospital
24	Cissy	18	1 + 0	Post CS sepsis	Mulago Hospital
25	Milly	18	0 + 0	Post CS sepsis/obstructed labour	Private clinic, Mulago Hospital
26	Juliet	16	0 + 0	Post abortion sepsis	Home
27	Carol	32	2 + 2	Eclampsia	Private clinic
28	Amina	23	3 + 0	Obstructed labour	Private clinic
29	Jordan	17	0 + 0	Post CS sepsis	Mulago Hospital
30	Aisha	18	0 + 0	Post CS sepsis, obstructed labour	Private clinic, Mulago Hospital

* Prior to this pregnancy.
† Unknown.

Jane, a mother of 6 who nearly died from an ectopic pregnancy, describes why she stopped using condoms for contraception:

> At times you can tell a man to put it [a condom] on but he refuses so you have to accept.

Often relationships are a 'business deal' where financial and practical support is exchanged for sexual acquiescence. Rose, who had a ruptured ectopic, explains how she needed a partner when her husband left her

> If I had not got this man who would have taken care for me at this time? If you don't have someone to take care of you, it is not easy because my mother cannot give me everything I want. I have to find a way, since I don't even work.

For many women, their reproductive health problems were as much social as medical. Betty, who had two spontaneous miscarriages and then a ruptured ectopic pregnancy, describes her prospects:

> It will depend on [my partner's] relatives. If they say I have to leave because all the children are dying, I will go back at may parents home and go back in my shop and work. I will forget about marriage and just enjoy life.

Women constantly referred to money—how it was obtained, what it was needed for and the choices that a lack of money forced them to make. Florence was in her eighth pregnancy. Three of her children had died in childhood and she had had one miscarriage. Aware of her risks she had sought antenatal care:

> I had been informed that at the government health centre they help pregnant women for free. I just needed [the cost of] transport 200/- (8p). So one day I had only 500/- (20p) and I went to the health centre, but when I reached there I was told to buy a book and a pen and I did not have enough money, because if I were to buy them I would not have enough money for transport back home.

Although most women are supported by their partners or close relatives, others are not and have to seek financial support from wherever they can get it. Juliet, the schoolgirl who had a hysterectomy following a botched abortion, was disowned by her family who believed that she must have encouraged the man who raped her. She remained in hospital for three weeks with infective complications and had to rely on friends and sympathetic medical staff to get medicines.

An added cost of hospitalisation is food. The supply of food to inpatients is irregular and money is therefore needed for women to buy their own:

> The hospital is good; it is the issue of food which is a problem. It is costly. [Your] husband may give you 5,000/= (£2) for food taking it for granted that at Mulago treatment is free. But if you have to buy medicine ... then you face problems in feeding yourself. (Mary)

All women mentioned positive aspects of their care and expressed thanks for what had been done. Many were impressed that the care was free, often implying that they expected to have been charged.

> They have treated me well, looked after me—even taking me to the theatre for operation. I didn't pay even a single coin ... I am really grateful for that. (Rose)

Mulago Hospital has been the only tertiary referral hospital in Uganda for many years and has persisted through many stormy years of civil wars and political unrest. In the past, chronic underfunding had given the hospital a poor reputation and there had also been concerns expressed about bribery and unofficial fee paying to gain services. However, no evidence of unofficial fee paying was found in any of our interviews—many women expressed surprise at the high level of care and found that care exceeded expectations.

> The health workers are very good. They are polite and humble, they assisted us so much, I would have died if it were not for them, but they attended to me immediately and did everything possible. That is why I am still alive. (Prossy)

The funding of medical care in Uganda is under constant strain. Women spoke of shortages at all levels of the health system. In the community this sometimes led to difficulties in accessing services. Patricia, a mother of two young children sought care at her local health unit for abdominal pain that turned out to be a ruptured ectopic pregnancy:

> Apart from the signs on the roadside that show that it is a health unit when you enter, nothing indicates that it is a health unit. All the buildings are closed, goats are moving everywhere and when you get the health worker, she abuses you. (Patricia)

Within Mulago, the women did not see the situation as so bad, although some complained that there were not enough free drugs to go around, and others noted the overcrowding. But women accepted that there were limited resources and appreciated the work done within those limits. One woman summed it up by saying,

> 'The beds are few but the patients are very many' (Amina).

Although delays in obtaining care or referral were common, there were very few examples of the actual medical care being of poor quality. Where this was found virtually all

were in the community prior to admission and were situations where early pregnancy problems were misdiagnosed. One woman was treated for four weeks in the community before the correct diagnosis of a ruptured ectopic pregnancy was made:

> It all started when very dark blood came out of me ... I felt things pinching me in the stomach, with a lot of pain. I went to the clinic and they told me that I had developed ulcers. They gave me medicine and I went home but still I had the pain. I went to [a nearby] health unit but I didn't find the doctor. I found there a health worker ... she told me I had syphilis and ... started injecting me. (Harriet)

For another woman with an ectopic pregnancy, the problem was not one of correct diagnosis, but of correct management:

> When my stomach started hurting me ... I was advised to go and see a health worker. We first went to a clinic and we were told that the foetus was growing inside the fallopian tube. The health worker gave me some tablets and told me to take them and if I don't get any change after one day then I should go back. (Patricia)

In this study, only two women were misdiagnosed at Mulago. One was seen in the emergency room with vaginal bleeding from what turned out to be an ectopic pregnancy and was thought to have pelvic infection, and another had a pelvic infection following an untreated retained placenta.

Many women criticised the attitudes of the health workers both in the health centres and hospital, speaking of their rudeness and apparent lack of empathy.

> [We] would shout and call the health workers, but they would take a long time to come, and when you deliver they would be harsh and say 'Kwata omwanawo' meaning 'get your child' and they would throw the child on your stomach as they worked on you ... they mistreat everybody, they don't behave well. (Joan)

Some of the health workers' comments had the effect of belittling the women:

> When I arrived there the health worker told me to sit. But the second health worker asked me 'who told you to sit down and dirty the place?' (Mary)

Comments like this may lead to women feeling isolated and alone. Many spoke of how they felt abandoned by the staff, or how their requests for help were ignored

> ... the health workers don't care about women who have come to deliver. A woman may be pushing a baby when the health workers are not around; they call them but they do not mind or care ... [after my operation] they were proud and said 'we have finished working on you, now you should take care of yourself'. (Akuma)

The isolation may also be expressed physically in the actions of the health workers.

> ... there are those who even put on gloves and still fear to touch you and use scissors to handle you, pulling you without mercy. And you regret that you came. (Florence)

Some women spoke of their desire for more information—both about their current condition and about health issues in general.

> You health workers who know about childbirth and everything should teach us so that we can be able to make good decisions. (Jane)

Although women were generally aware of their diagnosis, there were some notable exceptions. Justine underwent a caesarean section for a suspected placental abruption:

> Q. Do you have any other thing you want to talk about?
> R. ... I don't know why I had an operation.

Delays in gaining appropriate treatment were a significant problem. Some women with symptoms failed to seek care for either financial or social reasons. Some had difficulty getting to their chosen place of care due to a lack of transport. Others had inappropriate trials of treatment in the community with traditional healers or in health centres. And even when women finally reached the hospital, delays were common.

Although they are relatively expensive, many women will turn first to traditional healers or witchdoctors when they develop medical problems. Harriet first went to a traditional healer when she developed unusual vaginal bleeding and abdominal pain:

> We went to a traditional doctor and he told us ... that there is a person who is tampering with my spirits. He gave us traditional medicine and said if I use it I will be fine. He charged us money and asked us to bring a chicken.

There was a mixed experience of the health centres. Many women were referred rapidly and appropriately to Mulago Hospital from the local health centres when surgery was needed. There were, however, a number of women who experienced delays at the community health centres. The most common situation was for women who had already laboured for many hours at home to be asked to spend more time in labour at a health centre before referral for caesarean section. For some there were also administrative delays, especially in obtaining referral letters. Rose

ruptured her uterus after developing an obstructed labour at her local health centre. The baby was stillborn and she required a hysterectomy:

> When I attended the antenatal clinic, they would tell me ... that I will not be able to deliver well. One time they promised to give me a letter to go to a bigger health unit but they didn't give me the letter. When I got labour pains, I went to the health unit [After many hours in labour] they referred us to Mulago Hospital but it took us very long to get the letter. If they had referred me immediately, my child would not have died.

Many women referred to their mode of transport in the interviews, although none complained about it. No woman had her own transport—most used buses, borrowed cars, taxis or the bicycle/motorcycle taxis. Five women used health centre ambulances to transport them to Mulago. Although the women themselves did not refer to delays occurring due to the lack of transport, it was clear from some interviews that reaching the health facility had been difficult:

> We boarded a public taxi [minibus]. When we got out, [my friend] hired a boda-boda [motorcycle taxi] to bring me here. [The fetus] had already come out, it was only the placenta that had remained inside. (Florence)

Harriet, the woman who initially sought traditional health care for an ectopic pregnancy describes how she eventually reached hospital:

> A man called Seba put me on a bicycle and took me to the main road. As he bumped into potholes I felt a lot of pain and screamed, but he managed to get me to the road and I was being followed by my in-law. When we reached the road, a taxi came and brought me to Mulago. (Harriet)

Upon reaching the hospital, delays were common. Most women stated that although they were seen promptly by a doctor upon arrival, there were marked delays if they needed surgery. Women described waiting for up to 8 hours for emergency caesarean sections. Usually, this was because of long operating lists, but this was not always the reason:

> At around 2:30 pm the doctor examined me and sent me immediately to the labour room. When I reached there I was given 5 drips consecutively but the head failed to come out. Later another doctor came and suggested that they take me for vacuum to try and see. They tried the first time and it failed and also the second time it failed to bring out the child. At around 8:00 p.m. the doctor took my file and at around 9:30 they came for me and said that I was going to be operated. On reaching the theatre we were told that the doctors were not there, they had gone to have supper. (Amina)

Rose had a hysterectomy following uterine rupture and stillbirth. She described above her difficulty in getting referred to Mulago because she could not get a referral letter. She had already been in the second stage of labour for 3 hours when she was referred from the health centre. She also experienced delays at Mulago:

> I can say that if when I arrived here at 11.00 a.m. I had seen the health workers immediately my child would have survived. They took long ... [I was not operated on until] 6.00 p.m. in the evening.

The longest delays were for women with pelvic abscesses following childbirth or abortion who had to wait for between two and six days before obtaining surgery. Despite this, no woman in our study complained of the long waits.

A striking feature of the interviews was the lack of emotion shown by the women about their 'near miss' experiences. Despite all being interviewed in the days following a traumatic episode in which they came close to death, most women shared their stories unemotionally, rarely straying from the facts. Most appeared to have a calm acceptance of their situation and were able to talk with ease about the effects of the episode on their lives. Expressions of anger were rare. Many women spoke in religious terms about God acting as a healer and as One who can provide hope for the future. Where blame was apportioned, it was often directed at themselves.

> R. After operating on me, they came and told me that they removed my uterus, which means I will never produce a baby.
> Q. That is sad. When they told you, how did you feel?
> R. It was my mistake. I aborted so I could not say anything, because I allowed it. (Elizabeth)

DISCUSSION

In developing effective programmes to tackle maternal mortality, it is crucial to understand the perspective of those most likely to die. The Safe Motherhood Technical Consultation highlighted this in 1997,[2] but the voices of those most at risk—the poor of sub-Saharan Africa—are still rarely heard. The concept of 'verbal autopsies' was developed to try and learn from the experiences of those who have died,[5] but the lack of first-hand accounts for many of the events makes it a poor substitute. An alternative is to study women who have suffered maternal mortality 'near misses'. Although the study of these women is becoming increasingly important in the assessment of programme impact,[6] investigators have rarely utilised the fact that information from them can accurately chart the experiences of women at the greatest risk. In the West, definitions for NMMMs have used the level of care that the woman required (e.g. intensive care or massive blood transfusion[7]), but these are not suitable for the developing world. For

this study, we used the pragmatic definition of 'a disease of pregnancy that would probably have resulted in a maternal death within 24 hours had action not been taken'.

The powerlessness and dependency of many women in this study may come as a surprise to many European readers, but the results of this study must have been taken in context. Traditionally in Ugandan culture, the roles of men and women are strictly defined with men being breadwinners and the women homemakers. Their background of poverty and limited education restricts their ability to control their own lives. For many families, this places women in a subservient role within relationships, relying heavily on their male partner for financial support and decision-making, and being sexually compliant and looking after the home and family in return. A dysfunctional form of this arrangement was seen in many interviews, with women left hungry, ignorant or even raped. This degradation of women greatly contributes to maternal mortality by making contraception difficult, HIV likely, care-seeking complicated and delayed and health care sporadic. Empowerment of women must play a central role in health promotion programmes if maternal mortality is to be reduced.

The women in this study were universally grateful for the care they received. Although the fact that the hospital workers had just saved their lives is an important factor in this, it also reflects their low expectations. In Ugandan culture, empathetic care is usually reserved for those who are related and so for women to receive free and high quality care from strangers came as a surprise to many. However, despite their innate Ugandan courteousness, many spoke with shock at the poor attitude of some of the heath workers, and hinted at this being a factor in dissuading attendance for antenatal care and delivery. This problem has been well documented elsewhere[8] and is an important obstacle to overcome. Health workers currently have little incentive to encourage women's attendance as the facilities are already overcrowded and their working conditions poor. In state hospitals in countries with low GDP, it is difficult to see how this situation can change in the near future. However, microfinance institutions are now developing systems that provide low cost insurance, thus making private health care affordable (see www.microinsurancecentre.org), and this may provide a way of shifting the balance of power within the hospital setting.

Delays have long been recognised as being of great importance in maternal mortality and they were frequently seen in this study. The greatest delays came with operations for pelvic abscesses and they occurred for two reasons. Firstly, the infective nature of their problem required the theatre to be scrubbed and disinfected after the operation. Hence, these cases were delayed until the end of any particular operating list. Secondly, the subacute nature of their problem meant that emergency caesarean sections usually took priority—and the massive workload meant that there were rarely times when no women were waiting for a caesarean. In situations of strained resources, this situation is inevitable and cannot be resolved without more theatre space and staff.

CONCLUSIONS

This study has highlighted the difficulties faced by women with life-threatening complications of pregnancy in Kampala, Uganda. The pathologies that cause maternal mortality are well known, but this study demonstrates other contributing factors: women's status in society, the lack of resources, poor quality community health care, lack of health education and delays. Women's reluctance to attend health units may be partially attributable to the poor attitudes of some health workers. The problem of maternal mortality is as much social as it is medical and all these areas need to be addressed if maternal mortality is to be reduced.

Acknowledgments

This study was funded by the Rockefeller Foundation through the Makerere University *I@mak.com* programme.

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Accepted 11 April 2005