

Beyond the Numbers: reviewing maternal deaths and complications to make pregnancy safer

Gwyneth Lewis

Department of Reproductive Health and Research, World Health Organization, Geneva, Switzerland

'Whose faces are behind the numbers? What were their stories? What were their dreams? They left behind children and families. They also left behind clues as to why their lives end so early¹'

Avoiding maternal deaths is possible, even in resource-poor countries, but requires the right kind of information on which to base programmes. Knowing the level of maternal mortality is not enough; we need to understand the underlying factors that led to the deaths. Each maternal death or case of life-threatening complication has a story to tell and can provide indications on practical ways of addressing its causes and determinants. Maternal death or morbidity reviews provide evidence of where the main problems in overcoming maternal mortality and morbidity may lie, produce an analysis of what can be done in practical terms and highlight the key areas requiring recommendations for health sector and community action as well as guidelines for improving clinical outcomes. The information gained from such enquiries must be used as a prerequisite for action.

'A pregnant woman has one foot in the grave'

Correspondence to:
Gwyneth Lewis, Director
and editor of the United
Kingdom Confidential
Enquiries into Maternal
Deaths and member of
the Making Pregnancy
Safer Team, Department
of Reproductive Health
and Research, World
Health Organization, 20
Avenue Appia, CH-1211
Geneva 27, Switzerland.
E-mail: Gwyneth.Lewis@
doh.gsi.gov.uk

This traditional African saying summarizes the difficulties faced by pregnant women in many parts of the world. As discussed in Chapter 1, which provides a résumé of the global burden of maternal deaths and disability, each year throughout the world approximately eight million women are suffering pregnancy-related complications and over half a million will die². In some developing countries, one in 11 pregnant women may die of pregnancy-related complications compared to one in 5000–10,000 in some developed countries.

The most recent world estimate of the overall maternal mortality ratio (MMR) is around 400 per 100,000 live births. By the Regions of the World Health Organization (WHO), the MMR is highest in Africa (830), followed by Asia (330), Oceania, excluding Japan, Australia and New Zealand

(240), Latin America and the Caribbean (190), and the developed countries (20). These figures hide wide inter-country variations and even within countries major discrepancies exist between the rich and poor and urban and remote areas. With the exception of Afghanistan and Haiti, all other of the 22 countries with MMRs in excess of 1000 per 100,000 live births are in sub-Saharan Africa.

These figures represent the largest public health discrepancy in the world. Each death or long-term complication represents an individual tragedy for the woman, her partner, her children and family. More tragically, most deaths are avoidable. It is estimated that more than 80% of maternal deaths could be prevented or avoided through actions that are proven to be effective and affordable, even in resource-poor countries³. For example, reviews such as have occurred in Egypt⁴ and elsewhere have shown that the quality of care provided to the women is a key determinant in maternal outcome and that, sometimes, simple changes in practice can save many lives.

Why do mothers really die?

While it may appear simple to use MMRs for purposes of comparison or for tracking change over time or to analyse what vital statistics may be available to attribute the causes of death to clinical categories, neither method provides any information on the real and underlying reasons why women die.

MMRs give no indication of either from what clinical conditions women are dying, what factors led to their deaths or whether the majority of deaths occur amongst women from any particular groups in society or geographical areas. And MMRs cannot be used to determine the estimates of pregnancy-related complications which the women have survived but have resulted in long-term severe disabilities. In the UK, the apparently low MMR hides a 20-fold difference in maternal mortality amongst women from the most vulnerable groups in society compared to those from the most affluent⁵. These women died from a wide variety of causes and it was only when their deaths were assessed by the UK Confidential Enquiry into Maternal Deaths (UKCEMD) that the commonest factor, lack of regular contact with the health services, was identified. Overcoming these inequalities in access to health care will be the cornerstone of the forthcoming National Service Framework for Maternity and Children's Health in England.

Death certificates, where they exist, and even if the coding of cause of death is correct, also give no information on the real reasons why the women died. The main direct clinical causes of maternal death are listed in vital statistic data as haemorrhage, sepsis, eclampsia, obstructed

labour and unsafe abortion. But these numbers still hide the real reason why these women may be dying. For example a woman dying from haemorrhage may have not understood the need to seek care, may not have had money or access to transport, may have been deterred from seeking help by inappropriate traditional practices, may have received inadequate clinical care or may have been treated in a facility without access to blood products. Knowing the precise reasons why such women die will enable a start to be made in addressing the specific problems to be overcome. These may include community and personal awareness, the provision of transport, updating health care worker training or improving the blood supply.

The reality is that the vast majority of women die usually because they do not receive the health care that they need. This may be the result of a lack of basic health care provision or through, for whatever reason, an inability to access the local health care services. As discussed in Chapter 4 on skilled care, only 53% of women in developing countries receive assistance from a skilled attendant at birth. Some women are denied access to care because of cultural beliefs and practices, seclusion or because responsibility for decision making falls to her husband or other family members. In many cases, the failure of support for pregnant women by families, partners or their government reflects the societal value placed on women's lives.

Maternal complications and disability

Maternal deaths are the tip of the iceberg of maternal disability and for every woman who dies, many more will survive but often suffer from life long disabilities. These are not only personal and family tragedies, for example as described in Chapter 15 on obstructed labour and obstetric fistula, but their loss of the ability to work or support the family also carries a huge economic burden. Chapter 1 has described the inherent difficulties in trying to estimate the number of severe maternal morbidities. A conservative estimate of 20 disabilities per maternal death made by the WHO AFRO Region was used for a recent economic impact study. The results of this suggested that, unless women's health care provision improved, the economic burden from maternal deaths and disabilities in Africa alone would lead to a \$45 billion loss in productivity over the next 10 years⁴.

It is difficult to determine accurately the precise number of women suffering from morbidity for many reasons, not least the fact that in many parts of the world the woman will never have had contact with the health services. However, in the developed world, a number of studies have been published on the incidence of severe maternal morbidity, or 'near-misses',

but comparison between them is difficult because of the different definitions of morbidity used. The death to near-miss ratio in these studies ranges from 1:5⁶ to 1:118⁷ per maternal death. But whatever the death to disability ratio actually is, the fact is that, as with the MMR, it will always be too high. Since women are disabled by the same conditions that cause maternal deaths, reducing the risk factors for maternal deaths will also reduce the numbers of women who experience significant medical or psychological problems before, during or after birth, sometimes with long-lasting or permanent sequelae.

Looking beyond the numbers

Whilst the numbers of maternal deaths and severe complaints are stark, they tell only part of the story. In particular, they tell us nothing about the *faces behind the numbers*, the individual stories of suffering and distress and the real underlying reasons why particular women died. Most of all, they tell us nothing about why women continue to die in a world where the knowledge and resources to prevent such deaths are available or attainable. While it is important to keep monitoring overall levels of maternal mortality at global, regional and national levels, for both identification and advocacy purposes, statistics about the level of maternal mortality do not help us identify what can be done to prevent or avoid such unnecessary deaths.

Today, with better understanding of the difficulties involved in measuring levels of maternal mortality, and the cost of conducting a full-scale exercise to determine overall MMRs, there is increasing interest in directing a larger share of limited resources into efforts to understand why the problem persists and what can be done to avert maternal deaths and cases of severe morbidity. Answering these questions is vital for programme planners, managers and service providers. In order to help address this, the WHO's Making Pregnancy Safer initiative will shortly publish 'Beyond the Numbers'⁸, a guide which describes a number of strategies and approaches to review cases of maternal death or disability to help understand why mothers really die to enable the necessary actions to be taken on the results.

'Beyond the Numbers': a new approach to diagnosis

The methodologies for understanding why women die or suffer long-term complications, described in 'Beyond the Numbers', are designed to be a first step in the process of planning, implementing and evaluating strategies to helping reduce maternal deaths and disability. As with any

life-threatening clinical condition, a diagnosis needs to be made before the appropriate treatment can be provided. It is this crucial first step that has often been lacking in the design of well-meaning but eventually partially ineffective programmes for maternal ill-health reduction. The use of these techniques can help with the diagnosis of the underlying causes, for example, are women dying because:

they were unaware of the need for care, or unaware of the warning signs of problems in pregnancy?

or

the services did not exist, or were inaccessible for other reasons such as distance, cost or sociocultural barriers?

or

are women dying because the care they receive in traditional or modern health services is inadequate or actually harmful?

Answering such questions and taking positive action on the results is often more important than knowing the precise level of magnitude of maternal mortality. The various approaches described in 'Beyond the Numbers' will enable, and empower, health professionals and authorities to act on the answers to these and other important questions about why women die during pregnancy and childbirth. In planning any such review, it is important to build in sustainability from the beginning so that such activities become a routine part of clinical practice and health information systems.

Maternal mortality and safe motherhood committees, as well as all other stakeholders in maternal health, for example international agencies, non-governmental organizations, community groups and health advocates, will also be able to use the information generated from using these approaches. The results of these reviews can have a powerful advocacy role and can also be used by politicians and those in other positions of influence to raise awareness and mobilize resources.

In the UK, the most dramatic decline in a local MMR was achieved in Rochdale, an industrial town in the poorest area of England, which, in 1928, had a MMR of over 900 per 100,000 live births, more than double the national average of the time. Following local concern, the local public health department undertook a confidential enquiry into maternal deaths in the community and associated hospitals, action on the results of which reduced the MMR to 280 per 100,000 pregnancies by 1934, the lowest in the country. This decline took only 6 years and this achievement was all the more remarkable as it took place during a time of severe economic depression. As the report states: 'it is important to note that the results were obtained by a change in spirit and method and without any alteration in the personnel or any substantial increase in public

expenditure⁹. The review ascertained that the leading causes of death—haemorrhage, eclampsia and sepsis—were compounded by the women’s lack of knowledge about pregnancy and warning signs of complications and the far too frequent use of forceps and other techniques to deliver the women quickly. The local medical and midwifery profession worked together to introduce a public health education campaign, to reduce unnecessary obstetric practices and to introduce new standards of care. As the published report states ‘all available agencies such as the platform, the pulpit, the factory supervisor, and the press, were used to awaken the community to the need for antenatal care and the signs and symptoms of complications’.

The above case history clearly demonstrates how generating information about the real reasons why mothers die can be used by health professionals, health care planners and managers to save women’s lives. All the approaches described in ‘Beyond the Numbers’ go beyond counting the numbers of cases of death to understanding why they happened and how they can be prevented or avoided. The approaches can be adapted for use in any country and in any setting by anyone with a commitment to safe motherhood. Acting on the results of these studies offers an opportunity for all involved in planning and providing services for pregnant, delivering and recently delivered women to make a real and lasting difference to their lives and those of their families and communities. Depending on the results, and where the reviews took place, the outcomes may range from local to national public education campaigns, the mobilization of community resources, the restructuring of local clinics to make them more accessible or changing clinical practice by the development of local or national clinical guidelines. Experience from the use of these approaches has shown that although the initial implementation is often on a small scale by a few committed individuals, they can subsequently be implemented on a broader scale, including at the national level.

The five key approaches

‘Beyond the Numbers’ describes five different types of review or audit that can be used in a variety of settings, from the very simple to the sophisticated, to help reduce maternal deaths and disability. They can be used at different levels, from the national to local, and in communities, health facilities or both. Further, the approaches can be used for two specific health outcomes (maternal deaths and women who survive life-threatening complications) and for one kind of process (clinical care). These approaches are summarized in Table 1.

Whilst it is beyond the scope of this short chapter to describe each approach in detail, with its attendant pre-requisites, advantages and disadvantages,

'Beyond the Numbers' does just that. It contains a general overview, chapters on how to decide which approach may be best to adopt for a given situation or population, a general chapter on underlying principles common to each methodology and specific chapters for each technique. These specific chapters describe each methodology in detail, and the practical steps required to set up such a study as well as providing helpful case histories. The book is accompanied by a companion CD-ROM which contains practical examples of existing questionnaires that have been developed and used in undertaking such studies in a number of areas in the world. These are available for adaptation by others wishing to adopt similar methodologies. The information will also be available on the WHO RHR website in due course¹¹.

Deciding which of the approaches to use is influenced by two considerations, namely which level is appropriate for the review, and what kind of cases will be studied. In terms of level, there are essentially five options—the review can be conducted at the community, health care facility, or district, regional or national levels. In choosing which cases to study, a decision needs to be taken whether these will be outcomes or processes. Not all locations are suited to reviewing all types of cases. For example, auditing clinical practice, for resource-poor countries, may be more feasible at

Table 1 Summary of approaches described in 'Beyond the Numbers'

Approach	Definition
Community-based maternal death reviews (verbal autopsies)	A method of finding out the medical causes of death and ascertaining the personal, family or community factors that may have contributed to the deaths in women who died outside of a medical facility
Facility-based maternal deaths review	A qualitative, in-depth investigation of the causes of and circumstances surrounding maternal deaths occurring at health facilities. Deaths are initially identified at the facility level but such reviews may be expanded to identify the combination of factors at the facility and in the community that contributed to the death and which deaths were avoidable
Confidential enquiries into maternal deaths	A systematic multi-disciplinary anonymous investigation of all or a representative sample of maternal deaths occurring at an area, regional (state) or national level. It identifies the numbers, causes and avoidable or remediable factors associated with them
Reviews of severe morbidity (near misses)	The identification and assessment of cases in which pregnant women survive obstetric complications. These can be used in addition to reviewing maternal deaths through any of the other approaches described here There is no universally applicable definition for such cases and it is important that the definition used in any review be appropriate to local circumstances to enable local improvements in maternal care
Clinical audit	Clinical audit has been described as a quality improvement process that seeks to improve patient care and outcomes through systematic review of aspects of the structure, processes and outcomes of care against explicit criteria and the subsequent implementation of change. Where indicated, changes are implemented at an individual, team or service level and further monitoring is used to confirm improvement in healthcare delivery ¹⁰

Table 2 Different approaches at different levels and for different topics

Level	Outcome		
	Maternal deaths	Severe complications	Clinical practice
Community	Verbal autopsy (community-based death reviews)	No	No
Facility or groups of facilities	Facility-based deaths review	Severe morbidity or 'near miss' case review	Local clinical audit
National/regional/district	Confidential enquiry into maternal deaths	Confidential enquiry into near misses	National/regional/district clinical audit

the facility level and not be possible at the community level. On the other hand, both outcome and process are amenable to review at the facility level. It is unlikely to be possible to review severe complications at the community level because of the complexity of applying a standard and unambiguous definition of 'near miss'. Table 2 summarizes the different possibilities.

These approaches for investigating maternal deaths have been developed mainly for countries where levels of maternal mortality are high. However, the investigation of maternal deaths is also important in settings where maternal mortality is low. Evidence has shown that, even in such settings, many maternal deaths are the result of substandard care and could be prevented.

The importance of 'telling the story'

Most of these approaches are observational studies which take account of the medical and non-medical factors that led to a woman's death. They provide data on individual cases, which, when aggregated together, can show trends or common factors for which remediable action may be possible. They *tell the story* of how individual women died.

Participating in reviews such as those described here, whether by describing one's own contribution to the care of a particular woman, extracting information from the case notes or by assessing the case anonymously, is, in and of itself, a health care intervention. Experience has shown that the use of these approaches can have a major impact on those involved. Often those participating in the review are motivated to change their practice or service delivery, even before the formal publication of the results. These health care workers, who have seen for themselves the benefits from such relatively simple reviews, including the adoption of

simple changes in local practice, become advocates for change. They then motivate and enthuse others to undertake similar work and to help spread evidence-based best practice guidance.

Those participating in such reviews also never forget that each woman's death is an individual personal and family tragedy. Neither do they forget she had a unique story to tell. Tracing her path through the community and health care system and describing the actions that might have prevented her death have a meaningful personal effect. In the UK, as long ago as 1954, it was recognized that participating in such a study (in this case a confidential enquiry into maternal deaths) had a 'powerful secondary effect' in that 'each participant in these enquiries, however experienced he or she may be, and whether his or her work is undertaken in a teaching hospital, a local hospital, in the community or the patient's home must have benefited from their educative effect'¹².

Participating in these studies also builds on the natural altruism of individual or teams of health care professionals, who are prepared to freely give their time and effort in order to learn lessons to help save women's lives. These personal experiences lead to self-reflective learning which is as much, or even more a valuable tool for harnessing change as anonymous statistical reporting.

But perhaps one of the most powerful reasons for such reviews, reported by clinicians and midwives in different countries, is the personal and long-lasting impact that the death of a woman known to them has had on their own clinical practice and that of their institution. Most will say that having to seriously evaluate the care given to a particular woman, whose face they can still see and whose grieving family they can still remember, changed their clinical practice and subsequently saved many lives.

No name, no blame

A fundamental principle of all the approaches described here is the importance of a confidential, usually anonymous, non-threatening environment in which to describe and analyse the factors leading to individual women's deaths. Ensuring confidentiality leads to an openness in reporting which provides a more complete picture as to the precise sequence of events. Participants, including health care and community workers and family members, should be assured that the sole purpose of the study is to save lives and not to apportion blame. A pre-requisite, therefore, is that strict confidentiality, or anonymity, must be maintained. These reviews seek only to identify failures in the health care system, not to provide the basis for litigation, management sanctions or blame.

Learning lessons is a pre-requisite for action

Learning lessons and acting on the results is the whole purpose of using these approaches. There is no point in committing valuable resources to collecting information that just gathers dust on shelves. The information that is collected must be used to help improve maternal health outcomes and empower health professionals to examine their current practices or those of the facility in which they work. Because action is the ultimate goal of these reviews, it is important that those with the ability to implement the recommended changes actively participate in the process. It therefore needs to be agreed at the outset that the information obtained will be used for action.

The results of these reviews will determine what, if any, avoidable or remediable clinical, health system or community based factors were present in the care provided to the women. The lessons derived will enable health care practitioners and health planners to learn from the errors of the past. They will provide evidence of where the problems are and highlight the areas requiring recommendations for health sector and community action as well as clinical guidelines. The results can form a baseline against which the success of changing practice can be monitored. Therefore, in-built into the system, there should be an objective method to monitor how the recommendations are being implemented. This has two benefits: it provides a stimulus for health sector action; and it reminds the study team to be sure that their recommendations are based on firm evidence.

All of the approaches described here will result in recommendations for change. What is important is that the recommendations made should, particularly in poorer countries, be simple, affordable, effective and widely disseminated. They should also be evidence based. Most of the clinical recommendations likely to emerge will be very similar to the evidence-based guidelines which form part of the WHO's Integrated Management of Pregnancy and Childbirth (IMPAC) tools and these could be adapted for local circumstances and introduced swiftly without the need to start developing guidelines from scratch. (IMPAC is a comprehensive set of norms, standards and tools that can be adapted and applied at the national and district levels in support to country efforts to reduce maternal and perinatal morbidity and mortality. Available from Department of Reproductive Health and Research, WHO, Geneva. Consult the website <http://www.who.int/reproductive-health/index.htm> for other information.)

To summarize, without the ability to diagnose the problem of why so many of the pregnant women in the world die or suffer severe complications of pregnancy, the opportunity to identify the correct remedial actions for particular women in different circumstances is lost. There is no 'one size fits all solution'. Even though the causes and determinants may be

similar, each country, district, facility or community faces a unique set of problems and constraints and requires an individualized approach to overcome these. The philosophy proposed here and the methodologies for audit and case review briefly described are the essential first step in this process. Looking 'Beyond the Numbers' to learn lessons in order to save lives and to reduce the burden of severe maternal and neonatal morbidity is practical, effective and may require little in the way of additional resources. Continually acting on the results of reviews which tell the stories of why mothers died saves the lives of future mothers and babies, and respects and honours those women who died so that some good may come from such a vast number of avoidable tragedies.

The views expressed in this article are those of the author and should not be taken to represent those of the World Health Organization.

References

- 1 Callaghan W. Epilogue. In Berg C. *et al* (eds) *Strategies to Reduce Pregnancy-Related Deaths: From Identification and Review to Action*. Atlanta, GA: Centres for Disease Control and Prevention, US Department of Health and Human Services, 2001
- 2 World Health Organization. *Maternal Mortality in 1995. Estimates Developed by WHO, UNICEF and UNFPA*. Geneva: WHO, 2001
- 3 World Health Organization Regional Office for Africa. *Reducing Maternal Deaths; The Challenge of the New Millennium in the Africa Region*. Congo: World Health Organization Regional Office for Africa, 2002. www.afro.who.int/drh/index.html
- 4 Ministry of Health Egypt. *National Maternal Mortality Study*. Egypt: Ministry of Health, 1992–1993
- 5 Why Mothers Die. *The United Kingdom Confidential Enquiries into Maternal Health 1997–99*. London: RCOG Press, 2001
- 6 Mantel GD, Buchmann E, Rees H, Pattinson RC. Severe acute maternal morbidity: a pilot study of a definition for a near-miss. *Br J Obstet Gynaecol* 1998; **105**: 985–90
- 7 Waterstone M, Bewley S, Wolfe C. Incidence and predictors of severe obstetric morbidity: case-control study. *BMJ* 2001; **322**: 1089–94
- 8 World Health Organization. *Beyond the Numbers: Reviewing Maternal Deaths and Complications to Make Pregnancy Safer*. Geneva: WHO, 2004; In press
- 9 Oxley W, Phillips M, Young J. Maternal mortality in Rochdale. *BMJ* 1935; **304**: 304–7
- 10 National Institute for Clinical Excellence. *Principles and Practice in Clinical Audit*. London: The National Institute for Clinical Excellence, 2002. <http://www.nice.org.uk>
- 11 Website <http://www.who.int/reproductive-health>
- 12 The Department of Health. *The Confidential Enquiries into Maternal Deaths in England and Wales 1952–54*. London: Department of Health for England, 1954

Beyond the numbers: reviewing maternal deaths and complications to make pregnancy safer. Br Med Bull. 2003;67:27-37. doi: 10.1093/bmb/ldg009. Each maternal death or case of life-threatening complication has a story to tell and can provide indications on practical ways of addressing its causes and determinants. Maternal death or morbidity reviews provide evidence of where the main problems in overcoming maternal mortality and morbidity may lie, produce an analysis of what can be done in practical terms and highlight the key areas requiring recommendations for health sector and community action as well as guidelines for improving clinical outcomes. The information gained from such enquiries must be used as a prerequisite for action. M @article{Lewis2008ReviewingMD, title={Reviewing maternal deaths to make pregnancy safer.}, author={G. Lewis.}, journal={Best practice & research. Clinical obstetrics & gynaecology}, year={2008}, volume={22 3}, pages={. 447-63 } }. Each year, some eight million women around the world suffer pregnancy-related complications; over half a million of these women die. Although most of these deaths could be averted at little or no extra cost, even where resources are limited, if we are to take action and develop and implement changes to maternity services to save the lives of mothers and newborns, we need the right kind of information. This more in-depth information might not be available through national statistics on maternal death. The small number of cases makes the evaluation of maternal mortality practically impossible[2][3] Historically, the study of negative outcomes have been highly successful in preventing their causes, this strategy of prevention therefore faces difficulties when if the number of negative outcome drop to low levels. In the UK, for example, the most dramatic decline in maternal death was achieved in Rochdale, an industrial town in the poorest area of England. In 1928 the town had a Maternal Mortality Ratio of over 900 per 100,000 live births, more than double the national average of the time. "Beyond the Numbers: reviewing maternal deaths and complications to make pregnancy safer". British Medical Bulletin. 67 (1): 27-37. doi:10.1093/bmb/ldg009.