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Activism: working to reduce maternal mortality through civil society and health professional alliances in sub-Saharan Africa

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Abstract: *Partnerships between civil society groups campaigning for reproductive and human rights, health professionals and others could contribute more to the strengthening of health systems needed to bring about declines in maternal deaths in Africa. The success of the HIV treatment literacy model developed by the Treatment Action Campaign in South Africa provides useful lessons for activism on maternal mortality, especially the combination of a right-to-health approach with learning and capacity building, community networking, popular mobilisation and legal action. This paper provides examples of these from South Africa, Botswana, Kenya and Uganda. Confidential enquiries into maternal deaths can be powerful instruments for change if pressure to act on their recommendations is brought to bear. Shadow reports presented during UN human rights country assessments can be used in a similar way. Public protests and demonstrations over avoidable deaths have succeeded in drawing attention to under-resourced services, shortages of supplies, including blood for transfusion, poor morale among staff, and lack of training and supervision. Activists could play a bigger role in holding health services, governments, and policy-makers accountable for poor maternity services, developing user-friendly information materials for women and their families, and motivating appropriate human resources strategies. Training and support for patients' groups, in how to use health facility complaints procedures is also a valuable strategy.*

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Partnerships between health professionals and civil society organisations have been recognised as an essential catalyst for health systems strengthening and have contributed significantly to improvements in programme delivery in many sectors. In a recent landmark publication, Frenk et al called for a global social movement, engaging all stakeholders and linking together educational institutions with networks and alliances, including with governments and civil society organisations, to build new relationships in health systems.¹ A good example of how this has worked internationally is of HIV campaigners, who have challenged research and health institutions, pharmaceutical companies, funding bodies, politicians and policy-makers to take their issues seriously, gone to court to demand constitutional rights to health care for people living with

HIV, and been instrumental in achieving affordable antiretroviral treatment for so many, even in poorer countries.

With regard to maternal mortality, where the majority of deaths are preventable and in many countries occur in health institutions, there are opportunities to learn from the successes of HIV campaigns in making health services more responsive to women's needs. Operational research on maternity services in South Africa has identified the need for stronger, better coordinated health systems, development of a culture of organisational learning, and training for problem-solving as teams, with incentives for good management and supportive supervision.² This discussion paper looks at how activism can motivate for some of these to happen, using examples of campaigns in diverse

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situations for the prevention of maternal mortality, with lessons that may be useful for the African context, where the least progress has been made in reducing maternal deaths.

According to the World Health Organization (WHO), countries that have succeeded in making childbirth safer for women have three factors in common.³ First, policy-makers and managers have identified ways of approaching the problem and acted on that knowledge. Second, the focus has been on provision of care (including emergency care) by skilled nurse-midwives and doctors at and after childbirth for all women, in addition to antenatal care. Third, access to the necessary resources, financial and geographical, has been guaranteed for the entire population. Thus, information, commitment, universal access and professionalisation of service providers are essential for positive outcomes. In most of Africa, decisions about how maternity services function remain the preserve of senior health professionals and government departments, which have not been sufficiently effective in resolving the underlying causes of maternal deaths. Partnerships between civil society organisations (CSOs) and health professionals could play a more active role in motivating change.

Patient-centred care and human rights

Frenk et al advocate for health system reforms that emphasise patient and population-centredness, while recognising that poorer people are less able to make health services respond to their needs.⁴ Historically, changes in abortion law, antenatal care and childbirth in high-income countries have resulted from pressure from coalitions of women's organisations, health and legal professionals, parliamentarians and policy-makers, working together for the common goal of making childbirth safer and improving quality of care.⁴ The Changing Childbirth Initiative in the UK, adopted as government policy in 1994, aimed to ensure that maternity services were accessible, responsive and effective. Because of proposed changes to the policy agenda by politically savvy patient representative groups and women legislators, substantial women-centred changes to services were made.⁵ Quality of care and patient satisfaction indicators are now standard in audit tools used by health professionals in monitoring maternity services in the UK,⁶ but continued active scrutiny by patient representative groups is required to ensure quality standards are met and sustained.⁷

Failure to reduce preventable maternal deaths represents a violation of women's right to life, health, non-discrimination and equality. As signatories to international human rights conventions and to the Millennium Development Goals, States are obliged to provide the necessary services of sufficient quality to prevent these deaths. Use of a human rights framework⁸ provides tools and strategies for holding governments, service providers and policy-makers accountable for these goals, including the use of courts to uphold them. Authorities and institutions need to be made aware that the public has a right to monitor, scrutinise and document progress or lack of it in achieving these goals, and in the interests of transparency, reports must be publicly available in accessible language and formats. These rights may seem obvious to some, but the right to health care, as articulated in these frameworks, is not intuitively understood by many health professionals, especially those who see health care as a commodity to be bought by those who can afford it. As Freedman reminds us:

"A rights-based approach... must be grounded in a careful critique of the workings of power that have permitted appalling rates of maternal death to remain unchanged... [p]olicy making is a deeply political process whose success in addressing health problems is necessarily dependent on a reading of the power dynamics that underlie a specific situation... being attuned to the underlying dynamics of something as seemingly nonpolitical as the presentation of data... [I]f we approach human rights as a tool for transforming a system... then a rights-based approach can make a meaningful difference for the decision makers compelled to make a real policy choice."⁹

The HIV treatment literacy model

The treatment literacy model,¹⁰ developed by the Treatment Action Campaign (TAC) in South Africa, could be useful for activist groups in working with health professionals to address the underlying causes of maternal deaths. TAC used a "right to health" approach to HIV through a combination of protest, popular mobilisation and legal action. They emphasised building capacity among affected people, prioritising those who were disadvantaged, and through the cornerstone concept of treatment literacy. HIV education materials and methods were developed, including on the benefits and side-effects of treatment, embedded in the science of

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medicine, the political context, human rights, equity of access to health care, and the duties of governments. People living with HIV learned skills in asking questions of their health care providers in non-confrontational ways, so that they became partners in their treatment rather than passive and uninformed recipients. After training, TAC volunteers were attached to health facilities and community organisations to further extend campaign and education activities. They linked into TAC community networks and local organising activities, galvanising social mobilisation around access to treatment and care. A crucial part of this programme involved building self-worth and self-efficacy through the “HIV-positive” trademark, rejecting silent victimhood for people living with HIV. HIV support groups all over southern Africa received and benefited from treatment literacy training carried out by TAC.

The landmark campaign in which the government of South Africa was challenged over its failure to provide pregnant HIV-positive women with antiretroviral drugs that could have prevented the transmission of HIV to their infants, received national and international media coverage, also drawing attention to high prices charged by pharmaceutical companies to the detriment of poor people.¹¹ TAC continues to lobby governments, national and international funding and policy-making bodies for improved quality of health care in South Africa and universal access to antiretroviral treatment.

Implementing recommendations from confidential enquiries

The Treatment Action Campaign attributed rising maternal mortality in southern Africa to HIV, emphasising the need for pregnant women with HIV to be on antiretrovirals and also warning that certain antiretrovirals exacerbate anaemia, putting HIV-positive women at higher risk of complications if they have heavy bleeding at childbirth. Although HIV contributes to nearly half of maternal deaths in South Africa,¹² the underlying reasons for death are still haemorrhage and sepsis, preventable through timely and early intervention. Following the publication of the National Confidential Enquiry into Maternal Deaths 2002–2004 in South Africa in 2006, TAC made the following statement:

“The [Enquiry] is a call to action. It will be the job of civil society to monitor that the Department of

Health starts implementing these recommendations. If the Department continues to fail to implement them, then mass mobilisation and the courts will be needed to ensure that the Constitutional rights to health-care of women are met.”¹³

In fact, the recommendations of the 2005–2007 Confidential Enquiry were almost identical to those for 2002–04 (Box 1); nothing had changed (or not sufficiently). TAC’s then director Heywood argues that litigation without social mobilisation is insufficient for change. Significant resources for

Box 1. Confidential Enquiry into Maternal Deaths, South Africa, 2005–07: Recommendations¹²

- Protocols on the management of important conditions causing maternal deaths must be available and utilised appropriately in all institutions (including facilities which only provide antenatal and postnatal services) where women deliver. All midwives and doctors must be trained on the use of these protocols.
- Training should be provided for all health professionals working in maternity units in practical obstetrical and surgical skills. Skills should be provided in anaesthesia, especially in level 1 institutions.
- All pregnant women should be offered information, screening and appropriate management of non-pregnancy related infections and common medical disorders.
- Criteria for referral and referral routes must be established and utilised appropriately in all provinces. Emergency transport facilities must be available for all pregnant women in need (at any site).
- Post-partum care must be strengthened.
- Staffing and equipment norms must be established for each level and for every health institution concerned with the care of pregnant women.
- Blood for transfusion must be available at every institution where caesarean sections are performed.
- Contraceptive use must be promoted through education and service provision.
- The number of deaths from unsafe abortion must be reduced.
- Women, families and communities at large must be empowered, involved and participate actively in activities, projects and programmes aiming at improving maternal and neonatal health as well as reproductive health in general.

social reform can be released if they are fought for as rights, and linked to arguments about the obligations of governments.¹⁰ This intensity of activism has been missing in addressing maternal mortality, but is now emerging.

In May 2011, hundreds of concerned citizens and health professionals stormed the Constitutional Court in Kampala, Uganda, protesting the deaths of women in childbirth, in support of a coalition of activists who have taken out a landmark lawsuit against the government over two women who bled to death giving birth unattended in hospital.^{14,15} The Centre for Health, Human Rights and Development (CEHURD), a Ugandan NGO, and the families of the two deceased women argued:

“...by not providing essential medical commodities and health services to pregnant women, the government is violating the constitutional rights of Ugandans, including the right to health, the right to life, and the rights of women.”

The case brought to public attention the thousands of maternal deaths through negligence that have come to light since this case was filed.¹⁶ CEHURD called for a 2011–12 supplementary budget with increased investments in emergency obstetric care, staff, commodities and services in order to end Uganda’s crisis of preventable maternal deaths. There has not yet been a judgement in the case.¹⁷ Activists will have to use the momentum created by this publicity to ensure that the government acts.

The combination of factors that contribute to maternal deaths flag fundamental health system failings and can seem so complex that it is hard to know how to start the chain of actions to address them. Confidential enquiries are potentially powerful instruments of change since they provide details of how maternal deaths occur, but only if the recommendations made by the reports are acted on, and for the whole population at risk. Reports of confidential enquiries in the UK, published triennially since 1952, made a significant impact on prevention of maternal mortality and morbidity and were emulated as models in other countries.¹⁸ They target primarily the medical and midwifery professions, who have responded to the recommendations with increased training, supervision, guideline development and implementation, and outcome monitoring.

Although Botswana and South Africa have conducted national confidential enquiries, maternal deaths continue to take place in hospitals because governments are not addressing the systemic failures

that contribute to them.^{2,12,19–21} These include poor initial assessment and diagnosis of cases, especially at secondary level, failure to follow standard protocols at primary and secondary levels, inadequate monitoring of patients at all levels of care, poor clinical practices, inadequate supervision and lack of essential supplies.

Producing shadow reports for UN treaty monitoring bodies

States are obliged to report regularly on their progress in implementation of UN treaties and conventions to which they are signatories. In many countries, civil society organisations produce their own shadow reports, critiquing their government’s progress, highlighting why objectives or targets are not being met. These reports are important first steps, but their production alone rarely triggers improvements and has to be accompanied by organised campaigns that showcase what changes are needed, who is answerable for these changes, and how resources can be prioritised for change. Public debate on priority-setting in health-resource allocation is essential. In Tanzania, government claims of staff training for emergency obstetric care and family planning, with ambulances prioritised for poorly performing areas, were not matched with improvements on the ground. Women were still delivering at home without trained birth attendants and utilisation of the health facilities did not increase. The 2008 NGO shadow report for the Committee on the Elimination of Discrimination Against Women (CEDAW) identified that the quality of information women were receiving was poor, but it did not indicate steps needing to be taken to improve this.²² A Nigerian NGO shadow report for CEDAW, itemised point by point all the areas in which maternal health objectives could not be met because of failings in policy, legal and administrative areas,²³ again without any strategy for change.

Holding health professionals and the health system accountable

The commitment to professional competence and quality of care is a cornerstone of the code of practice for health professionals and managers, and yet in most of Africa they are rarely held to account for the standards of health care provided in the public sector.²⁴ Governments are accountable

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for the duty to create environments conducive for health staff to practice in a professional way. At the same time, health professionals should be accountable for the standard of care they provide, and for neglect or abuse of their patients. The Human Rights Watch report on South Africa detailed several instances of women in childbirth who had been neglected and disrespected by nursing staff²⁰ and made 35 recommendations, many suggesting how the complaints procedure should be improved and used to strengthen services (Box 2).

Similarly, a recent report of research in Kenya, co-authored by the Federation of Women Lawyers

(FIDA) and the Center for Reproductive Rights (CRR), detailed the physical and verbal abuse suffered by women seeking reproductive health services, including detention in health facilities for inability to pay fees.²⁵ Public sector health workers were unable to provide adequate care because of poor institutional support and shortages of funding, medical staff and equipment. Hospitals lacked the most basic supplies, such as anaesthesia, gloves, syringes, surgical blades, soap, disinfectant, speculums, and bed linen. Patients were required to bring in their own supplies or do without, for instance having episiotomies stitched without anaesthetic.

Box 2. "Stop making excuses": accountability for maternal health care in South Africa: selected recommendations. Human Rights Watch, 2011²⁰

- Revise through a transparent and participatory process the current maternal health monitoring indicators ensuring that they track adverse pregnancy outcomes and ensure that emergency obstetric care indicators are in accordance with "United Nations Process Indicators" for availability and utilization of obstetric services.
- Establish a joint committee to monitor government implementation of strategies to reduce maternal mortality.
- Appoint a full-time special officer to oversee the implementation of the recommendations of the Confidential Enquiries into Maternal Deaths.
- Instruct all community health centers and clinics to establish health committees and all hospitals to establish boards, and involve them in complaint processes as required by the National Health Act. Provide oversight to ensure that health committees and boards are fulfilling their duties.
- Work with nongovernmental organizations and community representatives, (particularly those on health committees) on developing public service announcements explaining patients' rights and complaints mechanisms. Ensure that such announcements reach poor, rural, and illiterate populations, as well as marginalised groups such as migrants, in appropriate languages.
- Improve patient education on rights and complaints procedures at health facilities, for example, by having audio or video recordings in all the official languages of the province that can be played to patients.
- Consistently and forcefully condemn, at the highest level, physical, verbal, and other abuse of patients, including women seeking maternal health services.
- Disseminate the Complaints Policy Guidelines to all health facilities.
- Ensure that investigations into patient complaints include the following essential features:
 - Examination not only of the conduct of individual or frontline health workers, but also of failings in oversight and management by health facility administrators and managers.
 - Responses to complaints that not only provide remedies to individual patients or take corrective action with individual health care providers but include systemic reforms to avoid similar problems reoccurring.
 - Develop and implement national and provincial structures for regular feedback on patient complaints and their underlying causes. Such a structure should ensure the participation of nurses and other frontline health workers.
 - Develop and implement a system for reviewing complaints mechanisms, on a regular basis, to ensure effectiveness.
 - Ensure that patients who are unsatisfied with responses to their complaints at health facilities know that they can access other avenues for pursuing a remedy, such as through courts, professional bodies, or the proposed ombudsperson for health.

To the South African Human Rights Commission:

- Conduct a public inquiry into the abuse of women in health facilities during pregnancy, delivery, and after birth and lack of accountability. Such an inquiry should examine not only the conduct of frontline health workers but also administrators, managers, and district and provincial health officials.

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The report attributed the long-standing abuse, humiliation and discrimination described by women attending Pumwani Maternity Hospital, Kenya's largest public maternity hospital, to government failure to take responsibility for these human rights violations, lack of accountability within the health system, lack of awareness of patients' rights, and the absence of transparent and effective oversight mechanisms. The conditions in maternity services were quoted as one reason why women preferred to deliver at home.

Recommendations included strengthening structures and public awareness to educate and protect patients' rights; requiring health care facilities to establish formal complaints mechanisms as part of licensing requirements; strengthening complaints mechanisms at Medical Boards, professional associations and councils; improved training of health professionals; increased funding from the Government to provide for equipment and supplies; public education on the right to health, and provision of information to judges and legal professionals on rights violations in the health care context.

The report and recommendations were disseminated to relevant bodies through the media, advocacy workshops, meetings with health professional associations and other influential bodies. In response, the government removed user fees for maternity services in all public health institutions and also appointed a new head of Pumwani Maternity Hospital, someone experienced in a reproductive rights approach to maternal health. The midwives' association invited FIDA to provide training in a rights-based approach to service delivery, while the office of the Director of Public Prosecutions indicated that they would assist FIDA to prosecute cases involving such abuses.²⁶

Also in response to this report, the Kenya National Commission on Human Rights commenced a Public National Inquiry on Sexual and Reproductive Health in June 2011. This type of inquiry is ground-breaking not only for Kenya but regionally, the result of extensive advocacy by FIDA and CRH, including a petition calling for an official inquiry. The inquiry was conducted via country-wide public hearings, testimonials and expert forums, the report of which is currently being finalised.²⁷ The campaign is embedded within the work of Family Care International and the International Initiative on Maternal Mortality and Human Rights in Kenya, engaging health facility staff and management committees with communities to promote women's right to safe childbirth and respectful care. There is

some evidence from this work that using a rights approach and encouraging partnerships between patient groups and health staff reduces disrespect and increases attention to quality of care.²⁸

Addressing skills and resource gaps

In 1996, the central public hospital in Nepal initiated a three-month training course for anaesthetist assistants who went on to provide anaesthesia for thousands of operations every year and were crucial for caesarean sections. Vigorous advocacy by Nepal's Safer Motherhood Network, an alliance of health professionals and NGOs, ensured that this cadre were accredited and reinstated after opposition from physicians had halted the programme.²⁹ Freedman argues that a clinical model in which only physician-anaesthetists conduct anaesthesia results in a far greater number of women dying in childbirth.⁹ The same case can be made for obstetricians. Training non-physician clinicians as well as medical and nursing staff to provide better quality obstetric care is a way of increasing the number of skilled staff available, to prevent cases escalating to emergencies, and to respond swiftly when they do, improving outcomes.^{30,31}

Surgical and anaesthetic skills contribute significantly to reductions in maternal and child mortality but are in short supply in Africa.^{32–34} For health facilities to manage obstetric emergencies correctly they need well-trained, well-supervised, skilled and equipped staff. In many African countries (Ethiopia, Mozambique, Malawi, Tanzania), non-physician clinicians have been successfully trained to carry out caesarean sections and provide anaesthesia for maternity cases.^{35,36} In Uganda there are only 75 surgeons and 10 physician-anaesthetists to serve a population of 27 million people. Most surgery in rural district hospitals is carried out by non-specialist doctors with anaesthesia conducted by 350 non-physician anaesthetists officers who have 18 months of training to complete a high-school qualification.³⁷ In Mozambique in 2002, surgical technicians performed more than 90% of all major obstetric surgery in the rural areas, with clinical outcomes comparable to doctors.³⁸ Forty or so years of experience have demonstrated the cost-effectiveness and high level of performance of these cadres, and their importance for safe childbirth in rural areas of Africa.^{35,36,39}

Opposition to the scaling-up of training of non-physician clinicians by medical and nursing professional bodies, which previously limited

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access to safe childbirth in Africa,^{35,40} is being overcome by clinical leadership and demonstration of improved outcomes, as in Ghana, Mozambique and Malawi.³⁹ As in the example of Nepal, civil society and health professional alliances could influence medical and nursing associations to have a wider vision of the whole health system, recognising the expert role of physicians and senior nurses as the trainers and supervisors of these valuable cadres.^{30,39}

Campaigning for voluntary blood donation

A very practical way that civil society can assist in prevention of maternal deaths is through mobilisation of volunteer blood donors from the public. Haemorrhage during childbirth tops the list of causes of maternal deaths in Africa and Asia,⁴¹ and one review has attributed 26% of these deaths to lack of blood for transfusion.⁴² Even in high-income countries blood supplies are lower than needed and blood transfusion services invest in campaigns that appeal to donors to “give now”, knowing that they or their families may need help at a later date and that society depends and thrives on reciprocal generosity. A customer-satisfaction approach is used to make people feel good about donating blood, paying attention to waiting times, staff attitudes, being open and accountable, seeking continuous improvement to the service, and responding in a timely manner to donor complaints.⁴³

The aim is to optimise donor loyalty and encourage regular donations 3–4 times a year, which is safer and more cost effective than recruiting new donors. Media campaigns to motivate blood donations in higher-income countries have become more direct and imaginative, mentioning maternal mortality both in the context of saving women’s lives but also the importance to the newborn of the mother surviving. Media use stories of people who have donated blood in a very positive light, including events where recipients meet donors. The key is to raise donor profiles, to show them as something precious, to be nurtured, and to reward their volunteer spirit as socially responsible. Staff who do well are also given recognition. In the process, donors, health professionals and staff work in partnership to protect the lives of women in childbirth, publicly and passionately. Video clips on YouTube show recipients thanking donors for having saved their lives, thus giving the process a human face. One features the husband of a woman who was bleeding heavily during a caesarean section, who says:

“...when I heard the doctor on the phone saying he needed more blood and he needed it right then, it was a scary thing. My wife’s life was in the balance... I am wondering what if someone at the end said: ‘Sorry, we don’t have it right now’... it just became personal. I’m much more serious about it and I try and give blood every three months since then.”⁴⁴



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Donating blood in Botswana

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His statement brings home the tragedy faced by families in less-resourced countries that do not have efficient blood supplies. Medical students at the University of Botswana used these clips to motivate university students to donate blood in the first few weeks of the new academic year.⁴⁵ Many of these students donated blood during school donation drives but lapsed when they started university. The risks of their blood being HIV- and hepatitis-positive climbs rapidly within the first few months of starting university, so campaigns linked to HIV education and testing at the beginning of their first semester also endorse safer sex messages and the importance of actively staying infection-free.

The 14th of June is promoted by WHO and the International Federation of Red Cross and Red Crescent Societies as World Blood Donor day, which aims to build a worldwide culture of voluntary (non-remunerated) blood donation and raise awareness of the need for blood donation. But one day of media attention and speeches is inadequate to create the culture change required. Many of the barriers to sufficient blood donations are local: non-existence of national blood transfusion services in many African countries, poor information about the whole process, for example unfounded beliefs of a risk of infection from donating blood, misconceptions about how the blood will be used, and fear of side effects and bewitching.⁴⁶ More intensive public education campaigns are needed to inform the public about blood donation, which could be

provided by alliances between international institutions such as WHO in collaboration with local branches of the Red Cross and NGOs like Rotary Club.

The way forward

The scientific and technical knowledge of what works to reduce maternal mortality already exists alongside an understanding of why health systems in Africa are failing to serve their populations. Partnerships and alliances imply better collaboration and communication between communities, activists, health care staff and professionals, managers and so on. There is a wealth of ideas of what needs to be done, from public inquiries to community members being supported to sit on health facility committees. The TAC model shows the intensity of activism needed to campaign for and achieve change, which in itself needs adequate resourcing. Donor support for this kind of advocacy and activism has flagged and needs to be renewed and expanded. There are many excellent and ambitious campaigns taking place and opportunities for practical involvement in African communities and elsewhere, some described in this paper, that need to move to the next level in monitoring and sustained action for achieving accountability. What is clear is that far greater efforts and resources are required to make an impact on maternal deaths, and that the changes involved will strengthen the whole health sector.

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