NGO’s Role in Community Based Monitoring of Primary Health Care Services for Dalit Women in Urban Slums

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Abstract
The discrimination and denial of health care is hardly recognised as a problem deserving attention. Being Dalit in India seriously impairs capabilities of persons to function in society. As one stands at the bottom of the social ladder, one’s risk of suffering premature death, poor health, and a lack of treatment and care is substantially higher than it is for the one with better socio economic position. (Vani et al; 2015, pp- 258). Dalit women are the vulnerable, the marginalised and the poor. With increasing urbanisation and migration, more and more dalit women are forced to live in abject poverty in the overcrowded slums. They are further rendered vulnerable to ill health, due to prevalent discriminatory practices found at the public health sector. This paper presents a Case study of a Bangalore based NGO, “Society for Peoples Action for Development (SPAD)”, who initiated the strategic intervention with Dalit women in Bangalore slums to achieve Community Based Monitoring (CBM) at the public health sector for the improved access to health services - a key strategy employed by the National Health Mission to ensure that health services to reach those for whom they are meant (Garg and Laskar 2010).

Keywords: Solidarity groups, slums, dalit women, public health sector, health promotion.

INTRODUCTION:
Women in India have been the focal point of the planning process since the eighties. The five year plans have envisaged step wise welfare, development and empowerment measures for women in India. The main focus of the planning process has been to ensure that every woman in the country irrespective of caste, religion, economic status etc. is able to develop her full potential and share the benefits of economic growth and prosperity.

In this context, when we look closely into the women’s specific programs, the health component has received marginal importance. In today’s scenario Health has become the most vital aspect of human development. The slogan, “Healthy Women, Healthy World” embodies the fact that as custodians of family health, women play a critical role in maintaining the health and well-being of their communities (Balambal, 2011).

It is important to understand that health is the center of holistic development. Poor health adversely affects overall quality of life and can disable and disempower the powerful. Hence health and empowerment has to go hand in hand.

In India various government health programs/policies for women have been implemented through National Health Mission. These programs are basically ‘incentive based’ e.g.: Janani Suraksha Yojana, etc. The positive impacts of these programs in relation to health seeking
behavior among women remain questionable. Since women in India belong to heterogeneous groups, the impact of these incentive based health programs on the marginalized section of women poses a challenge in achieving equity and equality towards health rights. The most important link between health and empowerment is missing in the government’s health programs.

While these programs seek to indicate impact through statistical data related to MMR, IMR, CBR, Fertility rate etc, there exists lacunae even in the statistics when it comes to data segregation based on caste and gender. However, region wise data segregation reveals that poor health indicators in regions with high concentration of marginalized women. In this context, when Dalit women’s health status is considered, it is evident that gender, caste and economic intersectionality influence the health of dalit women to a great extent in the Indian context.

Health inequality is the main cause of health inequity. It is the duty of the government to bring equity and to create enabling environment to achieve equality and health empowerment among the poorest and the needy.

Non-governmental organizations (NGOs) have been in the forefront to bear additional responsibilities whenever the country’s government failed to respond to the needs of the voiceless. In many circumstances the NGOs have played crucial role in community mobilisation to fight for any common cause. The efforts of the NGOs towards motivating, lobbying, planning and influencing policy making has never gone unnoticed.

Poverty, inequality and limited decision making power has enormous impact on the health of Dalit women. But with increasing urbanization and displacement due to development, a large section of the Dalit population has been forced to displace from their original habitat and are living in overcrowded urban slums under abject poverty.

Dalit women in urban slums are considered to be extremely vulnerable to various health hazards due to dehumanizing, unhygienic conditions and lack of basic amenities. Poor dalit women are victim of treble discrimination based on poverty, caste and gender which further complicate their access to health facilities. Discriminatory access to primary health services for Dalit women not only leads to lower utilization of health services (Acharya; 2010, pp 208-229) but also influences the health seeking behaviour and community health status.

In Bangalore, the public health care system run by Bruhat Bengaluru Mahanagara Palike (BBMP) is already facing severe shortage of funds, inadequate supply of medicines etc. This intern is affecting the deprived sections of the society, especially the slum dwellers. City Corporation with the current population of 10.1 million is grappling with various problems (bbmp.gov.in). The slum population is accounting for 30% of the city population, which is spread out in 542 slums (http://ksdb.kar.nic.in/slums.asp).

Dalit women living in these slums are further rendered vulnerable without sufficient access to services. The practice of irrational diagnostics and treatment, as well as corruption at all levels further adds to the problems. The discrimination and denial of health care is hardly recognised as a problem deserving attention.

Article 14 of Indian Constitution recognizes equal access. Thus a dalit woman’s health, especially those living in urban slums, needed special focus. But in the absence of any State sponsored initiatives in collectivisation and sensitization, Dalit women from few slums in the west zone of Bangalore city, under the aegis of an NGO-Society for People’s Action for Development (SPAD)
have come-together and initiated community action through Community based monitoring, - a social process towards achieving better health equity.

This paper proposes to project the strategic intervention with Dalit women in Bangalore slums by SPAD (NGO, based in Bangalore) in achieving Community Based Monitoring (CBM) at the public health sector for the improved access to health services, a key strategy employed by the National Health Mission to ensure that health services to reach those for whom they are meant (Garg and Laskar 2010).

OBJECTIVES OF THE STUDY:

1. To examine the discriminatory trend in existing Government health care structure in Bangalore city which erect hidden barriers for Dalit women in accessing health care facilities.

2. To document the process adopted by Bangalore based NGO (Society for People’s Action for Development) towards collectivisation of Dalit women for asserting their health rights through Community Based Monitoring intervention strategy.

METHODOLOGY:

This study follows the ethnographic method where descriptive research design is followed. The study also follows triangulation method where balance is maintained between qualitative and quantitative data. Primary data is collected through Case Studies, semi structured interviews and unstructured observation with stake holders of the CBM intervention process while secondary data is collected from the unpublished literature and annual report of the NGO –SPAD, along with census report and Slum board records.

BACKGROUND:

The Society for People’s Action for Development (SPAD) and its initiative towards collective mobilization of the marginalized:

SPAD, is an NGO based in Bangalore and has been instrumental in working for the health rights of the marginalised women, especially Female Sex workers and Dalit women living in slums of Bangalore. SPAD has 20 years of expertise in mobilising marginalised women in the slums and in initiating formation of Community Based Organisations.

The initial experiences of this NGO, was with Female Sex workers towards reduction of their stigma, discrimination and violence in relation to HIV/AIDS. The NGO conducted a study in 2006 with Female Sex Workers (FSWs) living in select slums of Bangalore urban District. This study was a comparative study between Dalit FSWs and Non Dalit FSWs and revealed that among all the respondents, the Dalit FSWs were increasingly vulnerable and more susceptible to HIV/AIDS due to their marginalised caste status and lack of bargaining capacity. This became more evident when SPAD segregated the data of PLHIV – FSWs based on caste. Out of the 55 PLHIV –FSW identified by SPAD, 60% of them belonged to the Dalit community. More over during the project period SPAD lost 12 PLHIV FSWs, of whom 9 were Dalit PLHIV FSWs. The findings of this study had encouraged the NGO to take up projects that would focus on the health of Dalit women (other than sex-workers) in slums.
SPAD's intervention with the Dalit women living in the slums was through consciousness rising approach. The intervention was planned and implemented through a five-year project ‘Access to health’ funded by Oxfam India, and aimed to improve access to maternal health services for Dalit women of Bangalore through the establishment of CBM groups in the public health system (Oxfam India 2014).

The CBM intervention was implemented in 17 Dalit slums in three major regions in the Bruhat Bangalore Mahanagar Palike (BBMP) limits, namely Avalhalli, Vijayanagar, and Kengeri. Each of these areas has its own Referral Hospital or Maternity Homes.

**STRATEGY ADOPTED BY SPAD TO IMPLEMENT CBM PROGRAM:**

During the initial phase of the program in 2009, a pilot study was conducted in select slums of Bangalore to identity the problems faced by Dalit women in accessing health facilities at hospital level. The pilot study revealed the evidences of discrimination faced by Dalit women while accessing health care in the Government Health Sector. The highlights of the Study conducted by SPAD are as follows:

a) 52% of the respondents were illiterates.

b) 60% of the respondents had availed treatment at the government hospital

c) 58% reported dissatisfaction regarding the treatment facility at the Govt Hospital.

d) The study came across 14 pregnant women, among whom 5 did not receive any ANC check-up.

e) Further the study came across women who had delivered new born, among them 9 did not undergo institutional delivery. Unable to bear the cost of transportation to the hospital and refusal of admission during the time of labour were the reasons for not undergoing institutional delivery. As a result, 3 reported still birth.

f) 14 respondents expressed dissatisfaction with the staff behaviour during the time of Child birth. 2 respondents had complications during delivery.

g) 76% of respondents reported that staff of the hospital demanded bribe during and after delivery.

h) 19% of the respondents were verbally abused during the time of delivery.

i) Among the 47 respondents who underwent sterilisation, 7 did not receive proper care and majority of them were demanded money for sterilisation. 26 of them were not provided any information regarding the side effects and 8 of them were refused and sent back.

j) Almost all the respondents who sought immunisation for the children faced discrimination in the form of verbal abuse, delay in treatment or refusal.

The base line study provided enough evidence to indicate discriminatory practices prevailing on the Dalit women at the public health sector. The major findings of the pilot study were that Dalit women lacked the ability to mobilize and assert their rights for better access to health unlike other women. Thus at this stage SPAD believed that mobilization of critical groups is an important component to bridge the gap between the vulnerable and the government and it is also critical for the success of intervention programs.
The CBM programme was implemented by establishing three different groups of women in the Dalit community. These groups were formed in different phases of the project period.

- Community Activists
- Solidarity Groups
- Maternity Home Monitoring Committees (MHMC)

These three groups function to empower women in the community and provide them with an institution through which they can vocalize their needs to actual health care service providers in organized meetings. New additions are always welcome to these groups; thus the exact number frequently changes. These groups work both together and separately to advocate for the maternal health rights of Dalit women in the community. Unstructured observations of the different groups over a period of time provided an understanding of the roles each of these CBM Groups play individually and how the groups interact with one another.

- Community Activists:
The Dalit women who were more vocal within their locality were identified and trained to become community activists by SPAD. The community activists have undergone series of trainings and capacity building so as to sustain their activism even after the closure of the project. Their main role was to create awareness within the community regarding health rights and to establish the solidarity groups to carry forward the activism. The community activists are also a part of the solidarity groups. They hold the reins of the entire CBM program.

- Solidarity Groups:
In order to improve the functioning of public health facilities through mobilization and networking, Solidarity groups of women are formed in different wards of Bangalore Mahanagara Palike. Solidarity groups are the back bone of the entire CBM program.

Solidarity group is a homogeneous group of Dalit women constituting 10 to 15 members who work voluntarily take up issues related to health rights and work unitedly for a common cause. These Solidarity groups conduct meetings once a month and they discuss and follow up on health and other issues in their neighborhood.

The roles and responsibilities of solidarity group include:

i. Identify and address health issues in their respective areas
ii. Receive capacity building training through NGO support, to understand health rights and also to advocate health rights to community members.
iii. Identify issues of negligence, refusal of health services, extortion of fees higher than the user fees, bad behavior of hospital staff, denial of services etc. in relation to the nearest PHCs and Maternity Hospital.
iv. Seek support of local area leaders, political leaders, doctors of the nearest health centers etc to solve health issues pertaining to their respective areas.
v. Advocate and support the community for availing social entitlements for the community.

During the study, the findings from the observation with the solidarity group members are as follows:
a) The solidarity group members have gained awareness on various health issues such as family planning, STI/RTI, ANC/PNC, TB, MTP, immunization etc.

b) Further the existing health issues of the community identified by the Solidarity Groups are TB cases, non-institutional delivery, incomplete immunization for children, STI/RTI problems among Dalit women, negligence in undergoing family planning, Pregnant women not undergoing ANC, Abortion/miscarriage.

c) Bribe and corruption issues in the hospital are directly confronted and advocated at the hospital level by the solidarity groups.

d) They have tackled issues ranging from public services (blocked drains, Issues related to Anganwadis) to community level issues such as family violence. They have ensured that various social entitlements are provided and some groups also save money and disburse loans.

e) The solidarity groups have increased their understanding of various social issues through discussions and capacity building. For example, they have surveyed their neighbourhood Anganwadis and PDS stores, filed complaints where needed and demanded better services. On the issues of ward committees, they have discussed its functioning and powers and submitted recommendations to state government and to their local Corporators.

f) The activities of the solidarity groups have resulted in increasing the confidence of Dalit women. They have raised their voice when necessary and have gained recognition and respect by solving short term problems.

- Maternity Home Monitoring Committees (MHMC):

MHMC was initiated to bring about accountability among the hospital staff and the local representatives for the improvement in the health care structure and service delivery. The MHMC constitutes selected members from the solidarity groups, community representatives like ward representatives, local leaders, hospital staff including doctor.

Interface meetings are organised between the community women and the MHMC in order to confront the problems faced while accessing services. These meetings have resulted in transparency between the service seekers and the service providers. MHMC also works towards improving the infrastructure and better health facilities.

In one of the MHMC interface meetings, the CBM group members confronted doctors with issues regarding the lack of a permanent doctor at one of the maternity homes, and the lack of a sonographer in the any of the JJR Nagar facilities. At the end of the meeting, the CHO addressed each of the cases that had been brought up and asked the doctors to help the women write individual petitions case by case, which she would then take to the BBMP Commissioner, the head of the BBMP, for consideration. She additionally agreed to allocate Rs. 10,000 to repair infrastructural issues in the facilities.
CBM practices primarily function to target these acts and increase accountability of government health officials and service providers. This study has shown that with the heightened monitoring, verbalization and capacity building among community members and CBM group members, higher-ups committing acts of bribery and corruption will no longer be tolerated by community members.

Semi-structured interviews were administered with stake holders of the CBM initiative. The stake holders included SPAD’s members who were involved in the project since its inception, the CBM group members, Community leaders, Hospital staff, and community members who were benefitted from this intervention. The questions were about their experiences, the challenges they faced and further about their future action plan.

According to the SPAD’s field coordinator Mrs.Leela, the challenge was in sustaining the functioning of each CBM group. She expressed that over a period of time the pace at which the solidarity groups were functioning proved that these groups would sustain in a long run, because the women members had realised the power of being in a collective. They were not only managing individual hospital issues but also the long pending ward issues such as drainage problems and water problems.

**BOX-1: Sustainable Activities by Solidarity Groups.**

“It was an overwhelming feeling for me personally, when Solidarity group members of JJR nagar slum announced that their long pending drainage leakage was solved because of their groups negotiation with the area corporator. These women have achieved more than what was expected from them. They gleam with confidence when ever I visit them”

-- Leela, SPAD Coordinator
The SPAD Coordinator stated that as the intervention year went on, she noticed that community members would start bringing problems to Community Activist group members. As the CBM groups’ capacity to handle problems increased, they stopped coming to SPAD for each problem. Over time, she saw that CBM Groups were able to independently do their own work, going out and demanding services on their own accord. Anyone willing to speak up about his or her problems in receiving proper services can be confident that members of the CBM groups will support them (Box 1).

It is important to highlight here the importance of capacity building in empowering women to challenge institutions in instances of corruption or bribery. As stated by Augustine, President of SPAD (Box 2)

Among several challenges SPAD’s team faced, there was one such challenge that in several occasions it is impossible to document corrupt situations as they only can be recorded by word of mouth, but SPAD has kept strong records of interface meetings and launched complaints to at least have a general understanding of the rate of such practices.

Stake holders from all levels of this study agreed about corruption, at the same time they agreed that it has decreased over time as a result of the implementation of CBM practices within the community (Box 3). According to SPAD President Augustine, ‘issues regarding corruption or negligence are addressed in solidarity groups and then systematically highlighted in interface meetings’.

Both SPAD and the CBM members experienced challenges while addressing issues of corruption and confronting the higher authorities because of lack of solid evidence.
The CBM members have expressed the sense of empowerment. They feel proud for being the part of change. They have developed an identity within the community. And women in distress approach them easily. Experiencing the fruits of justice has made them much more confident to take up higher challenges. They feel that Awareness is the key to their success.

**BOX-5: Observed Changes from Intervention**

*They rarely took any deliveries here, but since the solidarity groups and monitoring committees came about, there has been a big change. There are now C-sections being conducted here. The doctors now do not ask for bribes and work sincerely.*

-- Link Worker, 32 years old

Within the health care system itself, the CBM has reaped benefits. The Doctors and staff have been experiencing severe shortage of staff, and few lapses in the infrastructure, these issues have been highlighted to the higher authorities for further action. (Box 6).

Capacity building in relation to health rights and available health facilities has visibly translated successfully into community mobilization. However, a deep and consistent level of knowledge has not yet been spread throughout the community, and will likely only do so with time, increased manpower, and improved methods of information dissemination.

**BOX-7: lesser Discrimination:**

*The staff refused to touch us while treating because they feel we are dirty. I was refused ambulance, during the time of complication in childbirth. I lost my baby. Now I have received awareness and I know my rights. The staff behaviour has changed. They donot refuse services for us now.*

--- Community member

The community has expressed improvement in ANC practices, immunization attainment, and Public Distribution System Utilisation. Along with these improvements, the members also saw an increase in scheme utilization and inquiries. Link Workers observed better outreach. Decrease in anaemia cases among Antenatal cases and postnatal cases is another noticeable achievement of the intervention according to the link workers. There has been an increase in institutional deliveries and caesarean sections carried out in public health facilities (Box 5).

The need to increase accountability among government health officials is still a challenge. Community mobilization efforts has visibly permeated into the community but not throughout the community. This program has engaged Dalit women members. Dalit women experienced their new found strength of coming together. The feeling of togetherness resonates in their
voices. They no more experience caste based discrimination while accessing health care services. Being poor and being Dalit cannot make them vulnerable to health service discrimination. They have realised that those who discriminate them are at stake because lawfully these offenders can be punished. More so because of the strength of the community. It is hopeful that in time, as more women choose to take part in the committees and groups. (Box 4)

Community members always felt gap in approaching the staff for accessing services. The women have endured unequal treatment. But after the strategic intervention through formation of solidarity groups, the community initiatives gained visibility. This has served as a support system for Dalit women to pave way towards betterment and social change.

Interviews with CBM group members, SPAD Staff members, health service providers reveal that the atmosphere for accessing health services is cooperative. With CBM groups working together and launching complaints as groups, the responses of health officials and service providers since the onset of the intervention itself has transformed from hostile to friendly. The Community Activists expressed that they are able to approach health official or service provider personally, face-to-face.

INDIVIDUAL CASE STUDIES

Case Study 1:
Name: Mrs. Anitha, W/o Mr. Krishna, Age: 20yrs (Name Changed)

Mrs. Anitha had undergone complete ANC checkup in JJR-Nagar Hospital. Thus after experiencing contractions she was admitted in the JJR nagar Hospital and she delivered a boy baby normally. But after 8days of delivering the baby she experienced severe pain in the lower abdomen. She was rushed to the JJR nagar Hospital where the nurse informed that the pain may be due to Anitha's own negligence as she might have lifted heavy object. The nurse did not physically examine the case. Hence Anitha was taken to a private nursing home by her husband. After arriving at the private nursing home, the doctor physically examined her and was shocked to find a rotten cotton gauze that was negligently left inside Anitha’s birth canal. This had caused severe infection inside and was also causing stinking smell. Anitha was treated in the private nursing home and she had to spend Rs.15000/- from her pocket. This issue was raised in the interface meeting organized by the solidarity group and the Superintendent of the hospital warned strict action against the Nurse who had negligently handled the case. Further the superintendent committed herself to provide final checkup to all the delivery cases before they are discharged.

Case Study 2:
The houses of JJR nagar were receiving contaminated drinking water for a long period of time. This was mainly because the water connection pipes were in proximity with big open drainage. This water was unusable and hence the women in this locality (nearly 400 houses) had to collect water from a different locality. The Solidarity Group members of JJR nagar area initiated to solve this issue. They filed a complaint with the local Corporator and continuously followed up for 3 to 4 months. The corporator forwarded the letter to the in charge MLA. This resulted in a positive outcome. An engineer visited the area and inspected the matter and decided to get the drain cleaned up. Further a new bore well was installed. Separate water pipe connections were provided to the houses. 400 Dalit homes were thus benefited through CBM initiative.
Another issue with the big open drain was that it was causing flooding during the rainy season. The solidarity group members pressurized the Corporator to look into this issue. The flooding was causing seeping of drain water into the houses of slum dwellers. The local corporator forwarded a letter after constant follow up of the solidarity group members. Thus as a positive outcome the walls of the open drain was raised and constructed. Thus this problem was solved.

CONCLUSION

The major instrument of social exclusion is through discriminatory behaviour when people are excluded from important activities by virtue of their belonging to certain groups which, for whatever reason are viewed “unfavourably.” Even when inclusion occurs it is on unequal terms and conditions, (Vani, et al; 2015, pp258-259). This is quite evident in this study. Social exclusion of Dalit women in health sector is manifested in various forms which needs to be specifically defined for today’s scenario. Dalit women facing unequal treatment at the health sector in the form of denial, refusal, verbal abuse, delay, experimentation, negligence etc. cannot be easily defined as a form of exclusion but the causes for increase in MMR, IMR, etc. among the Dalit community can be easily related to the kinds of exclusion they are facing.

The health care sector has to be sensitive towards the issues of the marginalised groups and catering to the health issues of the marginalised women with non-discriminatory attitude will pave easy access to health care facilities and intern encourage the health seeking behaviour among the marginalised groups.

The NGO’s Strategy of establishing Community Based Monitoring Program is a model that can be replicated with other marginalised groups. It is an effective empowerment strategy which could enable the ability of the groups to interact freely and productively. The mainstreaming effort on Dalit women through economic and social empowerment programs has gained visibility and has been well documented over the period of time. But challenges lie in bringing health equity. This could be achieved through health empowerment programs. This approach would make them partners in their own development and enable them to bring an end to the multifaceted exclusion and discrimination that they have been facing in health sector. A focus on health empowerment of poor Dalit women is, therefore, central to reduction of abject poverty and abysmal inequality.

Finally, as rightly put forth, ‘Community empowerment for HP (Health Promotion) is rather less recognized and even less practiced. There exists vast talent and resources within slum communities. Strengthening community capacity in the form of community mobilization can help in improving awareness, demand and utilization of health services.’ (Agarwal, Satyavada, Kaushik and Kumar, 2007)

This case study has provided a comprehensive understanding of a community-based monitoring (CBM) initiative that has initiated greater participation of community. It is evident from this study that the intervention has successfully established a monitoring component for the healthcare structure. In examining the successes and challenges of the intervention process, this study has identified challenges in accountability towards, improved attitudes, and improved quality of care and facilities.

The mainstreaming effort on Dalit women through economic and social empowerment programs has gained visibility and has been well documented. But challenges lie ahead in bringing health equity. This could be achieved through health empowerment programs. This approach would make them partners in their own development and enable them to bring an end to the
multifaceted exclusion and discrimination that they have been facing in health sector. A focus on health empowerment of poor dalit women was, therefore, central to reduction of abject poverty and abysmal inequality.

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Abbreviations used in the Study

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<tr>
<th>Abbreviation</th>
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<td>NGO</td>
<td>Non-Government Organisation</td>
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<td>SPAD</td>
<td>Society for People’s Action for Development</td>
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<td>CBM</td>
<td>Community Based Monitoring</td>
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<td>MMR</td>
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<td>IMR</td>
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<td>BBMP</td>
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FSW  Female Sex Worker
PLHIV  People Living with HIV
ANC  Ante Natal Care
PNC  Post Natal Care
TB  Tuberculosis
MTP  Medical Termination of Pregnancy
MHMC  Maternal Health Monitoring Committee
PDS  Public Distribution System

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