

COMMENTARY

Legal and Ethical Considerations during Maternal Death Surveillance and Response

DOI: 10.29063/ajrh2018/v22i2.2

Luchuo Engelbert Bain^{1,2} and Eugene Justine Kongnyuy³*

Vrije Universiteit, Faculty of Science, Athena Institute for Research on Innovation and Communication in Health and Life Sciences, Amsterdam, The Netherlands¹; Centre for Population Studies and Health Promotion, Yaounde, Cameroon²; United Nations Population Fund (UNFPA), Abuja, Nigeria³

***For Correspondence:** Email: *lebaiins@gmail.com*; Phone: +31(0)205989170

Abstract

Maternal death surveillance and response (MDSR) is a promising strategy, to identify record and track key drivers of maternal deaths. Despite its potential in reducing maternal mortality, ethical and legal challenges need to be properly ascertained and acted upon, to guarantee its acceptability, sustainability, and effectiveness. This paper proposes a legal and ethical framework to guide practitioners and researchers through the MDSR process. Three (03) categories of both legal and ethical issues are discussed: namely the issues related to data, people and use of findings. Most challenges of the MDSR strategy have ethical and legal underappraisal origins, the most outstanding being the low maternal death notification rates. Efforts should be made for respondents to properly understand the rationale for the process, and how the data obtained will be put into use. Dispelling fears of possible litigation remains fundamental in obtaining quality data. Health care providers involved in the process need to understand their ethical and legal responsibilities, as well as privileges (legal protection). It is hoped that this framework will offer a structure to guide professionals in improving MDSR implementation and research. (*Afr J Reprod Health 2018; 22[2]: 17-25*).

Keywords maternal death surveillance, mortality, legal, ethical

Résumé

La surveillance et l'intervention en cas des décès maternels (SIDM) constituent une stratégie prometteuse pour identifier et enregistrer les principaux facteurs de mortalité maternelle. En dépit de son potentiel de réduction de la mortalité maternelle, les défis éthiques et juridiques doivent être correctement établis et mis en pratique, afin de garantir leur acceptabilité, leur durabilité et leur efficacité. Cet article propose un cadre juridique et éthique pour guider les praticiens et les chercheurs dans le processus de la SIDM. Trois (03) catégories de questions juridiques et éthiques sont discutées: à savoir les questions liées aux données, aux personnes et à l'utilisation des résultats. La plupart des défis de la stratégie SIDM ont des origines éthiques et juridiques sous-évaluées, les plus remarquables étant les faibles taux de notification des décès maternels. Des efforts devraient être faits pour que les répondants comprennent correctement la raison d'être du processus et comment les données obtenues seront utilisées. Dissiper les craintes d'éventuels litiges reste fondamental pour obtenir des données de qualité. Les fournisseurs de soins de santé impliqués dans le processus doivent comprendre leurs responsabilités éthiques et légales, ainsi que leurs privilèges (protection juridique). On espère que ce cadre offrira une structure pour guider les professionnels dans l'amélioration de la mise en œuvre et de la recherche en matière de la SIDM. (*Afr J Reprod Health 2018; 22[2]: 17-25*).

Mots-clés: surveillance de la mortalité maternelle, mortalité, juridique, éthique

Introduction

Maternal mortality remains unacceptably high, with about 830 women dying from preventable pregnancy- or childbirth-related complications every day. Maternal death is the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes¹. Over 99% of these deaths occur in low and middle-income countries (LMICs)¹. One target under Sustainable Development Goal 3 is to reduce the global maternal mortality ratio to less than 70 per 100 000 births, with no country having a maternal mortality rate of more than twice the global average by 2030¹. Properly assessing the progress with regards to reduction in maternal mortality remains a very difficult challenge due to paucity, non – inclusive, and incorrectness of data, especially from developing countries where most of these deaths do occur. Maternal death surveillance response (MDSR) presents a unique opportunity to appropriately identify, record and track key drivers of maternal deaths. Routine data collection at local and national levels is a core ingredient of this approach that will permit timely policy changes to properly and specifically curb preventable causes of maternal deaths. Not only does the MDSR provide a quality control tool for current policy measures directed at reducing maternal deaths, MDSR promotes routine identification and timely notification of maternal deaths and is a form of continuous surveillance linking health information system from local to national level². MDSR will enhance accountability mechanisms by providing information on whether policies and actions meant to reduce maternal mortality are effective³. Despite the promising nature of the MDSR approach in reducing maternal mortality, ethical and legal challenges need to be properly ascertained and acted upon in a timely

manner to guarantee its acceptability, sustainability, and effectiveness.

While the right of parents to determine freely and responsibly the number and spacing of their children was first articulated in the 1968 UN International Conference on Human Rights, the right of women to go through pregnancy and childbirth safely was first made explicit only in 1994 as part of the Programme of Action of the UN International Conference on Population and Development, ICPD⁴. Preventable maternal deaths seem to be concentrated among marginalized groups of women and they are marked by a lack of accountability⁵. Nationally and internationally, human rights approach incorporated into the strategic package of reducing maternal deaths can enhance accountability and responsibility^{5,6,13}. Human rights constitute a bridge between ethics and law. From a justice point of view, it is a serious moral – ethical concern that the estimated lifetime risk of maternal mortality in high-income countries is 1 in 3300 in comparison with 1 in 41 in low-income countries⁷. Amzat has argued that a rights-based approach, with special focus on respect of women's autonomy, would contribute in alleviating maternal mortality in Africa⁶. A human rights approach in current efforts to reduce maternal mortality appears plausible, because this problem has serious connections with country legal systems and health policy frameworks⁵.

Proper recognition and acting upon the “no blame, no shame” practice during MDSR has the potential of curbing under reporting of maternal deaths¹⁴⁻¹⁶. This issue has both ethical and legal components that need to be clearly elucidated and acted upon for the paradigm to achieve its intended goals. Actors within the MDSR cycle will feel safer and motivated in “faithfully” reporting and investigating circumstances surrounding maternal deaths without fear of litigation or stigma. Recognizing the legal implications of this endeavor warrant schooling of MDSR teams on the legal guarantees they have as they get the job done, as

well as making them act more responsibly when it comes to proper handling of privacy and confidentiality issues. Upholding the virtues of respect, guaranteeing privacy, and confidentiality, stops the activity from being a mere moral - professional responsibility, but also to be an ethical mandate in respecting engagements taken before respondents especially during the verbal - social autopsies. Failure to properly act on this will not only lead to distrust in the health system but endangers future interventions or research activities. In Kenya, it has been highlighted that not having legislation that clearly articulates the “blame free” principle hinders attainment of MDSR goals, especially when it comes to maternal death notification^{8,14-16}. The confidential enquiry into maternal deaths (CEMD) in the Republic of South Africa could be an example to follow, where review related material (forms, reports etc.) cannot be used for litigation or disciplinary processes¹⁷. These legal considerations are so important, especially when it comes to the terminology that is used during the MDSR process. Policy documents should be careful regarding avoiding words that could indirectly have blame implications. In Malaysia for instance, sub - standard care as a cause of death has been replaced with “remediable factors”. This makes the health care more comfortable and ready for change, rather than fall under weight of blame. The law however needs to draw the line between being accountable and meeting up to one’s professional responsibilities¹⁵⁻¹⁷. The law for instance in the Republic of South Africa (1997) and Kenya (2004) makes maternal death notification mandatory¹⁵⁻⁸. This can go a long way in improving upon the maternal death notification rates¹⁵. The line between responsibility and accountability of health care and MDSR staff can only be clearly drawn with a legal framework, specific to MDSR¹⁹. With many countries being at different stages in the MDSR experience, highlighting the possible ethical and legal concerns that could probably arise during the process could

be of interest to future actors in MDSR, researchers, and policy makers in better dealing with such challenges.

In August 2011, the Committee on the Elimination of Discrimination against Women (CEDAW), became the first UN human rights body to issue a decision on maternal mortality. They recognized ensuring availability and proper functioning of services that guarantee a safe pregnancy and childbirth as a fundamental human right²¹. The United Nations (UN) Human Rights Council has highlighted maternal mortality as an issue bearing not just on development, but also on human rights²². Maternal deaths are consequently gross violations of human rights, with shared responsibilities at different strata of society. We engage into this debate from a premise that challenges encountered during MDSR can be better understood and overcome if examined through ethical and legal lenses. For instance, maternal death notification remains a key obstacle in the MDSR cycle^{8,15}. Fear of blame, lack of guarantee of respondent privacy and confidentiality, absence of legislation to guarantee that findings will not be used for litigation purposes could account for low notification rates. The ethical and legal framework proposed is drawn from the literature, personal and field experiences of the authors. It is hoped that this legal and ethical framework will provide a structure to guide professionals in improving MDSR practice and research.

Discussion

Legal issues during MDSR

Laws may affect access to information (hospital records), protection of people involved (providers, investigators, and family members) in MDSR and the use of the results. Provisions of the law with regards to ownership, access and use of medical records, protection of health staff involved in the MDSR process and potential use of its findings

need to be clearly defined. Country specific guidelines based on existing laws will help reduce potential tensions that might occur during the implementation process.

Access to data

Legal access is generally needed to review hospital records. Whether all MDSR committee members all have legal access to hospital records should be carefully assessed and defined. If all members do, the potential of sensitive information revealed “on the streets” could have serious implications. It should be the responsibility of the committee members to keep the information secret, and sanctioning those potentially found guilty of revealing such information should be clearly spelt out, based on the country specific laws.

Protection of people involved in MDSR

Laws are needed to guarantee the immunity of those reviewing maternal deaths and other people involved from civil and professional liability. Data gathered during maternal death review needs protection by law as purely confidential and need not be disclosed or used in subsequent lawsuits. Safeguards to protect medical records through encryption and masking of patient identifiers could be used. Working in locked doors and cabinets or destruction of sensitive physical files (after MDSR committee consent) can be carefully evaluated and used. Conducting periodic data security audits could be a valuable way to ensure safety of collected data.

Use of findings of MDSR (results)

The aim of MDSR (and Maternal Death Reviews) is to understand why women die so that preventive strategies can be developed. Results should not be used to discipline providers or family members of the deceased. Patients and provider identifiers

should be kept hidden as much as possible. Legal backing should be used to prevent the use of information for litigation and members of MDSR committee should decline from giving testimony in court if they were part of the review. The same person should NOT participate in maternal death reviews and take administrative or legal action against persons involved in clinical care or MDSR process. The two processes should be separate and parallel.

Litigation

It is important for laws to be passed that clearly spell out the roles and responsibilities of the MDSR teams, as well as protecting them from litigation (immunity). For instance, in sensitive maternal death cases like those arising from clandestine abortions, without clear laws protecting both the informants and the data collection team, there exists a grey zone where without legal protection, potential shortcomings of the health care system (staff) and informants might be subject to litigation. The law must specify the role of the MDSR team as being not for “policing” and must protect the informants. Privacy and confidentiality must be upheld as legal obligations within the MDSR package. Without these standards put into law and made known to both the MDSR team and the informants, fear might disrupt the optimal functioning of this approach. A clear legal framework to protect workers is important, but this does not in no way disengage them from their responsibilities.

Oath taking

It might be of interest in some cases for MDSR committee members to legally go through an oath taking ritual in court to guarantee that information from informants shall remain anonymous and private. This could foster public trust and dispel fear, offering a unique opportunity for more

complete information with regards to causes of death to be obtained. Verbal autopsies especially narratives from the community could be very informative to improve quality of care. Legal experts in developing legislation specific to the MDSR and countries should look for ways to make MDSR practitioners, understand the legal imperative and obligations of upholding participant privacy and confidentiality.

Ethical Issues

The following are common ethical issues encountered during MDSR:

Privacy

Privacy applies to the person. Privacy refers to the individual desire to control who has access to him/herself. Privacy applies to the person as opposed to confidentiality which applies to data. Privacy is a person's desire of having control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others. Individuals have the right to limit access by others to aspects of their person - that can include thoughts and personal information. Taking informed consent from all patients, health care staff, family and community members before conducting interviews should not only constitute a legal but must be upheld as a key ethical imperative.

Anonymity

It involves removal of personal identifiers from documents. It is important to ensure confidentiality during MDSR. Anonymity entails that personal identity remains completely unknown. The names of the deceased should NOT appear in MDSR forms & database. Patient & staff identifiers in patient's folders, records and case summaries should be masked. Discussions should be

anonymous: 'no name, no blame' However, complete anonymity is easier for Confidential Enquiry into Maternal Deaths, but difficult to achieve especially in facility-based Maternal Death Reviews and verbal autopsy. In the absence of complete anonymity, the signing of a confidentiality agreement by those who have access to identifiable information should be considered.

Confidentiality

Confidentiality applies to data. It is the obligation to keep identifiable personal information private. Permission should be obtained to speak to family members and healthcare providers. A clearly signed interview consent form or obtaining permission "on tape" could be potential gateways to guarantee confidentiality. Identities of the deceased, relatives and providers should be kept confidential and known only to those collecting the data. Data collection forms, case summaries, review meetings and all reports should not contain personal identifiers. Documents containing personal identity should:

- Not be shared by email,
- Should be kept in locked office/cabinets (hard copy)
- Password protected files (electronic data).
- All notes with identifying information collected for MDSR should be destroyed, once MDSR reports are produced.

Confidentiality of the data obtained during the MDSR enquiry is a key legal – ethical imperative of MDSR. Confidentiality refers to the obligation of professionals who have access to patient records or communication to hold that information undisclosed. Privacy, as distinct from confidentiality, is viewed as the right of the individual client or patient to be let alone and to make decisions about how personal information is

shared. Confidentiality therefore falls within the main responsibilities of the MDSR committee. Studies from Malawi have identified lack of privacy as a key hindrance to the implementation of this approach⁸. In China, confidentiality and anonymity were key challenges identified to ensure the success of the MDSR⁹. Trusting relationships between the community and health care teams constitute the corner stone of this approach, for adequate and appropriate maternal death indicators to be obtained¹⁰. Upholding the ideals of privacy and confidentiality must remain key initial starting points for implementation of the MDSR. Proper training and education of the MDSR teams and the community with regards to the intentions of this approach remain imperative to curb abuses and fear to disclose useful information. Without guaranteeing respect of these ideals, underreporting and wrong information might distort the intended goals of the MDSR.

Beneficence

The benefits from findings from MDSR are enormous if properly acted upon. It has a big potential of reducing maternal mortality and morbidity. Data should be collected in a way that they can be analysed and used at different levels for the purpose for which they are collected. Data should have collected in a way that maximises analysis and response at different levels. Maximizing the use of data collected is a core justification of MDSR. Not using correctly, the collected data is unethical.

Autonomy or self-determination

Individuals are independent and can make rational decisions for themselves. It is the right of competent adults to make informed decisions for themselves, about their own medical care and participation in any review process or research. Family and community members should be:

1. Fully informed about the review process
2. Informed that their participation is voluntary
3. Informed that the interview can be interrupted at their request
4. Given consent forms should ideally be administered before family members are interviewed.

Consenting parties who participate in the MDSR should adequately understand what it entails, its relevance, and understand their right to freedom of choice (accepting or declining participation). The informed consent process could face some challenges: insufficient or inappropriate quantity and quality of information provided with regards to the MDSR, indirect coercion from health care staff (where patients think that what comes from them should be for the patient's good as a rule) and fear of being indexed in case they refuse to participate. For informed consent to make sense in this case, it should be a process and not an on the spot or one-time decision-making activity. A poor informed consent process in case of realized breach of confidence might disrupt trusting relationships between partners in the MDSR process. Proper education of the MDSR committee members with regards to the quantity and quality of information to be provided to respondents is a priority. When participants realize that they are respected and are aware this as an autonomous choice either to accept or refute participation, they feel respected and trust is consequently enhanced¹³. Reported fear of litigation, privacy and anonymity concerns probably arise from a poor informed consent process. Participants should be made to properly understand the rationale of the information obtained, and that it is not meant for potential punishment and that they are protected (in countries where laws are already in force with regards to MDSR) by law. Community involvement from the very planning stages of the process can foster trust, acceptability, ownership

and sustainability of such endeavors. A pilot study in Malawi using a community-linked maternal death review (CLMDR) approach to measure and prevent maternal mortality showed increased maternal death identification thanks to community involvement, increased quantity of available information for subsequent analysis and improved stakeholder involvement¹¹. Aborigo *et al* in Ghana have highlighted the importance of carefully considering sociocultural sensitivities during verbal autopsies. Some death types need to be approached with heightened caution during verbal autopsies¹².

The MDSR team must carefully consider the consent process based on the circumstance and community in question. In certain communities with strong cultural bonds between the traditional chiefs and the people, one might feel compelled to consent to the MDSR activity once the chief says ok, for fear of social exclusion. Combs Thorsen *et al* have suggested that in such circumstances, the individuals should always be told in the presence of the chiefs that participation in the activity is voluntary²⁰.

Charter for MDSR?

The MDSR committee should consider having a Charter for MDSR. This Charter is signed by

MDSR committee members and should be read at the beginning of every review meeting. Its purpose is to uphold ethical practices among MDSR committee members including confidentiality. It outlines the code of conduct for participants:

- Purpose of Maternal Death Review
- Arriving on time
- Respecting each other’s ideas and opinions
- Maintaining confidentiality: No name, no blame
- Active participation without violence
- No attempts to falsify records
- Accepting criticisms to improve clinical care
- Commitment to implement recommendations from Maternal Death Review

Legal and ethical framework for MDSR

Using evidence from the literature and field experience on MDSR, the following legal and ethical framework for MDSR has been proposed (Table 1). Three categories of both legal and ethical issues involved in MDSR have been identified: the issues with data, people, and use of findings from MDSR.

Table 1: Legal and Ethical Framework for MDSR.

	Legal	Ethical
Data	<ul style="list-style-type: none"> • Legal access to data • Data protection 	<ul style="list-style-type: none"> • Confidentiality – MDSR Charter can improve confidentiality • Anonymity
People	<ul style="list-style-type: none"> • Immunity – protection of people involved • Oath taking by MDSR committee 	<ul style="list-style-type: none"> • Privacy – ensuring informed consent can resolve privacy issues • Autonomy (self-determination)
Benefits	<ul style="list-style-type: none"> • Use of findings of MDSR only for the authorized purposes • Reduced risk of litigation 	<ul style="list-style-type: none"> • Beneficence • Improved quality of care and reduction of maternal mortality

Conclusion

With most maternal deaths being preventable, failure to eliminate these deaths translates to a failure in guaranteeing the right of the woman to life. This should more than ever before constitute an ethical – moral priority for global health actors. MDSR is a promising data collection and public health intervention tool when it comes to identifying key drivers of maternal mortality and acting upon them in an effective and timely manner. Legal and ethical barriers if not properly ascertained might render this approach unproductive. Access to data, protection of parties involved in the MDSR process, use of MDSR findings and litigation issues are key legal concerns that must be carefully ascertained. Ethical imperatives like ensuring privacy, anonymity, respect of autonomy, beneficence, and confidentiality can enhance trusting relationships between MDSR teams and the community. Monitoring and evaluation of the legal and ethical ideals proposed could go a long way to guarantee the sustainability of the MDSR process and achievement of its intended goals. Authors have proposed a legal and ethical framework for MDSR and hope that it will provide a structure to guide practitioners and researchers in improving MDSR practice and research in view to reducing maternal mortality.

Consent for Publications

The authors have read and approve the publication of the manuscript in its current form. This manuscript has not been submitted for publication elsewhere and has not been previously published.

Competing Interests

The authors declare they have no conflict of interest

Funding

None

Authors' Contributions

EJK conceived the initial idea. EJK and LEB did the literature searches and contributed intellectually. Both authors agree on the current version of the manuscript.

References

1. WHO | Maternal mortality [Internet]. [cited 2016 Jul 16]. Available from: <http://www.who.int/mediacentre/factsheets/fs348/e>
2. WHO | Maternal Death Surveillance and Response: Technical Guidance. Information for Action to Prevent Maternal Death. WHO. Accessed July 16, 2016. http://www.who.int/maternal_child_adolescent/documents/maternal_death_surveillance/en/.
3. Hounton S, De Bernis L, Hussein J, Graham WJ, Danel I, Byass P and Mason EM. Towards elimination of maternal deaths: maternal deaths surveillance and response. *Reprod Health*. 2013 Jan 2;10:1.
4. Programme of action of the International Conference on Population and Development. paragraph 7.3. New York: United Nations; 1994.
5. Gruskin S, Cottingham J, Hilber AM, Kismodi E, Lincetto O and Roseman MJ. Using human rights to improve maternal and neonatal health: history, connections and a proposed practical approach. *Bull World Health Organ*. 2008 Aug;86(8):589–93.
6. Amzat J. The question of autonomy in maternal health in Africa: a rights-based consideration. *J Bioeth Inq*. 2015 Jun;12(2):283–93.
7. WHO | Trends in Maternal Mortality: 1990 to 2015. WHO. Accessed July 16, 2016. <http://www.who.int/reproductivehealth/publications/monitoring/maternal-mortality-2015/en/>.
8. Kongnyuy EJ and van den Broek N. The difficulties of conducting maternal death reviews in Malawi. *BMC Pregnancy Childbirth*. 2008;8:42.
9. Gao Y, Kildea S, Barclay L, Hao M and Zeng W. Maternal mortality surveillance in an inland Chinese province. *Int J Gynaecol Obstet*. 2009 Feb;104(2):128–31.
10. Eyal N. Using informed consent to save trust. *J Med Ethics*. 2014 Jul;40(7):437–44.

11. Bayley O, Chapota H, Kainja E, Phiri T, Gondwe C, King C, Nambiar B, Mwansambo C, Kazembe P, Costello A, Rosato M and Colbourn T. Community-linked maternal death review (CLMDR) to measure and prevent maternal mortality: a pilot study in rural Malawi. *BMJ Open*. 2015 Apr 20;5(4):e007753.
12. Aborigo RA, Allotey P, Tindana P, Azongo D and Debpuur C. Cultural imperatives and the ethics of verbal autopsies in rural Ghana. *Glob Health Action*. 2013;6:18570.
13. Bueno de Mesquita J and Kismödi E. Maternal mortality and human rights: landmark decision by United Nations human rights body. *Bull World Health Organ*. 2012 Feb 1;90(2):79A.
14. Smith H, Ameh C, Godia P, Maua J, Bartilol K, Amoth P, Mathai M and van den Broek N. Implementing Maternal Death Surveillance and Response in Kenya: Incremental Progress and Lessons Learned. *Glob Health Sci Pract*. 2017 Sep 27;5(3):345–54.
15. Smith H, Ameh C, Roos N, Mathai M and Broek NVD. Implementing maternal death surveillance and response: a review of lessons from country case studies. *BMC Pregnancy and Childbirth*. 2017 Jul 17;17:233.
16. WHO | Beyond the numbers [Internet]. WHO. Available from: http://www.who.int/maternal_child_adolescent/documents/9241591838/en/
17. Moodley J, Pattinson R, Fawcus S, Schoon M, Moran N, Shweni P and National Committee on Confidential Enquiries into Maternal Deaths in South Africa . The confidential enquiry into maternal deaths in South Africa: a case study. *BJOG: Int J Obstet Gy*. 2014 Sep 1;121:53–60.
18. Ameh CA, Smith H and van den Broek N. Maternal Death Surveillance and Response in Kenya. Geneva: World Health Organization; 2015. http://www.who.int/maternal_child_adolescent/epidemiology/maternal-death-surveillance/case-studies/kenya/en/ Accessed: 10th of November, 2017
19. Bandali S, Thomas C, Hukin E, Matthews Z, Mathai M, Ramachandran Dilip T, Roos N, Lawley R, Igado O and Hulton L. Maternal Death Surveillance and Response Systems in driving accountability and influencing change. *Int J Gynaecol Obstet*. 2016 Dec 1;135(3):365–71.
20. Combs Thorsen V, Sundby J, Meguid T and Malata A. Easier said than done!: methodological challenges with conducting maternal death review research in Malawi. *BMC Med Res Methodol*. 2014 Feb 21;14:29.
21. CEDAW-C-KEN-CO-7.pdf [Internet]. [cited 2018 May 22]. Available from: <http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-KEN-CO-7.pdf>
22. Bueno de Mesquita J and Kismödi E. Maternal mortality and human rights: landmark decision by United Nations human rights body. *Bull World Health Organ*. 2012 Feb 1;90(2):79-79A.