Addressing Health Inequities through Community-led Advocacy in Bangalore: Experiences, Successes and Challenges

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A few years ago, during an 'interface meeting' of community members and the staff at a BBMP (Bruhat Bengaluru Mahanagara Palike) Referral Hospital, one woman stood up to tell the story of her daughter Fatima* who had recently had a normal delivery in the hospital. She had complained of discomfort, but the nurse said that this was normal and discharged her. A week later, the discomfort had not abated, fever had set in and her family noticed a bad smell. Fatima's husband, who was against the decision of going to a government hospital, now took her to a private nursing home. There, the doctor pulled out cotton from her cervix and discovered an infection. Fatima was admitted in the nursing home for a number of days and her family incurred expenses of about Rs. 10,000. On hearing this from her family, the Superintendent of the Referral Hospital promised an investigation. When activists met her a couple of weeks later, she said that the hospital's practice was to insert tampons to protect the women's episiotomy stitches from blood. The nurse had forgotten to remove the tampon before discharge!

In response to this incident (and 2 similar ones reported at the interface meeting), the Superintendent stated that she had called a special meeting and changed the discharge procedure, with a doctor now examining each woman before discharge. But the story does not end here. While no new cases have been reported at this hospital, field activists working with SPAD (Society for People's Action for Development, who had organized the meeting) recently heard of another such case in a BBMP Maternity Home some 15 km away. Unfortunately, they were not able to trace the woman as she had moved away from that locality. There is no functioning grievance redressal system in hospitals, plus the BBMP Health Department has become hostile to the SPAD activists and is unlikely to investigate the matter further. In this impasse and other such situations, activists have asked 'Should we be trying so hard to convince women to go to government hospitals?'

SPAD began working with Dalit and Muslim women in 27 slums in south west Bangalore in 2010 to improve their access to government health services. While no community monitoring programme exists in Bangalore's government hospitals, the community women have formed their own monitoring committees which regularly visit various hospitals run by BBMP and the State Health Department. Their reception by hospital staff ranges from tolerance to indifference to hostility. But they have been able to achieve some results - abuse of Dalit and Muslim women has reduced, as have demands for bribes, and some services have improved. The structural issues and disputes over appropriateness of care, referrals etc. have proved harder to tackle. At the local (slum) level, solidarity groups set up by SPAD have found it easier to take up social determinants of health such as water, waste management and security issues. Here too, financial demands such as loans for savings groups and cash compensation for flood damage have been easier to realize than, say, better services at the local anganwadi.

The Urban Health Care Scenario

Like other cities, Bangalore suffers from fragmentation of government health services, with institutions and outreach services run by BBMP, the State Health Department, the State Medical Education department (through Bangalore Medical College and autonomous institutions), ESI and national institutes such as NIMHANS. Within BBMP itself, services are fragmented – for example, a woman delivers at a Maternity Home or Referral Hospital, but has to collect some of her maternity benefits from the Urban Family Welfare Centre (UFWC) which initially registers her through its outreach programme. Fragmentation is present in other social-sector and essential programmes – for example, the zones for services through BBMP (wards) are different than those for water and drainage (provided by BWSSB, the Bangalore Water Supply and Sewerage Board), which are further different from the school zones of the Department of Education. For any person, but especially one from a marginalized group, negotiating these various jurisdictions and getting one's work done is not easy.

The outer, newly expanding areas of the city are poorly covered, with some wards lacking any government health facilities. Further, many existing primary facilities are poorly staffed or underequipped. As a result, secondary and tertiary hospitals in the city have a huge primary care load. A survey conducted by SPAD at Vani Vilas Hospital, a tertiary-level institute for gynaecological and obstetric care managed by Bangalore Medical College, revealed that more than half of the 320 women interviewed had normal deliveries (with most being uncomplicated).

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Ironically, 96.6% of them had visited another facility before coming to Vani Vilas. They either found them closed, lacking staff/facilities, or were referred out for reasons like having high BP, anaemia, or need for a C-section. One woman was referred because the BBMP Maternity Home didn't have the 'injection to increase labour pain' (most likely oxytocin).

In addition to all this, the out-of-pocket expenditure for patients accessing government health services is striking – some examples:

• Pregnant women spend thousands to pay for diagnostic tests and scans as well as medicines from private labs as government facilties don't provide these services – various surveys by SPAD have revealed median costs of Rs. 2000-5000 for antenatal care per pregnancy.

• The treatment for dengue, chikungunya etc. has been missing in most government hospitals. Those that do have services have sometimes refused to admit patients. In one slum, SPAD activists found many families who had 2-4 members admitted in private hospitals for these diseases and had taken crippling loans to cover the costs.

• Very few government hospitals provide medicines for chronic diseases, which cost at least hundreds of rupees each month.

• Some poor patients are able to get free or discounted tertiary care through government-supported insurance schemes, CM relief fund etc. but incur routine post-operative expenses. Some cases examined recently by JAAK (Janaarogya Andolana Karnataka) were of patients who had heart surgery at Jayadeva Hospital, a government autonomous institution and were paying about a thousand rupees every month for medicines thereafter.

• At hospitals managed by Bangalore Medical College (an autonomous government institution), BPL patients receive a discount of 50% for diagnostic tests. Given the volume of tests prescribed, even this amount can add up – a wastepicker recently operated in one of these hospitals incurred almost Rs. 40,000 for tests, scans, blood and travel even though her bed and surgical charges were waived.

City-level Advocacy on Health Issues

City-level health issues in Bangalore have been taken up by informal and formal networks such as Janaarogya Andolana Bangalore Urban (JAABU), the city chapter of JAAK, which is in turn the state chapter of Jan Swasthya Abhiyan. From 2011-2013, JAABU's advocacy ranged the spectrum from reports and consultations to protests. Many important issues were raised and discussed, but no real progress was achieved on any of them. In late 2012, JAABU representatives were informed that the National Urban Health Mission (NUHM) was to be launched with Bangalore and Bhuvaneshwar as pilot cities. There was an opportunity to participate in a series of roundtables organized by the Karnataka Health Systems Resource Centre (KSHSRC) with the support of the Public Health Foundation of India (PHFI). This led to deep divisions within JAABU on whether to participate or not in these deliberations, with some considering the process co-option and others looking at it as an opportunity.

Eventually some members participated in the roundtables, including myself. There was strong participation from 'civil society' and medical and social issues, communitisation, convergence and governance were discussed. The draft approach paper developed by KSHSRC reflected this (though, with inputs from all stakeholders, it turned into a confusing document!). But the subsequent Programme Implementation Plan (PIP), drafted based on specifications from the MOH, GoI, was disappointing. The focus was on building new PHCs, upgrading old ones and communitisation (through Mahila Arogya Samitis and ASHAs) to 'generate demand' without any horizontal or vertical integration. There was little focus on referral systems, comprehensive care , and other issues highlighted in the roundtables. Also, the plans for NUHM changed to a nationwide launch and the promised funds were reduced significantly.

Another opportunity came up when the Technical Resource Group, chaired by Harsh Mander, visited Bangalore in late 2013. This time SPAD and other organizations presented very specific recommendations at the primary level, such as:

• Rather than appointing ASHAs (who could get controlled from above), the members of MASs should be allowed to manage the responsibilities jointly. The NUHM draft framework provides this as an option.

• MASs should be federated at the ward level and members included in the ward committees (mandated under the Karnataka Municipal Corporation Act)

• BBMP Link Workers should be absorbed into NUHM, possibly by training them to become ANMs

• Members of ward committees and the staff of referral centres should be included in the ARS of the local PHC to address social determinants, referrals from the PHC etc.

Our recommendations were discussed and similar concerns have been raised by NUHM staff and consultants later, but none of them have resulted in any concrete changes as of yet. NUHM was 'launched' in Bangalore in January 2014, but implementation in the field began more than a year later. So far, some MASs

have been formed and ASHAs selected with the help of SPAD and other field organizations. But the fragmentation continues – recently, a newly-minted ASHA (who is also a SPAD field activist) escorted a woman in labour to the nearby Maternity Home, where the doctor refused to admit her because she had moved to Tamilnadu after marriage. When the ASHA protested, the doctor responded that ASHAs report to the nearby UFWC and Maternity Homes have nothing to do with them! Ultimately, the ASHA had to take the woman to Vani Vilas Hospital for delivery.

There is some energy and an influx of funds into the cash-strapped BBMP after NUHM activities commenced – health camps are being organized regularly in slums and there is improved outreach. But there are some puzzling developments as well – when asked about medicines for non-communicable diseases, officials stated that these would be provided in facilities based on demand and that ANMs/ASHAs would conduct field surveys to estimate the burden of disease. Aren't there enough published studies on NCDs to use as reference – why is a fresh survey required? However, it is early days yet for NUHM-redux.

In the meantime, the divisions within JAAK led to a split and JAABU went into hibernation. Individual groups continued their work and advocacy to differing levels of success. In the past year, organizations have started coming together again and the annoncement of JSA-NHRC public hearings have given an extra fillip.

'Are you the Doctor or am I?' Experiences at the Local Level

While mobilizing communities for health rights in Bangalore has had some successes, there have been many setbacks as well. In March 2014, the Chief Medical Officer (CMO) attended an interface meeting organized by SPAD and was shocked at some of the evidence presented. Some Medical Officers and staff were hauled over the coals for poor attendance, corruption and high numbers of referrals. The CMO promised to overhaul the BBMP health system. But subsequent developments indicate that political pressure was brought on her to reverse her stand. She refused permission for SPAD to conduct further interface meetings, and since then not a single one could be organized.

In the meantime, the activists and solidarity groups members have become more confident and, in some cases, politically active. There is regular interaction with elected representatives, and this bore fruit recently when one sympathetic Corporator became the Chairperson of the Standing Committee for Health, BBMP. He invited SPAD representatives to raise the problems faced in one particular hospital in a public meeting with media presence. He identified with and agreed to tackle issues of corruption, though it is not clear how much he connected with the other issues. In fact, political 'interference' may be detrimental in increasing the number of deliveries at the hospitals – BBMP doctors have become extremely risk-averse and have said that they do not want to deal with the fallout from a death in the hospital. The result is that BBMP hospitals, even Referral Hospitals which have specialists, rarely go above 2-3 deliveries a day, while Vani Vilas conducts 60-80 deliveries every day and faces almost all the maternal and infant deaths.

Some doctors do appreciate the community's involvement – a newly upgraded CHC near Kengeri (formerly a satellite town, now part of Bangalore) has specialists and the requisite nursing staff, but lacks furniture and equipment. Their OT has been poorly constructed (with windows!). The Health Department has asked the doctors to use ARS (Arogya Raksha Samiti) funds or user fees to get the OT repaired! The solidarity group in the area approached the elected representatives and was able to get some necessary equipment for the CHC. They are still trying to address the OT problem – elections have delayed a public meeting with the local MLA.

At the organizational level, there are also challenges in building capacity on health issues and in overcoming the adversarial relationship between the community and hospital, . An activist recently shared the story of a woman who said she was told by her doctor that her infant had died in utero. She then rushed to another hospital where she delivered a live baby normally. But after the case was documented, it was found that the doctor had given a referral slip and called for an ambulance. How this reflects on her skills is a different question, but she cannot be accused of callousness. Unfortunately, some genuine cases get missed or buried in this atmosphere of suspicion.

Conclusion

Community-led advocacy, with the requisite capacity-building and support, can play a crucial role in improving access to health services and thus address health inequities. But the challenges of the urban space, along with information and education assymetry as well the unwillingness of the health system to cooperate, can limit the effectiveness of this advocacy. The challenge is to create effective partnerships between health systems, political structures, health experts and the community to effectively address community health needs.