

Covering the Last Mile of
Maternal Health Programming:
Overcoming Systemic Blindspots
through Community Based Insights

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Fifth Global Symposium
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COVERING THE LAST MILE OF MATERNAL HEALTH PROGRAMMING: OVERCOMING SYSTEMIC BLINDSPOTS THROUGH COMMUNITY BASED INSIGHTS

OCTOBER 11, 2018

FIFTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH, LIVERPOOL, UK

Facilitator: Jashodhara Dasgupta (National Foundation for India) Speakers: Michele Sadler (CulturaSalud, Chile) Aminu Magashi Garba (Africa Health Budget Network, Nigeria) Lynn Freedman (AMDD, Columbia University, United States of America)

Sunisha Neupane (PhD student, Nepal)

Participants: 25 participants, conference attendees

Background

Maternal and Neonatal Health outcomes have improved overall but mortality among marginalised communities is still high. The workshop was organised at the fifth global symposium on health systems research, to deliberate on how routine and emergency health care services may be provided in a culturally appropriate fashion so that socially disadvantaged communities accept and utilise the necessary lifesaving services. The session proposed by COPASAH, builds on the roundtable that took place in New Delhi in March 2018 and draws upon the questions and insights that members have been discussing around maternal and neonatal health (MNH) care. The SDG focus on 'Leaving No One Behind' allows a fresh opportunity to revisit the way MNH programming has been defined, designed, financed and implemented in the last two decades. While there has been a decline in maternal and neo-natal mortality, most LMIC countries did not reach their MDG targets, with limited attention to considerable social, economic, geographic and demographic disparities. Despite substantial funding to maternal and neonatal health programmes, health systems remain weak and inadequately equipped resulting in sub-standard outcomes.

Objectives of the workshop:

Considering this background, the workshop deliberated on what needs to be done differently to understand and address maternal and neo-natal health needs of marginalized communities to address locational and demographic disadvantages as well as social inequities. The workshop explored some crucial questions, including: Who gets left behind and why? Are our health system priorities and approaches aligned with the key concerns of 'left behind' communities? Do we sufficiently understand community motivations and ally our systems and approaches with these? Is the community (especially marginalized women) included in the solution and priority setting process? Do health providers provide care in a way that is of high quality as well as respectful and aimed at improving compliance and follow up? How can a reciprocal relationship of shared concern around maternal and

neonatal well being be developed along with the community? What does reciprocal accountability mean in this paradigm of care and do we need to move beyond checklists and score cards? The workshop intended to draw upon the experiences of the participants to interrogate these questions and identify solutions. Program managers, donors, researchers and activists attended the session, and skilled facilitation enabled the participants to both challenge and learn from each other. The focus of the session was to think out of the box, draw upon lessons learned – successes and failures, from other community-owned processes.

Building on previous COPASAH learnings

While the conversation around the need for community centred, community accountable interventions in the field of reproductive and sexual health is one that COPASAH has engaged in in the past year with its partners, the forum of the global symposium provided the opportunity to reach out to people from different backgrounds, countries and roles, beyond the community practitioner. Building on the rich experience that community practitioners brought to the New Delhi Roundtable, COPASAH was able to challenge and share with these new stakeholders: 1) new and deeper insight into how marginalised communities perceive and experience maternal and neonatal health care 2) deliberate upon the need for research and analysis to better document their realities and 3) facilitate an understanding of both the challenges and opportunities of our existing approaches in different contexts. The lessons from this session will also be taken forward at the COPASAH Global Symposium planned in October 2019 in New Delhi.

Structure of the Workshop

The workshop adopted a participatory approach, and was divided into three stages of 30 minutes each.

1. The first stage comprised of four provocations by presenters from different parts of the world, in different contexts - ethnic minorities of Latin America, financing for maternal health Nigeria, racial disparities in maternal mortality and morbidity in North America, and the maternal health challenges in rural mountainous Nepal. These provocations highlighted various equity dimensions of the problem, ending with questions being posed to the workshop participants.

2. In the second stage the participants were divided into three groups, each guided by a facilitator, to discuss three specific questions. These are 1. How do we develop policies to address the maternal health concerns of marginalized women, such that are sensitive, participatory and prioritize the concerns of these communities? 2. How can we do research/evidence building differently? 3. How can we implement programs and policies that are accountable and inclusive?

3. In the third stage each group provided a brief summary to the larger group and the session ended with the Chair summarising some of the key lessons that had emerged.

STAGE 1: Provocations



Michelle Sadler: a professor of anthropology spoke about indigenous women's experiences with maternal health in Chile, began with a story. It's 2009, the Head of the Women's Health programme of the Chilean Ministry of Health is touring the North of Chile, presenting the NEW model of personalized childbirth to the communities. He presents in an indigenous aymara community in the Andes, and talks for half an hour about the wonders of this new model, which puts women and families at the centre of care, where labouring women can walk freely and give birth in the position they choose, where they can be accompanied by a person of their choice. A leader of the community, a man, stands up to say: "Sir, will all due respect, this is what we have been doing for thousands of years".

What does this story have to tell us? How arrogant can biomedicine get to be? Is it not one more clear example of colonialism? The biomedical model of childbirth has in most cases ignored other health systems and imposed its ways, and in the way swept away indigenous practices.

Ok, but let's be fair. Maternal and infant mortality have decreased, we are doing OK, aren't we? Is that enough? The complexity and problem is that hospital birth does not translate into better birth experiences for women and families (and we could add even in better mortality rates in some contexts). In every country, policies are making more women go to give birth at hospitals, where they are abused. The world is talking about the epidemic of abuse /disrespect in CB, Latinamerica has coined the concept of OBSTETRIC VIOLENCE as a kind of systematic gender violence, which includes an excess of obstetric interventions and

abusive interactions. Where the biomedical –or lets better say technocratic model of CB is the norm- the excess of obstetric interventions is common to all women (doesn't discriminate for social status, and the more privileged women are, the more unnecessary cesareans they experience). But other forms of abuse –verbal, physical, blaming, scolding, humiliating, or ignoring- are much more frequent in the most vulnerable. And to all of the above, we can add a lack of cultural awareness.

Michelle urged the participants to think “What is CULTURE?”. Culture is a blindspot.

Culture is usually only acknowledged in “others”, in this case in those with different “health belief systems” than biomedicine. So there is MEDICINE (in capital letters) and “other health BELIEF systems” (science over belief), without recognizing that biomedicine is also a cultural product, to be more specific, a Western physiologically oriented health system (and we could add androcentric). We could call it a physiologically oriented ethnomedicine. So when biomedical practitioners face the “other”, culture comes into the room, the big elephant comes into the room. Culture comes in the body of the other, and only the “cultural” other.

We have reduced culture to registering "medical uses and customs", conferring them a "folkloric" character. But is it way more than that. To understand culture is first to understand we all have culture, and in health interactions, that biomedicine is culture too, and that it is the medical system with more power. To integrate culture is much much more than giving families back their placenta or “allowing” them to squat during birth. It is to understand the heterogeneity of cultures themselves, in dynamic and transformative processes. There is no one kind of mapuche woman or family, as there is no one kind of “white” woman, and we cannot just put every “other” in a certain cultural basket.



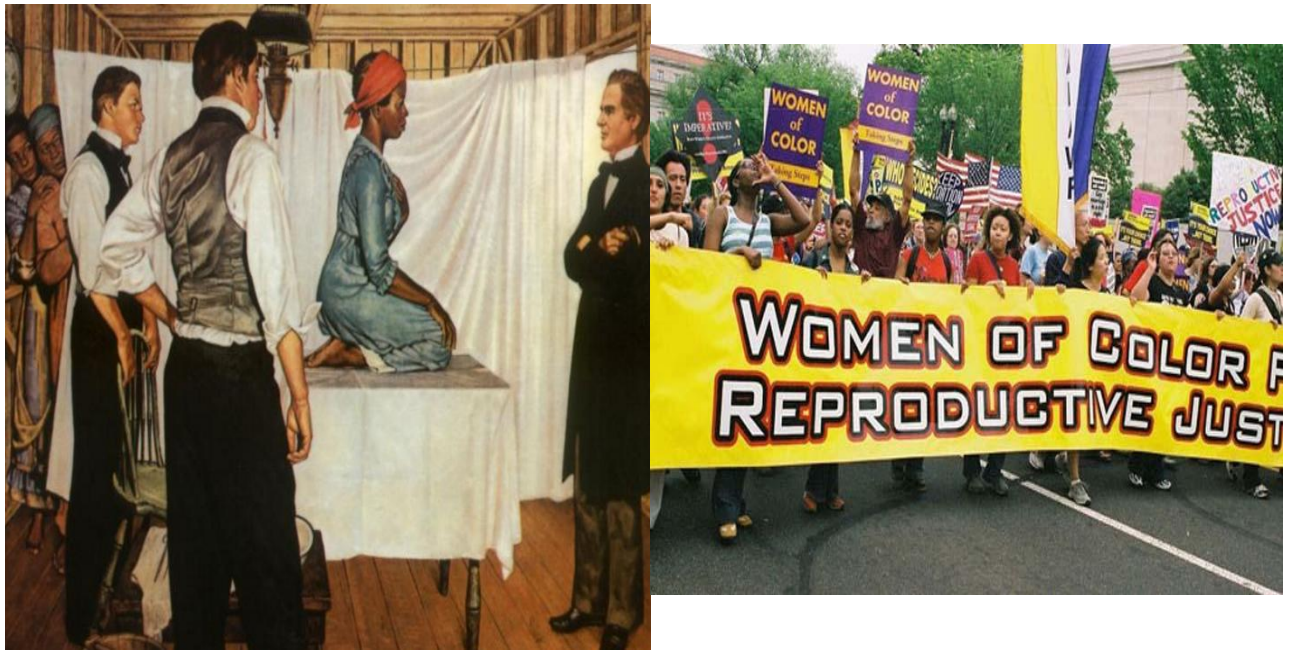
This is a mapuche woman, this a mapuche woman too. We cannot just assume they need the same for being mapuche. The cultural encounter is an interactive social process which changes us all. A profound comprehension of culture implies a relativization of one's conceptions, representations and practices by those of the other, that is, a conscious process of reflection and analysis, it implies cognition (understanding the meaning of "cultural" differences and metabolizing them), affection (care, non-discriminatory), and politics (empowerment of communities in health matters). And it needs us to embody that

we all have culture, and that all cultures are valuable and that we can learn from them. It needs humility and compassion, to see us all as human beings who deserve the same care.

Imagine how different the story would have been if the Chilean Ministry of Health had understood they had something to learn from indigenous communities before writing the NEW policy of child birth.

Lynn Freedman: A professor at the Columbia University, spoke from an urban North American standpoint, of New York City, where her centre has been conducting research on disrespect and abuse faced by women during childbirth. Very recently NYC did a bunch of surveys on maternal mortality and severe maternal morbidity and the results showed that there is deep and growing disparity among different groups, most significantly, Black non-Hispanic women in NYC have 12 times higher maternal mortality than white women. This is the background fact and the blindspot that's emerged through our research is that it is not the demographic factor of race, but the system of racism that is at the root of this disparity. This is a shift that we need to make in research on inequities in health. In NYC there is an emerging discussion about this – what does it mean to build racism into work on maternal mortality and understand disparities from this lens? First, it is essential to recognize that racism has a history.





The slide above on the left is a photograph of Dr. Marion Sims who is known globally as the father of gynaecology and obstetrics, who learnt to do surgery fistula operations and develop many gynaecological tools by experimenting on slave women without anaesthesia. This history is very much alive in the reproductive justice movement led by women of colour. It is not just about the brutal use of women's bodies for others purposes, but also the devaluing of black women's motherhood. So black women come into a facility carrying this history, and the very same behaviour from a provider will be experienced differently by different people, because they bring with them not just with their race but also their history and experience with racism. This brings us to the second important consideration – the emerging area of work on what is called toxic stress or the weathering thesis – the question of what it means to live a lifetime in a society as the object of racism? To live with the stress of racism for your entire lifetime. This body of work is coming to measure how the political and social conditions of racism manifest “under the skin”, try to understand how that can have an effect on your ability to go through child birth safely. When we work in any society, we are very clear that women of colour lead the movement, that means we have to be very thoughtful about how we work in solidarity, what is our own positioning and how we remain aware of it. That is also a blindspot that we as public health researchers, so that we may be able to research differently these pressing questions.

Sunisha Neupane (Nepal): began with recalling how she went into her PhD field with assumptions about what the WHO tells us about what is required to address maternal health globally. When she went to the field she found herself in a place that is 16 hours away by bus and 6-7 hours walking from Kathmandu in Nepal. In the area, most men are migrants and women are typically taking care of their households entirely by themselves. Having spent four months there, Sunisha realised that she was no longer able to ask why people don't go to the health centre. They would ask back, where are the traditional birth attendants and this was the program that existed before the push for institutional childbirth. When you try to look at what happened to traditional birth attendants, you find that in 1991 very much influenced by the UN, Nepal stopped training TBAs, and all women no matter where they lived were encouraged to go to health centres and they were given incentives. In areas which are flat, it worked and MMR did decrease. But what about women who are far away in the mountainous region and are asking "where are the traditional birth attendants"? By 1997 there were no more TBA's left. So going forward, as a researcher, she poses the question to other researchers – who decides the research questions? Who decides what services are given or taken away? Whose questions are being used to define maternal health improvement and in turn informing policies? The questions of global researchers, or the questions of rural mountainous women who live with the uncertainty of not knowing whether they will live or die in childbirth?



AminuMagashiGarba (Nigeria): spoke about the material basis of policy making in Nigeria – the budget question. Nigeria has a very high GDP, over 500 million, but yet, a large proportion lives below the poverty line. The DHS shows that majority of women are still delivering at home, and those who are delivering in facilities only about 30% are being attended by a skilled birth attendant. The Antenatal coverage is just about 10%. So why is the budget to finance services so low. Over the last 10 years the budget is just around 5%. Only about 25% is being released. It is a country that has a big private sector, which is typically accessed by the rich people and Africa has a lot of wealth inequality.

STAGE 2: Group Work

Q1: How can research be done differently?

1) Ways of including the marginalized – speak to them about their problems before research questions are informed by their position. How research comes with pre-existing ideas on what research needs to be done

2) Reluctance to dissect and understand failures

2) Taking research back to communities – donors should have budget lines for this, it is usually disregarded.



3) Expectation that marginalized persons should participate in research on a voluntary basis

4) Scope for proposals to be open ended – especially in participatory research. At the moment everything from the research questions.

5) Questions tend to be very linear – a system thinking implies that different parts of the system are moving at the same time, and so linear frameworks are not very useful by themselves.

7) who drives the research agenda – understand ways in which see the margins better – questions should emerge from those who live at the margins – their lived realities need to be understood much better. Context tends to be thought of in a very mechanical way, rather than how it really interacts with the context. This is particularly important in case of marginalized

8) Very little focus on quality, lots of research looks at coverage.

Q2. How can policies be designed such that they respond to the concerns of the most marginalized?

1) Policies need to be tailored to different populations, and this means facilitating decentralisation in an effective way.

2) There must be scope for periodic review and change in policies, because it is clear that everything cannot be known through research before a policy is implemented

3) Researchers should not believe that their research is necessarily going to give them the most appropriate policy. Research only answers certain questions, but policy making requires many more aspects to be taken into account, and that is where context comes into play. The same evidence from different countries may not result in the same policies.

4) Politics drives research as well as policy making and that is why even when research shows that a policy doesn't work everywhere, it still continues to be pushed because an entire industry to promote that policy develops around it. This is particularly detrimental to those at the margins.

5) Policy making should give as much importance to qualitative as it does to quantitative research. Oftentimes, we think of quantitative research as the holy grail of "evidence", when in fact it masks a lot of realities that qualitative research can uncover. Moreover, we must also think of ways in which quantitative research can be done more thoughtfully.



Q3. How can programme implementation foster accountability and inclusiveness?

1) From the inception of the programme, accountability has to be built in. Usually accountability is thought of as something that monitors implementation, but it must even be incorporated at the time of inception of a program.

2) Who decides funding of programs? There is a need to organise communities, so that they participate effectively in program design and demand budgets to implement programs.

3) Mechanisms to give feedback – town hall meetings, direct feedback to facilities, using media are some of the ways in which feedback can be given, but this should be incorporated into program design as well, so that the system is more interested in listening to this feedback.

STAGE 3: Summing up

We think about "those communities" and "their cultures", but maybe we must think about the cultures of the health system, and the providers – such as the culture of impunity when they interact with patients and communities. Talking about "our" culture – the researchers, doctors, scientists, policy makers – is considered quite taboo. And so we are completely blind about our own culture, hence the need to take off our blind fold. We hope that going forward we are more sensitive to people choices, autonomy, belief systems. We need to question whether cultures are set in stone; all cultures are dynamic including our own. The other important point to take away is that it isn't about race, caste, gender – but racism, casteism, sexism. This way of articulating inequities questions not the community but the structures that all of us are part of.

The question of power was also tabled here. If the entire health system is predicated on the exploitation of those who are powerless, we are no different and we also use power in different ways. We are all in positions of power, and we must be mindful of that position – our own class, race, gender. It is the question of respectful acceptance that is important when we are talking about solidarity. Ultimately as researchers if we want to include those who are marginalized/discriminated, we must call for a culture of respectful acceptance of diversity and plurality, and to be open to new questions, new methods, new unblinkered findings.