Women's groups' perceptions of maternal health issues in rural Malawi

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Summary

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Correspondence to: Mikey Rosato, MaiMwana Project, Box 2, Mchinji, Malawi **m.rosato@ich.ucl.ac.uk** Background Improvements in preventive and care-seeking behaviours to reduce maternal mortality in rural Africa depend on the knowledge and attitudes of women and communities. Surveys have indicated a poor awareness of maternal health problems by individual women. We report the perceptions of women's groups to such issues in the rural Mchinji district of Malawi.

Methods Participatory women's groups in the Mchinji district identified maternal health problems (172 groups, 3171 women) and prioritised problems they considered most important (171 groups, 2833 women). In-depth qualitative data was obtained through six focus-group discussions with the women's groups, three with women's group facilitators, and four interviews with facilitator supervisors.

Findings The maternal health problems most commonly identified by more than half the groups were anaemia (87%), malaria (80%), retained placenta (77%), obstructed labour (76%), malpresentation (71%), antepartum and postpartum haemorrhage (70% each), and pre-eclampsia (56%). The five problems prioritised as most important were anaemia (sum of rank score 304), malpresentation (295), retained placenta (277), obstructed labour (276). and postpartum haemorrhage (275). HIV/AIDS and sepsis were identified or prioritised much less because complexity and contextual factors hindered their consideration.

Interpretation Rural Malawian women meeting in participatory groups showed a developed awareness of maternal health problems and the concern and motivation to address them. Community mobilisation strategies, such as women's groups, might be effective at reducing maternal mortality because they can draw on the collective capacity in communities to solve problems and make women's voices heard by decision-makers.

Introduction

Malawi has one of the highest maternal mortality ratios (984 deaths per 100000 livebirths) in the world.¹² The risks of pregnancy are indicated by the words used to describe a pregnant woman in the Chichewa language: either *pakati* (between life and death) or *matenda* (sick). In Malawi, behaviour at the village level can contribute to maternal mortality, for example, most births and deaths of pregnant women happen at home,³ and some behaviours within the community could hinder timely and appropriate care-seeking.⁴⁻⁶

Community mobilisation interventions have been successful for improving neonatal health,⁷⁻⁹ but only one trial is known to have assessed the effect of community mobilisation interventions on maternal mortality rates.⁹ This trial noted that participatory women's groups in Nepal substantially reduced neonatal and maternal mortality, but maternal mortality was not a primary outcome of the trial and the number of deaths was small.

The success of community mobilisation interventions to reduce maternal mortality depends on understanding women's perceptions of the health problems affecting them. This information can assist in creating more effective and acceptable interventions.¹⁰ However, culturally, issues surrounding pregnancy and childbirth are viewed as strictly in the domain of women.^{11,12} Furthermore, rural women are not often given opportunities to speak about their issues or be listened to by policymakers or people in local positions of power.¹³ Unsurprisingly, women's concerns remain invisible to both policymakers and members of their own communities,¹⁰ and responsibility for these issues falls to the individual women themselves.

Previous studies that have asked women about their perceptions of maternal health issues have generally focused at an individual level on the gaps and misconceptions in women's knowledge, with the aim of developing and prescribing interventions for health education to change knowledge and behaviour.¹⁴⁻¹⁹ In this paper, we present the collective perceptions of groups of women in the rural Mchinji district of Malawi about the maternal health problems they face and the issues they feel are most important. Our article is not a presentation of actual prevalences but of women's group perceptions of the issues they feel affect them. The implications of these findings are discussed in relation to strategies to improve preventive and care-seeking behaviours and reduce maternal mortality.

Methods

Setting

Malawi has a population of 11 million people, a gross national product per person of \$190, a life expectancy for women of 46 years,¹ and is a poor country whose development challenges are exacerbated by chronic food



Figure 1: The action cycle of the women's group community

insecurity and HIV/AIDS. According to the Malawi demographic and health survey for 2004, the total fertility rate was 6.0 children per woman, female literacy was 62%, infant mortality rate 76 per thousand, neonatal mortality rate 27 per thousand livebirths, and perinatal mortality rate 34 per thousand births.1 57% of women had the delivery at a health facility and 56% were assisted by a skilled attendant. The Mchinji district has a population of roughly 380000 people and lies in the central region of Malawi. The main ethnic group is Chewa (90%), with smaller numbers of Ngoni, Senga, and Yao. At the start of this study, we obtained socioeconomic data for the 35 002 women of childbearing age enrolled in our trial. Of these, 30% had no education, 62% had primary education, and only 8% had secondary or higher. 24% were younger than 20 years, 41% were 20-29 years, 22% 30-39 years, and 13% 40-49 years. The district has one district hospital (a first referral and secondary health facility), four rural community hospitals, seven health centres that provide maternity care, and three additional health centres that provide antenatal care. There are around 750 people per hospital bed.

The MaiMwana project is a research and development initiative to improve maternal and newborn health covering a total population of 156784 in the Mchinji district. One research component is a cluster randomised controlled trial to test the effect on mortality of a participatory intervention through women's groups with an integrated process evaluation exploring the accessibility, appropriateness, and feasibility of the interventions. Ethics approval for the trial was given by the Malawi National Health Sciences Research Committee in January, 2003.

Data collection

Quantitative data was obtained through the monitoring system of the women's group intervention. The groups followed a participatory community-action cycle supported by trained local facilitators (figure 1). In this cycle, women meet and engage in discussions moving through four phases where they: identify and prioritise maternal and neonatal health problems; develop locally feasible and appropriate strategies to address them; implement the strategies; and assess them. The basic cycle is described in more detail elsewhere,^{7.20} although the MaiMwana cycle has been adapted to be more appropriate to the Malawi context.

Quantitative data for this paper was taken from two of these meetings—meeting two, where groups discussed and identified all the maternal health problems that they felt affected them (not solely those that lead to death; figure 1), and meeting five, where groups discussed and prioritised the five maternal or neonatal health problems they felt were most important in their community. The groups completed summary forms after these meetings detailing the results of their discussions. These discussions, the problems identified, and the five problems subsequently prioritised formed the catalyst for the mobilisation of communities. Feasible strategies that made the best use of local resources were developed and subsequently implemented by the women's groups to address the top priorities. In subsequent cycles, the lower priority problems will be addressed.

In-depth qualitative data was also obtained through nine semi-structured focus-group discussions and four semi-structured interviews to provide detail and context to the quantitative data obtained by all groups. These methods explored several issues, including how and why problems were identified or prioritised.

In meeting five, the groups assessed the lists of maternal and neonatal health problems they had developed in meetings two, three, and four. The groups began with a discussion about the costs and benefits of prioritising and working on five problems rather than trying to address all the problems identified. Subsequently, the groups discussed and agreed a list of criteria they would use to select the most important problems. All group members used these criteria to vote for the maternal or neonatal health issue they felt was most important in their community. Finally, the number of votes was converted into a rank and the top five issues were taken forward as those to be addressed by the group for the rest of the cycle. Tie-breaking votes were done if a draw made identification of only five priority problems impossible. Although all groups used individual member voting and subsequent ranking to identify the priority problems, they used a range of different methods, which they themselves selected, to facilitate this process. Most groups used blind preference ranking, with members having one vote each (some groups used the same method but members could choose three or five problems each). Some groups, who identified fewer problems overall, also used pair-wise ranking (a method in which the importance of all problems were systematically compared with every other problem). Because of the robustness and participatory nature of the process, disagreements over final ranks were rare. Disagreements were solved by reaching consensus through facilitated discussion. Additionally, groups were encouraged to revisit their priority problems at any point if they felt it necessary.

An important potential bias was the role the facilitators might have had in inducing groups to report problems. The facilitators were expected to be guides rather than leaders in the women's groups. When selected, the criteria for the facilitators included that they should come from the communities in which they would work and that they should be similar to the women who would subsequently attend their groups. Also, facilitators were not health workers and, although they received extensive training in facilitation skills, they received only very basic training in issues relating to maternal and neonatal health. They were also trained to use participatory tools to stimulate discussion and picture cards depicting some of the major maternal and neonatal health problems for clarification. As a result, the facilitators were expected to be able to guide women to actively



Figure 2: A MaiMwana women's group discussing maternal health problems in the community

identify problems and priorities themselves rather than to lead them. Extensive observation of meetings supports these expectations. Although in some instances the facilitators were seen to involve women superficially, on the whole facilitators supported the women to take the lead in making decisions. For example, facilitators were seen to only use the cards to clarify problems after their identification by the groups.

Study population

3171 women and 2833 women, respectively, identified all important maternal health issues (meeting two) and prioritised the five maternal health problems they felt were most important (meeting five). The women's group intervention was implemented in 24 randomly-selected population clusters (mean population 3000 people) with an average of nine groups per cluster. All women in these population clusters were eligible and had the opportunity to attend the groups (figure 2). All women were invited by facilitators or group members to attend either individually or through community meetings. Women of childbearing age were particularly encouraged to attend. The women included in these discussions were predominantly of Chewa ethnicity and ranged in age from 15 to 78 years. Most women involved in identifying maternal health problems also participated in prioritising the health problems, but a small proportion of women were only involved in one or other of these activities because of changes in group membership.

Focus groups were done with six women's groups to supplement the quantitative data. These groups were purposively sampled to represent the range of diversity of characteristics across all 204 groups, such as socioeconomic status, ethnicity, intervention combination, urban-rural mix, and individual characteristics of local facilitators. 67 women took part in these discussions, and ranged in age from 15 to 50 years. Of these women, 90% were married, 39% had no education, 55% had some primary education, and 6% had some secondary education.

Most respondents were of Chewa ethnicity (84%), Ngoni ethnicity (14%), and Senga (2%) ethnicity, representing the district profile. All women in the focus groups had also participated in discussions to identify and prioritise maternal health problems. A further three focus groups were done with the 24 trained local facilitators running the women's groups. These respondents were all born in or were living in the communities in which they were working, all were women, 92% were Chewa and 8% were Senga, and ranged in age from 21 to 32 years. Additionally, 71% were married and all had some secondary-level education. Finally, interviews were done with the four MaiMwana staff supervising the local facilitators and the running of the women's groups. These respondents were all experienced in community development work, all had secondary and some tertiary education, ranged in age from 28 to 50 years, and three were female and one was male.

Data processing and analysis

Data from the summary forms on the identification and prioritisation of maternal health issues were available for 172 and 171 women's groups, respectively, of 204. The remaining 33 groups are still completing or have recently completed the meetings. 119 of the 172 groups who identified problems categorised issues by period, the remainder did not. Verbal consent from the groups was given for the data produced through the monitoring system to be used to explore and assess the implementation of the groups. Some maternal health problems do not have a direct translation in Chichewa. However, they are known and described by their most severe or obvious symptoms. As a result, problems were inferred from the symptoms identified or the group's consensus about which maternal health problems the symptoms represented. A Malawian nurse and doctor assisted in this inference process. After review for accuracy, consistency, and completeness, the data was entered into a Microsoft Access 2002 database, exported to SPSS 11.0, and analysed with descriptive statistics to assess distributions and trends. Issues identified were ranked on the basis of percentage of groups who identified them during discussions. Women ranked problems higher when they felt them to be more important. To indicate this ranking in the aggregate score, problems were given a score by multiplying the number of groups who prioritised the problem by five if the highest priority problem, four if the second highest, and so on. These scores were subsequently added together and used to rank the priority problems for maternal health (maximum possible score 171×5=855).

Data from the focus groups and interviews were audio recorded after receiving verbal consent from respondents. Data in Chichewa were translated into English by a bilingual speaker. To ensure conceptual, grammatical, and syntactical equivalence, translations were subsequently reviewed collaboratively by the researcher who obtained the data and the translator (both bilingual Chichewa-English speakers), and the lead researcher (English speaker). This team made decisions about the best terms to use. All data were subsequently transcribed and imported into MAXqda 2 (VERBI Software version 2), where a system of codes and memos was used by the lead researcher and the researcher who obtained the data. As described previously,²¹ this method sought to develop an analytical framework based on the data by coding and highlighting pertinent excerpts that showed emerging themes. Subsequently, in an iterative process, the researchers refined their analysis, ensuring that the themes built up were cross-checked with other data within and then between transcripts, so that the validity of emerging explanations was tested and improved. The qualitative data was also used to interpret and contextualise the quantitative data.

Results of quantitative and qualitative analyses have been fed back to local facilitators and supervisors. To encourage groups to have the freedom to address their own concerns rather than be swayed by those of other groups, the results will be fed back to groups after the first cycle of the intervention has been completed.

Role of the funding source

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all data in the study and had final responsibility for the decision to submit for publication.

Results

In the meeting to discuss problem identification, 172 groups identified an average of 13 maternal health problems per group (range 4–29). 78 different maternal health problems were identified, with varying degrees of severity. The 119 groups who categorised problems by period identified an average of six in the antenatal period, four intrapartum, and four postpartum. Some

	Problem or symptoms identified (literal translations from Chichewa)	Problem inferred	n (%)	
1	Lack of blood	Anaemia	149 (87%)	
2	Malaria	Malaria	137(80%)	
3	Staying of the placenta	Retained placenta	133 (77%)	
4	Failing to deliver and not enough room to pass	Obstructed labour	130 (76%)	
5	Coming first with the hand/foot/face/cord and bad position	Malpresentation	122 (71%)	
6=	Bleeding before birth	Antepartum haemorrhage	120 (70%)	
6=	Bleeding after birth	Postpartum haemorrhage		
8	High blood pressure, swollen ankles, and blurred vision	Pre-eclampsia	97(56%)	
9	Miscarriage	Miscarriage	70 (41%)	
10	Convulsions	Eclampsia	61 (35%)	
Table 1: The ten maternal health problems most commonly identified by women attending MaiMwana				

Table 1: The ten maternal health problems most commonly identified by women attending MaiMwana women's groups in Mchinji District across all periods (n=172)

	Problem or symptoms identified (literal translations from Chichewa)	Problem inferred	n (%)
Ante	partum (n=119)		
1	Lack of blood	Anaemia	96 (81%)
2	Malaria	Malaria	87 (73%)
3	Bleeding	Haemorrhage	78 (66%)
4=	High blood pressure, swollen ankles, and blurred vision	Pre-eclampsia	43 (36%)
4=	Miscarriage	Miscarriage	
6	Convulsions	Eclampsia	35 (29%)
7	Back pain	Back pain	15 (13%)
8=	Open bowels	Diarrhoea	11 (9%)
8=	HIV/AIDS and sexually transmitted infections	HIV/AIDS and sexually transmitted infections	
10	Coming first with the hand/foot/face/cord and bad position	Malpresentation	5 (4%)
Intra	partum (n=119)		
1	Failing to deliver and not enough room to pass	Obstructed labour	96 (81%)
2	Coming first with the hand/foot/face/cord and bad position	Malpresentation	78 (66%)
3	Bleeding	Haemorrhage	54 (45%)
4	High blood pressure, swollen ankles, and blurred vision	Pre-eclampsia	32 (27%)
5	Staying of the placenta	Retained placenta	23 (19%)
6	Bursting of the womb	Ruptured uterus	11 (9%)
7	Lack of blood	Anaemia	9 (8%)
8=	Malaria	Malaria	6 (5%)
8=	Convulsions	Eclampsia	
10	Stillbirth	Stillbirth	5 (4%)
Post	partum (n=119)		
1	Bleeding	Haemorrhage	84 (71%)
2	Staying of the placenta	Retained placenta	78 (66%)
3	Malaria	Malaria	29 (24%)
4	Lack of blood	Anaemia	26 (22%)
5=	Abdominal pain, fever, and discharge	Sepsis	23 (19%)
5=	Breast problems	Breast problems	
7	High blood pressure, swollen ankles, and blurred vision	Pre-eclampsia	19 (16%)
8	HIV/AIDS and sexually transmitted infections	HIV/AIDS and sexually transmitted infections	17 (14%)
9	Convulsions	Eclampsia	6 (5%)
10	Diarrhoea	Diarrhoea	4 (3%)

problems such as anaemia, malaria, and haemorrhage were identified as taking place in more than one

period. Women appreciated that identification of problems was the essential first step to improving prevention and management of the problems in the future.

"We have discovered these problems and when we learn these problems they should what?...they should vanish... because after discovering this problem we have realised the way of life we should lead...after discovering this problem we can know that to end it I should rush to hospital...I can avoid certain death if I deliver at the hospital"

Focus group discussion-women's group members

The most commonly identified problem across all periods was anaemia, identified by almost nine in ten groups (table 1). More than three-quarters of groups identified malaria, retained placenta, and obstructed labour. An almost equal proportion of groups (70%) identified malpresentation, antepartum haemorrhage, and postpartum haemorrhage. Fewer groups identified pre-eclampsia, miscarriage, and eclampsia. HIV/AIDS (31%) and sepsis (18%) were not in the top ten problems identified. Almost all groups felt that they were in the best position to identify these problems because they knew them through their own experiences and those of their friends and relatives. As a result, most groups thought the process of identification straightforward.

"The importance is that these problems are faced by us alone...when discovering the problems we did not struggle because this was happening to us ...we were remembering what we were experiencing and explaining immediately"

Focus group discussion-women's group members

Anaemia, malaria, and haemorrhage were by far the most commonly identified maternal health problems in the antepartum period (table 2). In the intrapartum period, most groups identified obstructed labour, malpresentation, and haemorrhage. In the postpartum period, haemorrhage and retained placenta were identified as the predominant problems.

In the prioritisation meeting, groups were encouraged to select, from their lists of maternal health problems identified, the five problems they felt were most important so that they could develop strategies to address them. Only limited data are currently available on these strategies, and preliminary analysis shows that the most common strategies discussed were: incomegenerating activities; accessing bednets; training traditional birth attendants; bicycle ambulances; and civic education. The groups themselves chose the criteria on which to judge importance. Severity and commonness were most frequently used to establish the importance of a problem. Respondents defined a severe problem almost exclusively as one that leads to death, and a common problem as one that was experienced within their own community frequently, by many women, and recently. Severity was considered to carry more weight than commonness so that even rare problems could be prioritised if they were considered to be severe enough.

"Severity is the most important thing...they choose severity above commonness because...it may be common but not kill many people but it can be severe and kills everyone who has it...they are prioritising to save lives rather than just trying to keep people healthy...if it is a severe problem that can kill somebody then we need to stop that one" 24 different problems were prioritised by 171 groups. The most important problem was anaemia, which scored 304 out of a possible 855 (figure 3), and ranked in the top five maternal health problems in half the groups (47%). Anaemia was regarded as common, severe, and often resulting in death. It was seen as a long-term illness that was difficult to treat and needed prompt action.

"This issue of lacking blood [anaemia] it really takes a long time to treat and that is one way in which a person could die before they are cured...if there is little blood in the body we could see that if an individual was to delay with treatment or assistance...you could find death faster"

Focus group discussion-women's group members

Malpresentation (295) and retained placenta (277) were ranked in the top five by 43% of groups. Malpresentation was considered to be very severe because there was almost a certainty that either the mother, the baby, or both, would die. Like anaemia, malpresentation was considered a common problem that many women experience locally.

"One of the most contributing factors to maternal death in Mchinji is malpresentation...so people feel it is very severe...because most of them while they were prioritising they said once you are in that situation it is *pakati*—between life and death—its either you dying or the baby dying...and we have seen our friends going with that problem so we really need to do something"

Interview-supervisor

Obstructed labour (276) was prioritised by 41% of groups, postpartum haemorrhage (275) by 40% of groups, and malaria (195) by 38%. Malaria, in addition to being severe and common, was felt to be important because it could be the cause of other problems such as anaemia and jaundice.

"Because when a woman could suffer from malaria...she could be seen to have a weak body...maybe even lacking blood because the body could be hot all the time...this is why we chose malaria because everything comes from malaria"

Focus group discussion-women's group members

25% of groups prioritised antepartum haemorrhage (169). The cumulative score for antepartum and postpartum haemorrhage was 444, which ranked haemorrhage above all other problems. Antepartum and postpartum haemorrhage were prioritised for similar reasons to the other problems but were also perceived to be difficult for communities to manage locally without accessing other external resources.

"It [haemorrhage] is mostly found in the village...it is very common...it has also the problem of control... control is difficult for them...it is difficult to control such problems within the community"

Focus group discussion–local facilitators

Eclampsia (74) was prioritised by 13% of groups, pre-eclampsia (54) by 8% and HIV/AIDS (27) by 5%. Sepsis (12) was prioritised by only 2% of groups and ranked twelfth. The respondents gave several reasons why HIV/AIDS and sepsis were ranked so low. HIV/AIDS and sepsis were considered complex illnesses that lacked coherence in their symptoms or the problems they caused, which made distinguishing them from other problems difficult.

"It is unlike other problems...if you have malaria you know you have malaria...you have the symptoms but HIV/AIDS has many symptoms so it is difficult to say I have HIV or not..."

Interview-supervisor

"The problem here is that HIV/AIDS is identified by medical personnel...they themselves [community members] cannot find out that this problem is here because the people haven't been tested...of course we know that there is this problem but in our village nobody has been tested so how can we prioritise it?"

Interview-supervisor

There is still a taboo surrounding HIV/AIDS that makes open discussion or prioritisation of the issue inappropriate within communities, despite the knowledge and acceptance that the disease exists.



Figure 3: Ten maternal health problems prioritised as most important by women attending MaiMwana women's groups in Mchinji district

"In some communities they are still closed...I think it is lack of sensitisation and awareness of HIV/AIDS...they know the problem is there but they can't air it...so it is very difficult to say you have HIV/AIDS in this community...they cant accept it...but in this village the women are really serious about it because they said there have been mothers dying of HIV/AIDS related illnesses so I think we need to do something and we are keeping orphans in our houses so really it is a problem"

Interview-supervisor

Additionally, HIV/AIDS was thought as a general problem that could affect anyone rather than a specific maternal health problem, and considered an untreatable disease and therefore fruitless to address.

"Why prioritise something that you can do nothing about...this problem doesn't even have treatment so even if we are going to prioritise it how are we going to address it"

Focus group discussion-women's group members

First priority ranking was different from the cumulative priority ranking described above. Malpresentation (16% of groups) and postpartum haemorrhage (15%) were the problems most commonly identified as the first priority, which indicated how severe and common these problems were judged. Fewer groups prioritised malaria as priority one, although the disease was most commonly ranked priority four and priority five (8% in both cases). Women's groups perceived malaria to be an important but routine problem that was easy to identify, and quick and simple to treat even when there were delays in seeking treatment.

"Malaria is a disease whereby you could go to hospital and receiving Fansidar [sulfadoxine-pyrimethanine]...at this very moment you could feel better... as for malaria even when you could delay with treatment or assistance it could be quickly treated"

Focus group discussion-women's group members

Discussion

Women's groups in rural Malawi identified and subsequently prioritised anaemia, malpresentation, retained placenta, obstructed labour, postpartum haemorrhage, malaria, antepartum haemorrhage, and eclampsia as their most important maternal problems. HIV/AIDS and sepsis were identified and prioritised much less commonly. Groups regarded severity as primary criteria and commonness as secondary criteria to assess importance. This study shows that, through collectively sharing experiences, groups of women can identify most maternal health problems, recognise how important they are, and want to address them.

The main limitation of this study was the process through which problems were identified. Some clinical maternal health problems do not exist as a coherent idea of illness in the community but rather as disparate symptoms. In many of these cases, women's groups were

guided to assign instances of the co-occurrence of their most severe or obvious symptoms as the clinical problem these symptoms most commonly describe. The groups were guided to do this by the trained facilitator using the picture cards and the discussion tools. Since this process did not allow an in-depth exploration of exactly what the groups meant by each problem identified, some problems might have been over or under identified and thus over or under prioritised. Since some maternal health problems do not have a direct translation in Chichewa, misidentification might also have taken place through the process of inferring the problems identified by the groups from the Chichewa terms used to describe them. Furthermore, although our experiences have highlighted that the problems raised and their prioritisation came predominantly from the women themselves, there is the potential that in a few cases the results might have been biased by the facilitator. Our sample was large but our study was done in one district in Malawi with a population coming predominantly from one ethnicity. Furthermore, women selected themselves to attend groups and this might make the sample systematically different from the general population in relation to certain demographic characteristics.

We would argue that the process by which women identify problems they perceive as important, and go on to develop strategies to deal with them, is intrinsically valuable, irrespective of whether or not they represent the epidemiological pattern. Taking a more literal approach, however, what would be the effects at population level if women addressed the problems they have prioritised? No data are available for the prevalence of maternal health problems in community settings in Malawi. The best data for comparison are from an institutional review of direct and indirect causes of maternal deaths. The incidence data showed: postpartum sepsis caused 20% of institutional deaths; obstructed labour caused 15%; anaemia 9%; HIV/AIDS 9%; postpartum haemorrhage 8%; meningitis 8%; complications of abortion 7%; eclampsia and pre-eclampsia 5%; malaria 4%; and retained placenta 3%.4 These data are similar to women's groups' priorities, but, importantly, the two datasets are not directly comparable. This paper presents data from a community rather than an institutional population and includes all problems, not only those that lead to maternal deaths. Furthermore, the data are for perceptions rather than prevalence. These perceptions were developed through consideration of a wide range of factors, only one of which is prevalence.

Women's groups distinguished haemorrhage by the period in which it happened. Haemorrhage was in the top three most commonly identified problems in all three periods. Combining scores of antepartum and postpartum haemorrhage makes it by far the leading problem identified. Although a small proportion of this result could be attributable to the misclassification of normal bleeding particularly during and after birth, a systematic review by WHO showed haemorrhage was the leading cause of maternal death in Africa (point estimate 34%, range 13-44%).²²

The most obvious underestimates by women's groups of complications seem to be HIV/AIDS and sepsis. Data from the summary forms show that few groups identified HIV/AIDS (9% antepartum and 14% postpartum) and sepsis (19% postpartum) as problems, and only HIV/AIDS was prioritised in the top ten most important problems (ranked tenth with a score of 27). In 2004, infection and HIV/AIDS were in the top five main direct and indirect causes for maternal deaths in Malawi.⁴ Additionally, a paper reviewing causes of over 200 maternal deaths in Queen's Hospital in Blantyre showed that nearly three-quarters of maternal deaths in a population accessing a tertiary care hospital had an infection-related component.²³

Assessment of the data reveals that the discrepancy is predominantly a function of the problems themselves and the local context. HIV/AIDS and sepsis are considered to be complex illnesses that are difficult to identify and distinguish from other problems. For example, in Malawi all febrile illnesses such as sepsis, infection, and malaria are commonly termed malungo.24,25 Even clinicians struggle to diagnose these problems without laboratory tests. In the case of HIV/AIDS, several focus groups stated that it was a problem that could affect anyone rather than specifically mothers. The local context exacerbates these difficulties because there still exists a reservation to discuss issues around HIV/AIDS in rural Malawi, and these group discussions were held early in the lifetime of the women's groups. Only 15% of pregnant women in Mchinji district have gone for voluntary counselling and testing.26 Few people know their status, and thus assessment of prevalence and the effect on maternal health is impossible. Furthermore, in Mchinji district prevention of mother-to-child transmission of HIV services and highly active antiretroviral treatment (HAART) are both only available in two out of 14 health facilities, and voluntary counselling and testing in only six, so they are not accessible to much of the population. This situation explains why HIV/AIDS is judged untreatable and why the groups felt there was little point trying to address it. The availability of HAART is, however, changing rapidly. Another study showed that scalability of HAART is feasible and cost effective in similarly poor communities of Malawi.27

The differences between the frequency of identification and the prioritisation of problems bear some consideration. On the whole, the problems most commonly identified were also the highest priorities. In some cases—such as malaria—a common problem was thought to be less of a priority. We have already noted that priority depended on both frequency and perceived severity. Severity itself depended on several dimensions: chronicity, the difficulty of treatment, particularly using local resources, the potential for fatality in the event of delay, a specificity to mothers and pregnant women, and the potential to co-affect both mother and baby. Women in groups thus consider themselves to be at high risk from the problems and feel that the consequences can be serious. These findings suggest that, as well as raising awareness, women in groups have developed certain attitudes that underpin the intention to change behaviour,²⁸ and indeed expressed their motivations to move from identification and prioritisation to addressing problems.

Traditionally, health education interventions and those at a health facility level have been the key elements of most safe motherhood programmes, despite little hard evidence to suggest they are effective in poor communities.²⁹ To improve preventive and care-seeking behaviours, an increase in knowledge and a change in attitudes is necessary.28 The data for the perceptions of women's groups presented here suggests that a great deal of this capacity already exists in communities. Furthermore, whereas earlier studies suggest that women as individuals do not have a comprehensive awareness of the problems that affect them,14,15 our study suggests that this capacity can be accessed and channelled through women meeting and collectively discussing these issues. This process enables women to clearly identify their maternal health problems, recognise their importance, and generate motivation to address them. Thus women's own perceptions of their problems could form a vital resource for communities and policymakers whether or not such information indicates epidemiological prevalence. In Africa, maternal health has had a low priority with policymakers because of poor epidemiological data, but also because of poor community involvement in decision-making about health priorities. Research in Nepal has shown that women's participation is potentially important⁹ in reducing mortality, but we must await the findings of our randomised controlled trial in Malawi to see if maternal mortality rates at population level will be reduced by the mobilisation of communities through women's groups. Community mobilisation strategies could be effective and efficient in rural Africa because they would build on the capacity that already exists, and tap into the collective knowledge and deeply felt concerns of rural women.

Rural women in Malawi have a mature understanding of their maternal health risks and problems. Women's groups made careful judgments about maternal health priorities on the basis of both prevalence and severity. Their voices need to be heard by decision-makers, and the participation of women in finding solutions to the huge risks of pregnancy in Africa is possibly the most important part of the solution.

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Conflict of interest statement

We declare that we have no conflict of interest.

Contributors

M Rosato designed the study and the data collection tools, collected interview data, did the quantitative and qualitative analysis, and wrote the first draft of the paper. Q Soko managed the collection of the quantitative data and B Kunyenge collected the focus group data and assisted in the qualitative analysis. S Lewycka, A Costello, D Osrin, and M-L Newell designed the main trial study. T Phiri managed the project, C Mwansambo and P Kazembe were the directors, and M Rosato, S Lewycka, and S Vergnano were technical advisers. All authors criticised drafts of the paper, and M Rosato and A Costello were responsible for subsequent collation of inputs and redrafting. C Mwansambo and A Costello are guarantors for the paper.

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