

## Chronicles of Deaths Foretold

*A civil society analysis of maternal  
deaths  
In seven districts from the states of  
Odisha, West Bengal, Jharkhand and  
Uttar Pradesh, India*

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This report documents the stories of about 140 women who did not survive pregnancy and childbirth. Over the last ten years India has been a central player in the global crusade to reduce maternal mortality, as India has consistently been the largest contributor to this unfortunate phenomenon. Although India still ranks among the top five countries globally in terms of absolute numbers of maternal and child deaths, the country has made encouraging progress in tackling mortality among mothers and children. Despite the rapid reduction, India still contributes more it still contributes more maternal deaths to the global total each year than any other country because of its very large population and annual birth cohort<sup>1</sup>. In India, the major causes of maternal mortality continue to be haemorrhage (37%), abortion (10%) and sepsis (11%), in addition hypertensive disorders and obstructed labour are also commonly found (4%, 5%). Anaemia continues to be a major problem among women, despite large scale national programmes to improve haemoglobin levels in pregnant women. It is significant that 'Other causes' including communicable and non-communicable diseases, chronic illnesses and trauma are responsible for one-third (33%) of maternal deaths yet have received limited attention.

The three delays model of factors leading to maternal deaths gained momentum during the 1990s and highlighted social factors such as lack of awareness, low decision making among women as responsible for the first delay. Inadequate financial resources and lack of transport have been emphasized as reasons for the second delay. There has been intensive policy focus in the form of the National Rural Health Mission (subsequently National Health Mission) which has included different components like the *Janani Suraksha Yojana* to promote institutional delivery, strengthening health systems through additional deployment of staff and additional training as well as explicitly entitled free services through the *Janani Shishu Swashtya Karyakram*, all aimed at this one problem. In order to motivate, counsel and ensure safe childbirth especially among women belonging to below the poverty line (BPL), and schedule castes and schedule tribes (SCs/ STs) and track them, a scheme called the *Janani Suraksha Yojana* (Mothers' Protection Scheme or JSY) was launched by Government of India (GOI) in 2005. This included a conditional cash transfer to encourage women to come to hospitals to access 'skilled attendance at childbirth'. Another important feature of the scheme is the Accredited Social Health Activist (ASHA) who has been selected from the community for every 1000 population. The ASHAs act as a link between the ANM and the community to ensure basic and timely services for ANC, delivery care, PNC and immunization services for children, identifying high risk pregnancies and referrals and giving counselling on contraceptives. The government of India

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announced another scheme to ensure entirely free maternal and newborn health services called the *Janani Shishu Suraksha Karyakram* (JSSK or Mother and Child Protection Programme, launched July 2011). The scheme has also a provision for transportation of pregnant women to hospital in case of emergency. In India, the pace of moving to institutions for childbirth picked up speed after the introduction of the JSY and the availability of free transport to hospitals. In addition to these schemes, the GOI has instituted a comprehensive approach to health system strengthening and improved monitoring through its National Rural Health Mission since 2005 (now the National Health Mission<sup>1</sup>). This has included improvements in infrastructure of health facilities, and addition of health providers on contractual basis to meet the shortfall. However the question remains unanswered in terms of what happens to women who could not or did not manage to go for an institutional childbirth, although that group also constituted several million in the country.

A series of surveys over the years have shown that uptake of key services like ANC services and Institutional Delivery services have increased and Maternal Mortality has also reduced over the years. However there have also been concerns that the regions where the problem was more acute to start with have shown the least progress. These unfortunate stories from eastern UP, Jharkhand, Orissa and West Bengal provide us an important insight into how, despite all the policy efforts, many women continue to die. Maternal mortality is considered a preventable phenomenon and these case studies allow us to understand what worked in terms of current policy provisions and what did not, and we can learn important lessons on how the policy and programmatic provision can be improved to serve the needs of these women better.

The selection of blocks, districts and field investigators was done with this consideration: the partners who are working in the field have a strong base among the community, long experience of the local reality, and an intention to work with the health system towards improvement. They include NAMHHR partners in Odisha (SODA), West Bengal (ASHA), Jharkhand (Healthwatch Forum Jharkhand) and Uttar Pradesh (Healthwatch Forum UP). From Oct. 2013 to Dec. 2015, a process of maternal death surveillance and conducting CBMDR was begun by these civil society groups. The sites for this Community-based Maternal Death Review (CB-MDR) included seven districts across four states, including 23 development Blocks. Our main source of data is the community and our key respondents included **family members** of the deceased woman, especially if they happened to be present when the woman was seeking care. These usually included mother-in-law, husband, and father-in-law, brother-in-law, sister-in-law, co-sisters or mother, and sometimes neighbours and **ASHA**. In a few cases doctors and ANM were also interviewed. The objective was to record the bereaved family's experiences, and through their stories-

- i. To analyze each case and prepare a District Review about the quality of life-saving interventions, towards providing programmatic recommendations for the health officials, managers and policy actors, to ensure prevention of maternal deaths in future
- ii. To build non-adversarial approach to CBMDR involving FLWs and providers, for identification of health system gaps that affected maternal health services, towards taking corrective action

### Marginalization and social exclusion

<sup>1</sup> See - <http://nrhm.gov.in/nhm.html>

The CBMDR sites were purposively selected to examine experiences of socially excluded and marginalized populations: among Scheduled Castes, Scheduled Tribes/ Particularly Vulnerable Tribal groups (PVTG), Muslims and poor rural women. Predictably, all the women whose lives the study tried to understand can be considered to be from marginalised communities. The study areas like Godda in Jharkhand or Mayurbhanj in Orissa are tribal areas, Murshidabad and Malda and West Bengal have poor Muslim populations whilst in Azamgarh, Banda, Mirzapur most of the women who died were from either Dalit or OBC or Muslim background. In recent years there has been an effort to understand and address marginalisation in the RMNCH+A approach through a 'High Priority' area approach which addresses hard-to-reach areas. This study provides an opportunity to examine whether this approach is sufficient to address the problem of marginalisation and vulnerability.

Most of the women had characteristics of many kinds of vulnerability at the same time. Conditions of poverty, social marginalization, lower levels of education and home-based poorly-paid hazardous livelihood, poor contact with health systems and low access to health information coexisted in their lives. In addition they were often at higher obstetric risk because of early and repeated childbirth, higher levels of anaemia, short stature, and low weight. Their location, occupation, and lack of access, poor health system capacities and similar determinants are often seen as discrete vulnerabilities; however in most cases these are compounded disadvantages especially for marginalized communities who are poor, live in areas which lack health facilities and at the same time have bad or no roads which hampers access, and many face social isolation or stigmatization. Taken together this creates a **multiplying or compounding web of risks and vulnerabilities which cannot be disentangled** and addressed discretely through interventions addressing specific risks and vulnerabilities.

The current approach to maternal death prevention and maternal safety is derived from distilled global experience and comprise of a continuum of care framework with provision of routine pregnancy care services and ensuring safe delivery through skilled birth attendants. The global wisdom and concern is summed up in the sentence "*Much of the burden of maternal mortality is routinely preventable with known, cost-effective interventions that those of us in the developed world take for granted: good nutrition, antenatal care, skilled attendance at delivery, emergency obstetric care, and family planning. It is unconscionable that poor coverage, poor quality, and inequities in the provision of these essential MNCH interventions persist in ....*"<sup>2</sup> This statement was made in the context of Sub Saharan Africa but is equally applicable to the study areas. This study allows us to examine whether this assumption holds true: that what worked in the developed world would work equally well in such areas.

## Findings

In India it was assumed ensuring ANC, promoting institutional delivery and providing a graded set of emergency obstetric care services would be sufficient to reduce maternal mortality. However through the stories of these dead women, we observe that the antenatal care provided was ineffective in either understanding risk or addressing complications. While on the one hand the data shows that registration of women for ANC is increasing, and managers are congratulating themselves on this achievement; the study draws attention to the fact that ANC in all study locations is perfunctory and

<sup>2</sup>The PLoS Medicine Editors (2010) Maternal Health: Time to Deliver. PLoS Med 7(6): e1000300. doi:10.1371/journal.pmed.1000300

at best limited to distribution of Iron Folic Acids and providing Tetanus Toxoid injections. The more life-saving function of abdominal examination, screening for toxemia or anaemia is irregular. Clear cases of high risk pregnancies have not been identified or appropriately referred. However nearly all the women were contacted by the ASHA and had at least one ANC. It emerges the ANC as is being done today does not fulfil its expected function of screening risks and vulnerability effectively. At the same time the role of the Level 1 institution which is equipped to conduct normal deliveries is also very limited in managing emergencies. At best they work as stabilising institutions on the way to a higher centre of care, and at worst they have been seen as responsible for either delaying care or even starting a problem through either poor quality or mismanaged care.

However the communities are concerned about their own healthcare in pregnancy and seek treatment from a variety of sources including the public as well as the private and the formal and the informal. Unfortunately the key role of the private providers, both formal and informal receives very little priority in the overall design and planning of the maternal health programme in India. In many cases the public sector provider is known for providing private services, and this practice too is ignored. Another area of low priority is the home-based care for childbirth. Assuming that there is an inherent danger or risk involved in such practices, the approach has been akin to 'stamping out' a dangerous practice. The informal providers, including dais and quacks have not only been de-legitimised, but also their practices have been ignored rather than understood. Since they are not seen as legitimate, there is no effort to understand their role in the current health-seeking practices of communities, nor any efforts to build a partnership towards greater safety for women. However such practitioners not only continue to enjoy the trust of many women, but are often the only available providers in many contexts.

**Management of Obstetric Emergencies** is at the core of all strategies to reduce maternal death. Over the years the understanding has evolved that a range of obstetric emergencies can occur unpredictably and a system of skilled care during delivery along with provisions for quick emergency transport to appropriate Emergency Obstetric Care facilities allow for such emergencies to be managed. Levels of Emergency Obstetric Care facilities have been outlined internationally and adapted within the Indian context. Ability to promptly manage convulsions associated pregnancy (eclampsia), conduct Caesarian-Section operations, and promptly provide blood transfusion have been identified as critical to save mother's lives. But what we observe in these stories is different. The families could not sense any 'urgency' or added concern in the entire referral procedure. The emergency management procedures seemed routinized in the receiving hospital; without any effort to facilitate care for a life-threatening emergency such as early admission, starting immediate treatment, providing the required EmOC service without making the family run around, and so on. What we see instead is families are expected to arrange for blood, get additional tests done, buy medicines; often very late in the night. The ASHA, ANM and the PHC, who are supposed to be the pillars of safe delivery, are not able to play a facilitative role in hospital settings (and they are not even expected to, by design). There appears to be no consideration for the fact that the families of these women are not only poor, extremely stressed and not very educated, but also in an unfamiliar place. If one adds perceived negligence compounded with lack of sensitivity or empathy in the health system, we should not be surprised that some families opted for a 'discharge-on-risk bond' which led to a death in some cases.

#### Recommendations

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As a matter of management principle, one needs to debate which could be a ‘better’ approach in such situations: to strengthen *routine* management through targeted *input*-provision, or developing an ***adverse outcome management approach*** which does not only include specific inputs but focuses on crucial *processes*. The routine care approach was adopted because it was seen as successful historically in Western Europe and North America and in recent times in countries like Sri Lanka, Thailand and other countries in East Asia and Latin America and was globally accepted as a common strategy. In the case of Western Europe, the decline in maternal mortality rates also mirrored the evolution of health care systems, such as aseptic surgery techniques, availability of antibiotics, safe blood transfusion; as well as social changes like women’s empowerment, leading to greater autonomy and contraceptive use. In other countries like Sri Lanka, Cambodia, Malaysia and Thailand health system strengthening was embedded in the process of nation-building, which included social empowerment measures like equitable healthcare and empowerment of women.

But the situation in India today is somewhat different. While on the one hand there is rapid economic growth and more money is available overall, there is also increasing inequity – both economic and social. The idea of free and equitable access to healthcare services does not have unqualified support in the policy arena. Society continues to be hierarchical, and social marginalisation affects a very large proportion of the population. Discriminatory mindsets, both social and patriarchal, are embedded in society at large, which includes functionaries of the health system. It is difficult to provide ‘affirmative’ healthcare support without examining the different gaps and understanding the reasons behind them. A *health systems approach bereft of a socio-cultural analysis* of the specific situations will be inadequate to develop the appropriate system responses which can be coded as an ***adverse outcome management approach***.

The current approach of Priority Actions in high-focus districts and vulnerable populations has two major limitations. The first is that it primarily includes more ‘inputs’. It also has a very limited definition and understanding of ‘vulnerable populations’. The primary measure of vulnerability that is used is ‘reaching the unreached’ and clubs a diverse range: from the poor, urban slum dwellers to tribals, and even adolescents. There is **no analysis of why the system fails these people** and there is an assumption that “implementing and monitoring high impact interventions” will be sufficient to address equity. If we are serious in wanting to address disparities it is necessary to move from this ‘input-focused’ high priority area approach to a **‘highly vulnerable population’ approach** which integrates inputs with processes and is informed by existing health care practices and social cultural understanding of health determinants among the vulnerable communities. Some of the key imperatives of this approach could include the following:

#### A. ***Developing a Highly Vulnerable Populations Approach***

- ✓ Mapping of Vulnerabilities and Risks and the existing health care practices in areas where maternal health outcomes are poor, not showing the anticipated improvements and where the proportion of marginalised communities is higher
- ✓ Developing an appropriate cadre of providers – new personnel like emergency patient facilitators at secondary and tertiary care hospitals as well additional training to improve quality of care through improved interpersonal interactions, and adverse management outcomes skills.
- ✓ Identifying niches within existing practices and practitioners for building an alternative safety plan – including the support of Dais and Informal providers where appropriate; and

focussed on saving lives, and developing context specific plans from home to institution and from ante natal to postpartum period.

- ✓ Developing appropriate IEC/BCC messages using appropriate methods including traditional/ folk media which are aimed at building upon people's own concerns around maternal and new born safety

**B. 'Prevention and management of adverse outcomes'- a problem solving approach to maternal care**

- ✓ Skills training for ANMs and LHVs as well as doctors in peripheral centres, to interpret the data coming into the MCTS, and screen the high-risk cases. Further training is required for building their capacity to develop "Birth Plans" for specific cases who already show high-risk signs
- ✓ Developing Appropriate Protocols and Procedures for managing adverse outcomes –
- ✓ Using a team approach as well as ICT to support decision making as well as communication between members of the team located in different spaces. The team would include public and private providers located in different spaces from village to the tertiary care facilities.
- ✓ These protocols and procedures would need to be done for
  - a. Management of Risks and Complications during Pregnancy
  - b. Strengthening the Referral Chain
  - c. Providing effective Comprehensive Obstetric Care Services to the marginalized
  - d. Monitoring 'performance' of the 'adverse outcome management' system – Team based, learning approach to monitoring performance.

Maternal death reviews have been institutionalised for some time now, however its effectiveness is still not clear as they are usually conducted by providers and include a strong bio-medical perspective. This study is based on a different premise where the community perspective was considered important to identify how the distance between communities and the health system may be reduced, and how the health system could be appropriately equipped to address the problem in difficult areas. On behalf of NAMHHR we earnestly hope that the lessons that these 140 women have taught us through their deaths will indeed not be lost and become a blessing for the millions of other marginalised women who are faced with the same risk.

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On behalf of NAMHHR

<sup>i</sup> Ministry of Health and Family Welfare, Government of India, Jan 2013: A Strategic Approach to Reproductive, Maternal, Newborn, Child and Adolescent Health in India (RMNCH +A)