Southern Regional Meeting of CommonHealth

Date: January 20-21, 2018

Venue: Asha Niwas, 5thStreet, Rutland Gate, Chennai, Tamil Nadu

Introduction

Dr Subhasri, Chairperson of CommonHealth welcomed the participants and CommonHealth was introduced to the participants, considering many of them were attending the CH meeting for the first time.

Subhasri introduced herself as and gave a brief introduction to CommonHealth. She recounted several organizations coming together as a coalition in order to take forward the struggles and aims together and described some of CH's key achievements.

- In the Dead Women Talking process, 124 maternal deaths have been documented along with 21 organisations across India. It was presented at the national and state level forums. The following queries from the audience were clarified.
    - What is a maternal death definition
    - The MDR committees are supposed to be there at sub-district and district level. But these do not function regularly, and it address only medical aspects. But aspects did not look into social causes, and we documented the social issues through a social autopsy tool [Narrated examples of social determinants].
    - UNICEFs mapedir project also did this but this was different. Because there, the experts did but here the community members themselves were involved and thus the quality of information was also different.
- Three districts in Gujarat (2 tribal) through women sanghathan's , they assessed the quality of maternal health care. Apart from medical aspects, women's perspectives - the dignity aspects, the availability of toilet facilities cleanliness were also documented and discussed.
- The safe abortion thematic area is yet another aspect. The issues of access were also discussed.
- We are working in contraception, abortion, maternal health – we need to look at a coordinated approach to monitoring reproductive health services.
- This a small group, where we are trying to understand how can take these forward through your association. Today we are planning to take different issues from different groups to share at the state specific level.

Session-1: Reproductive health and health care in the southern states – current scenario

The session chaired by Dr. Sundari Ravindran had two presentations. The scenario of RH services in Tamil Nadu and Karnataka were presented.

Overview of reproductive health care services in Tamil Nadu

On behalf of Dr. Balasubramaniam P from RUWSEC, Ms. Bhuvaneswari presented his slide presentation on the current scenario of reproductive health and health care in Tamil Nadu.

Tamil Nadu has good network public health facilities and has better Reproductive health indicators; Therefore the presentation brought out the critical indicators of concern, along the socio-economic indicators, health infrastructure, ANC and immunization, delivery care, contraceptive use and reproductive health status in comparison to previous years. [The indicators presented are added in the appendix].

Some of the key concerns in the state that emerged in that presentation are:

- The female age at marriage according to SRS, 2013 is 22.4 years. However, One out of five (18.3%) women age 20-24 in rural area was found to be married before 18 years according to NFHS 2015-16.
- Post RCH, NRHM and currently under NHM, large investments to provide maternal health care at PHC level are mainly and only for delivery care services.
- Accessibility to health facilities ranges between 82-90 percent according to DLHS-4, and there is an increased utilization of PHC's for deliveries.
- However, there is a decline/drop in performance of the ANC and child immunization indicators between 2007-2008 and 2012-2013. This is attributed to the move from sub-centre and community based care to PHC centred care. Due to the same reason, the HSC staff have been moved to PHCs, thus weakening sub centres.
- While almost all deliveries have become institutional, public sector share in delivery has increased, especially the PHC level, the General Hospital level remains constant.
- In the area of contraceptive use, the men's role in contraception is negligible or involvement is very limited. The unmet need for contraception in the state has remained constant and slightly increased for spacing methods according to NFHS-4 data.
- Reproductive health status: Although TN is considered a developed state, the anemia levels are very high, C-Section deliveries in the private sector is above 50 per cent and also experience of women facing male sexual violence is as high as 40.6 percent.
- With regard to the abortion scenario: the state has been under reporting the presence of abortion and sufficient evidence is not available on this.
- In 2012-13, a decline in knowledge levels about HIV/AIDs was observed. Similar drop was observed with regard to awareness/Prevalence of Reproductive tract infections, menstrual

health problems. Further care seeking for RTI was found to be low indicating low care seeking. The reason has been attributed to Government focus shifted from preventive, promotive care to curative care.

Overview of reproductive health care services in Karnataka

Sister Teena Xavier presented the Karnataka Janaarogya Chaluvali- KJC-People's Health struggle of Karnataka. Her presentation brought out certain key points for the audience.

- KJC emerged in order to translate health rights at the local level and thus create socio-political groups to enhance the language of discourse through cadre of health activists.
- KJC is a Political struggle to defend marginalized communities and the public health system against privatization, corporatization and commercialization of health care.
- The aim and belief of KJC is "only a nationalized health care system which is community-controlled and governed by the Constitutional principles of social justice, equity, non-discrimination, transparency, accountability can ensure socially just, equitable, free, non-discriminatory, good quality health care, sensitive to the needs of all citizens will enhance citizens life".

The strategies followed by KJC were:

- Politicize health care by pushing the health care discourse out of researchers, 'experts', NGOs, medical practitioners and other elite gate keepers' domain into the citizens' / people's domain.
- Build solidarity across progressive socio-political movements to draw in newer groups to articulate health rights issues
- Build a core cadre of health rights activists.
- Reclaim people's ownership over the public health system demanding from it accountability, transparency, quality and equity.
- Work with communities to generate 'evidence' and build a discourse from people's lived realities and experiences.
- Confront the state with such 'evidence' of denials violations and discrimination

Following this, she presented the Maternal Health outcomes of the state of Karnataka, in comparison to other southern states, based on the secondary sources of statistics available.

The presentation clearly depicted that the state's poor performance and health status of women through the indicators/prevalence for IMR, MMR, quality of ANC care, anaemia, complication during pregnancy, delivery and postpartum and other reproductive problems such as vaginal discharge and menstruation.

Further, following the need for evidence creation, not just for research purpose, but for creating the accountability demanded by the citizens, in the district of Gulbarga, enumeration and documentation of maternal deaths was done by KJC. Based on this documentation (for a period of 7 months) and the district's birth rate, if one were to calculate the MMR, it turned out to be a shocking 334.4 /1,00,000 live births.

The results also revealed that

- Among the 70 maternal deaths identified between April 17 to November 2017, the interviews done with 55 families who suffered maternal deaths in Kalburgi revealed:
    - 45% were less than 25 years of age
    - 37% of the women this was their FIRST pregnancy
    - 71% belonged to SC/ ST and Muslim community
    - 71% were anaemic.

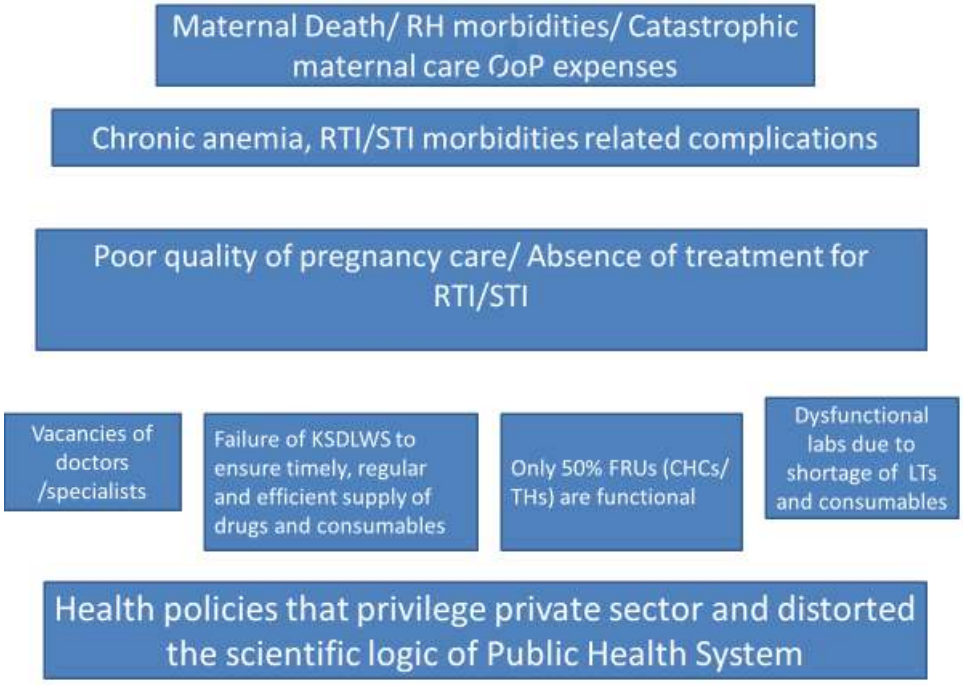
The presentation brought out the nature of Karnataka's present health systems, where the public health system if failing amidst an exploitative private sector.

Some of the key pointers were – declining budgetary allocations, huge vacancies in the health workforce, added with negative practices of doctors not being available in public facilities, diverting patients to private practice and unethical practices by government doctors using government hospital facilities. A detailed list of issues with drugs supplies and consumables were also shared, where one of the key surprising issue was leakage of government medicines and lab consumables that are routinely siphoned off to private medical stores, labs and clinics. The presenter also presented insights of the nature of dysfunctional PHCs and poor quality of care that affected the maternal health status of women. Factors such as weak EmOC transportation facilities, public doctors directing to private facilities leading to fragmentation and loss of continuity and follow-up in AN care with serious consequences.

- It clearly emerged that not only the private sector is dominant service provider and predatory in their approach to patients but also aggressively show resistance to regulation and democratic accountability. Maternal deaths in private hospitals are found to be routinely unreported and get "settled" for a fee. Further the context of rampant unwarranted hysterectomies and appendectomies, explained the exploitative nature of private sector's presence in the state.

- The Karnataka Government's Health 'Assurance' schemes, handing over PHCs to private entities, contracting out various services and the corresponding funding process and procedures for these schemes implied that the PPP schemes are to erode the Public health system. Such practices was explained about how women in the marginalized communities are denied care in private empaneled hospitals and eventually ended up with high out of pocket expenditures.

The entire presentation was consolidated, through this diagram



The three concluding points of the presentation were:

- Karnataka's health care policies are responsible for a dysfunctional public health system on one hand and growth of the profiteering unethical private sector on the other.

- This poses a direct threat particularly to survival and well being of women from marginalized communities

- It is crucial to increase government spending on strengthening public health system while withdrawing "assurance" schemes that are siphoning off public funds for private profit.

Discussion from the Floor

- Karnataka situation is an eye opener and shocking. Community ownership and resolving at the community level is a very strong determined effort of JCS.
- In Tamil Nadu, in the HIV field the same problems exists – in 2013, PWN did a stock out monitoring, and these problems emerged. Medicines for syphilis and gonorrhea are not supplied, and testing kits are also not coming- Kousalya, PWN
- In Karnataka, insurance policy always goes only to private, although structures exist in government. In government hospitals even general medicines are not available. They write 10 and give only 5 tablets. Even in big hospitals, both urban and rural areas it is the same situation.
- In Karnataka, none of them have free delivery even with BPL, because they scold a lot. Only 12 percent got JSY benefits, which is 1800 Rs.
- In Tamil Nadu, unlike the Karnataka civil society's efforts, civil society was not taking up these issues of private sector dominance.
- In Kerala, Abortion access seems to be mostly unsafe abortion and illegal providers since women do not like to go to known public places.

Session-2: Emerging Issues in the Southern Region

There were two presentations in this session. There were representatives from Kerala and Karnataka, who shared the emerging issues based on the recent research carried out by the respective organisations. Rakhal Gaitonde chaired this session.

Factors influencing women's achievement of their postpartum reproductive intentions

Dr. Sundari Ravindran presented on the factors influencing women's achievement of their postpartum reproductive intentions, a study conducted in Thiruvananthapuram district, Kerala.

- Objectives: This study is carried out by Health Systems Research Initiative India, Trivandrum (HSRII). The objective of the study was to a) explore women's postpartum contraceptive and

reproductive intentions and b) to assess factors associated with whether or not women are able to meet their postpartum contraceptive and reproductive intentions

- Study Design:
    - A community-based survey of pregnant women of all parity starting from sixth month of gestation following through to six months post-partum.
    - Baseline, to document stated reproductive intentions and reasons for these.
    - At 6 weeks post-partum to document pregnancy outcome and health status of the mother and new-born.
    - At 24 weeks postpartum to document achievement or otherwise of stated reproductive intentions.
    - A survey among husbands of the pregnant women to know their knowledge and prior use of contraception and their reproductive and contraceptive intentions after the current child delivery.
    - In-depth interviews with recently delivered women from the study area to capture in greater detail a range of childbirth and postpartum experiences related to achievement of reproductive intentions, and with health care providers providing pregnancy and delivery –related care in the study area
- Findings: The in-depth interviews with 30 women with diverse experiences revealed that 14 achieved their contraceptive intentions; only 7 achieved their reproductive intentions
- Women who wanted contraception but could not use were due to : Poor physical health following delivery and hence sterilisation not encouraged plus the fear of modern female reversible contraceptive methods OR unwillingness of the husband to use male sterilisation; Poor mental health (postpartum psychosis?); underage and uncertain life circumstances (Intimate partner violence and impending separation)
- Women who did not intend contraceptive use but are current users were those who: decided to stop with one child because of traumatic childbirth experience; persuaded by health care providers at the time of delivery; and feared female sterilization but adopted because husband backed out of vasectomy

- Women who lost their infants and those who were pregnant within 6 months postpartum where: Stillbirths and neonatal death – appear to have happened despite the best medical care; two of three women were pregnant again within six months and one instance of termination using medical abortion pills

- Women who suffered prolonged postpartum morbidity were those: who started the pregnancy in compromised state of health: e.g. auto-immune disorder that caused anti-phospholipid antibody (APLA) to be positive; rheumatic heart disease; hernia; second sterilisation after sterilisation failure, severe backache could barely walk or even sit up straight and prolonged Infection following episiotomy or c-section at the site of surgery; reproductive tract infection; poor mental health (postpartum psychosis?)

- The backdrop for poor achievement of reproductive intentions were a) Relatively high levels of pregnancy / delivery related morbidity b) Poor health of the neonate and c) Anxiety about fertility.

- The intention behind to choose a natural method are: Poor knowledge and fear of female reversible methods of contraception and low levels of modern contraceptive use by men

- The general attitude to fertility control was to not interfere with it using artificial methods. Couples would use natural methods till they had the desired number of children and then undergo female sterilisation. It appears that this is the general message that women get also from their peers, health care providers at the community level and from popular magazines.

- Provider Perspectives: All providers had a favourable view of female sterilisation and the condom which were also acceptable to clients; Almost all providers also favoured the Copper-T and male sterilisation, but also reported that these were not favoured by users; Nurses, JPHNs and ASHAs were apprehensive about hormonal methods. Their position was that hormonal methods “caused problems”, they were chemicals ingested by the body which could be harmful to health; Nurses, JPHNs and ASHAs clearly believed that natural methods were good to adopt. On the other hand, all the doctors said that natural methods were impractical and unreliable, resulting in unplanned pregnancies at short birth intervals.

- Many of the providers, especially ASHAs and JPHNs talked about women’s lack of freedom to decide on whether or not to use contraception and which method to use. Similarly, all providers reported that male sterilisation was the least used method. ASHAs and JPHNs reported that they encouraged women who were contraindicated for sterilisation to request their husbands to go through vasectomy. There were rarely any takers.

- Conclusion and Implication: Because Kerala has achieved below-replacement -level fertility, family planning services do not seem to be high priority any more, although the main objective of the programme is to improve maternal and child health and not merely reduction of fertility. Policy attention is needed towards short birth intervals and the low use of reversible methods of contraception.

- Women and men are poorly informed about methods of contraception, especially about female reversible methods. In a state with near universal literacy, the widespread dissemination of such information to young people would be feasible and is an urgent priority.

- Capacity-building in contraceptive counseling for ASHAs and JPHNs, and Anganwadi workers who run programmes for adolescent girls would go a long way towards better dissemination of accurate information in the community.

- Contraceptive counselling should not be restricted to one or two encounters during the postpartum period, but provided at various points during pregnancy. Those who express a desire to adopt contraception after delivery need to be followed-up and offered the methods of their choice at the right time.

- Concerted efforts are needed to promote male methods of contraception including vasectomy. Service delivery points in PHCs with male service providers who would provide information, counseling and services to men at specific times suitable to men would be a strategy worth considering.

- The veneer of universal institutional deliveries, relatively low maternal mortality ratios and very low infant mortality rates in the state masks the huge burden of pregnancy and delivery-related morbidity, and neonatal morbidity resulting in poor quality of lives and high levels of out-of-pocket expenditures on health. Studies are urgently needed to document, understand and address this problem.

- Despite their high levels of education, women do not seem to be able to make informed and independent decisions related to reproduction and contraception. Gender-sensitive sexuality and life skills education at the school and college levels may help equip young women and men with the information, skills and attitudes supporting more gender-equal relationships within marriage and a sharing of responsibilities for contraception, childbearing and child-rearing.

Unnecessary Hysterectomies in Karnataka

Sister Teena Xavier from Karnataka Janaarogya Chaluvali presented on "Unnecessary Hysterectomies in Karnataka".

- This was part of KJCs fact finding exercise over a period of 2 months.. This was carried out in 38 Lambadi Tandas in 19 Panchayaths of 4 Taluks in Kalaburagi district. The methodology adopted were: Group discussions with the women; line-listing of hysterectomies; in-depth interviews and collection of medical records**.**

- Findings from line listing: 98% of the 707 women line-listed underwent hysterectomies in 61 private facilities; Among the 61 private hospitals just 4 hospitals accounted 344 (55%) of all hysterectomies and 51% aged <35 yrs and 22.5% aged <30 yrs at the time of hysterectomy.

- Findings from 82 in-depth interviews: All 82 women had hysterectomy done in private facilities; women spent an average of 26,500/- which ranged from 10,000/- to 2 lakhs; all out of pocket expenditure and no insurance schemes; 68 of 82 (83%) of the women interviewed complained of continued health problems; 3 deaths of young women below 25 years and 11 women with severe postoperative complications.

- Analysis of medical records by KJC panel of medical experts: Three experts separately, independently reviewed a total of 66 medical records and clinical histories to assess whether hysterectomy was indicated, whether principles of good clinical /surgical practice were followed and whether records were complete and correct.

- Government Enquiry Committees constituted by the Dept of Health and Family Welfare and yet another constituted by the Karnataka State Women' Commission submitted a 12 page report and 105 page report with CDs of interviews with doctors and women respectively.

- The violations identified by ECs and KJC expert panel included that Hysterectomies were unwarranted, flouting standards of good clinical practice, flouting surgical protocol and insufficient, erroneous and large scale manipulation of records:

- The KJCs panel identified the following ethical violations: Abuse of power in a care-giving relationship; women wilfully mislead by instilling fear of cancer, provided distorted grossly unscientific information and inevitability of hysterectomy; Informed consent not obtained, Women were not given any information regarding the procedure or the possible complication or risks; Hysterectomy and appendectomy were undertaken together where women were not

aware of one or the other; Private doctors targeting very young, poor, illiterate women and exploiting their vulnerability (STDs, RTIs, pressure to contribute to the family, difficulty in managing menstruation) for profit; Nexus created to recruit unsuspecting women; Wilfully withholding information; Ignoring problems evident in the test reports and failure to make necessary referrals

- Campaign and legal efforts around hysterectomies included: A one-year long education in the Tandas of Aland and Gulbarga Taluks; Extension of education campaign to the slums of Gulbarga town; Organizing the hysterectomy victims; Protests and campaigns which led to the formation of ECs and implementation of the EC recommendations; Complains with KMC, MCI, District authorities and different Commissions by the Victims and KJC; Writ-Petitions and an yearlong work through evidence building on private health care violations leading to the KPME amendment process in Karnataka

- Conclusion; State and family control of women's bodies; Dysfunctional preventive component in the public health system; Medical profession becoming a business rather than a service (Erosion of professional ethics, medical avarice and lack of regulation); Current Indian medical education, training and practice reinforces gender bias and norms of patriarchy; Government health policies fuelling exploitation and no law specifically to protect patient rights leading to KPME amendment process in Karnataka

Adolescent reproductive health – Experience from RUWSEC

Ms. Jamuna spoke of the issues of adolescent reproductive health, and explained how early pregnancy and abortion is an issue with the adolescents. There are provisions for safe abortion legally, but due to delayed recognition of pregnancy by young girls, they reach late. There is also delay in providing care. Women are affected bodily and emotionally. The adolescent's health is very poor.

She corroborated how anaemia is contributed to by changing macro economic factors in urban areas. She explained how more hours of travel time for rural industrial working girls to reach their workplace in urban areas, work shifts operating in most industries contributed to the anaemic status of young women. She spoke about the context where young people do not take care of their health.

They also face consequences during menstrual cycle and their inability to take leave given the insecurity over their jobs. They do not have places to change their napkins due to lack of sanitation facilities in industrial and factory workspaces. Due to which they do not drink enough water in order to ensure they do not need to use the toilet.

The idea of supplements such as iron tablets are generally disliked by younger generation associated to its smell.

At the rural areas, she explained how napkins are unavailable. Although it is available at the PHC it does not reach the community since nobody wants to carry the distance the big boxes into the community from the PHC– at the same time, the quality is low and one single pad cannot withstand absorption of bleeding for 8 long hours. Lack of implementation issues, causes several such problems to adolescent's reproductive health.

Maternal Death Review(Audit) in Tamil Nadu

Dr.Sudharshini presented the government led maternal death review experience in TN over a timeline

- Since 1996, all health functionaries were sensitized on the need for reporting of all maternal deaths. Reporting was done using a specified proforma within 24 hrs. All reported maternal deaths were investigated and institution based audit was done by district level health managers within 15 days. However, the clinical audit, case sheets being rewritten, less motivated staff, supervisors tend to being protective there was very little information on the quality of care, and non-medical causes were not identified.
- Then in 2004, there was community based Maternal Death Audits happening. In 2010, facility based maternal death audit through video conferencing from Chennai took place. In 2013, it advanced with special maternal death auditing mechanisms.

Then, she stated the procedures that take place during the maternal death.

Process of Maternal Death Audit:

- Within 24 hours of maternal death occurrence both in government and private facility the FIRST INFORMATION REPORT has to be sent to Commissioner of Maternal and Child Health/ Mission Director NHM by Deputy Director of Health Services of respective Districts
- Source of Information can be obtained according to the type of the case.
- In case of maternal death, information can be obtained from VHN of the respective area, In charge MO of the concerned PHC/ Urban PHC, In charge MO of the CEmONC centre (DMS and DME Institution), In charge MO of the Private Hospital concerned or daily reporting in the State CEmONC Whatsapp group.

- In case of absconded / Left against Medical Advise mothers information can be obtained from Dean/ Supdt/ CMO of Medical College Hospitals, CMO of DHQ / Taluk Non taluk Hospitals should report to DDHS concerned, DDHS will verify in the field and report accordingly.

- At the District: FIR Received in O/o, DDHS within 24 hours of Maternal death. District Maternal and Child Health Officer O/o, DDHS, VHN, SHN, CHN - immediately they should visit the institutions and deceased mothers residence and collect the relevant details

- Special MD Audit – Panel of 2 experts will visit all facilities from AN Registration/ AN Check up (HSC/ PHC/ SDH /DH/ MC/ PVT)/ Referred Institution / House hold level visit immediately and submit the report within 5 days to SHS, District Collector, DDHS – Rs. 10000/- per case (expert fees, fuel, contingency) is budgeted in PIP

- In charge MO of the concerned PHC – MO should conduct the detailed investigation of every maternal death by personally visiting the various service providers and field health functionaries and meeting the relatives of the deceased using the standard verbal autopsy format. The time line of investigation is within 15 days of occurrence of Maternal Death

Further, supporting the explanation about the audit procedures, her sharing about the model of FIR sent from the districts gave a clear idea about the procedures and necessary information needed. Apart from this, the detailed explanation about the role of District Maternal Audit Committee was gave a clear understanding of the responsibilities of each person in the field.

- This committee will meet once in a month and discuss in detail regarding Maternal Death including relatives of the deceased mother, service providers including Govt and Private Institutions concerned.
- The various factors that led to the death of the mother will be reviewed
- Experts in the Committee will suggest corrective measures to prevent further maternal death
- District Collector who is the chair person will send detailed report to MCH Commissioner/MD NHM

Then there is the State Maternal Death Audit Committee which comprises of the following persons: Secretary (Health and Family Welfare), Commissioner Maternal, Child Health and Welfare; Commissioner Municipal Administration, Director, Institute of Gynaecology, Director of Public Health and Preventive Medicine, Director of Medical and Rural Health Services, Director of Medical Education and Deputy Director, Institute of Public Health, Chennai Expert Resource Persons.

The question raised about increasing mortality or improved reporting took a twist and made the audience ponder. Finally, it was said that: the number of maternal deaths apparently increased, due to improved reporting and not due to increase in mortality. The lessons learnt from experiences in Tamil Nadu has proved that the effective implementation of all the lessons learnt from various levels of Maternal Death analysis has proved to be successful in the reduction of MMR in Tamil Nadu. Nearly 200 hours per year is spent by MD NHM for conducting this state level Maternal Death analysis through VC.

The analysis was mainly based on the factors such as causes of death: respiratory, ectopic, anaemia, cardiac arrest, hypertensive disorders, haemorrhage, heart disease, sepsis and others, Gravida wise maternal death, age factors (5% of total deliveries of mothers more than 30 years contribute to 19% of maternal deaths) and antenatal death causes. The special strategies that were used to tackle issues contributing to maternal death based on the analysis were also shared as follows:

S.N	Problem statement	Name of the Activity	Special strategy
1	8% of HOB contributes to 30% of Maternal deaths	120 HOB block strategy	Additional sterilisation camps, interval IUCD promotion
2	10% of total maternal deaths is contributed by heart disease complicating pregnancy in mothers	Reintroduction of inj.Penicillin for Rheumatic heart disease identified children through RBSK up to 18 years	Inj.Penicillin should be made available from CHCs for Rheumatic heart disease identified children through RBSK up to 18 years once in three weeks. Special card to be maintained for regular follow up
3	5% of total deliveries of mothers more than 30 years contribute to 20% of maternal deaths	To bring mothers more than 30 years also as high risk category	More than 30 years AN mothers to be booked as high risk mother and regular follow up to be given

S.N	Problem statement	Name of the Activity	Special strategy
4	Out of total maternal deaths 23% is attributed to antenatal deaths in which 15% is contributed by sepsis which indirectly means that abortion deaths of unwanted pregnancies by over the counter abortifacient drug sale and incomplete abortion done by untrained quack.	1.Promotion of PPIUCD upto PHC level 2.Provision of MVA services upto CHC level involving PHC doctors 3.Provision of MMA drugs upto CHC level 4.Door step delivery of contraceptives through ASHAs 5.Strong legal action against untrained quacks	Strict monitoring and supervision for implementation of the above activities in the field level by JDHS and DDHS.
5	Visitors and migrants mother tracking	Re registration of visitor mother in Revamped PICME	Revamped PICME to be rolled out for the entire state.
6	Urban unregistered mothers tracking	CRS linkage with revamped PICME	All unregistered mothers especially in urban areas will be forced to register in the PICME through urban health Nurse for getting the Birth Certificate of the child.

Although, the procedure was very clear, it also had other challenges which were discussed pertaining to the Commitment of the PHC MO– inherent bias, difficulty in assessing the quality of care in the institutions, wage loss for the attender, fear of disciplinary action, commitment of the District collector. None of the recommendations were social recommendations except medical representations. The causes and strategies were not corroborated evidences. The concluding way forward was thought to be - maternal near miss death audit, that came as a critical quest.

Dr. Sundari added how there is lack of data on the percentage of deaths due to HIV, variations by caste etc. Similarly, the true realities of higher order births are not enquired rather a forced regulation can change things is assumed by authorities.

Domestic violence and RH – Experience Sharing from RUWSEC, Tamil Nadu

Kalavathi from RUWSEc orally presented the causes of domestic violence in her field area. She attributed DV primarily arising due to alcoholism, suspicion of promiscuity of wives and in households where male irresponsibility is a characteristic of the men. Although it causes injuries to women, they fear and do not reveal the truth. They are afraid of repercussions. The fate of the women rests where sexual violence and forced sex causes pregnancy and abortion is never accepted by husbands.

Similarly, more than women, men are mostly the enquirers regarding abortion in the helpline that RUWSEC runs.

Also, women many times go for unsafe abortion due to lack of financial ability.

Even in our field area men push women for contraception. However, when women go to hospital for deliveries without any consent from women, they are inserted with PPIUCD. This is a violation of rights. She faces problems, especially when women's family members take decision for her regarding the reproductive aspects.

Domestic violence is a community problem, and RUWSEC through groups, offers legal help and medical support to women who seek such assistance.

Even providers lack awareness about the Domestic violence Act leave aside the women…women are unable to use these provisions and there are several looholes legally in laws associated to these as well.

Tribal women and Reproductive Health in Tamil Nadu – Experience from Sittilingi

Dr Sangeetha, a medical officer from Tribal Health Initiative, Sittilingi presented the maternal health initiatives and experiences of women from Sittlingi valley with respect to accessibility of health care services.

Sittlingi valley, a land of tribals comprises the kalrayan and the Lambadis, who migrated from Rajasthan, Andhra Pradesh and other parts of India. This valley is nestled between the two hill ranges – Kalrayan and Sitteri. This valley has 21 villages with 95% of the people being tribes. For any medical emergencies, the accessibility, affordability and availability of health care in the region was once a serious quest. The tribal folks living in the region have to travel by foot through the surrounding forest to reach Salem or Dharmapuri district. But, the scenario has been gradually taking shifts favouring the people. The Infant Mortality Rate (IMR) of the region in the early 90's was 147/1000.

During this crucial period, the introduction of the Tribal Health Initiative came as a boon, which assisted in the health issues of women. The initiatives included: Health Auxiliary Program; Field clinic, Antenatal care, safe home deliveries; High risk detection. The IMR reduced from 147/1000 to 20/1000.

Then came into existence, the National Rural Health Mission in the region. Although, funding was a problem, the Public Health Centres (PHCs) played a major role. There were awareness camps and

programs frequently conducted, routine health screenings and check-up. The critical pregnancy period of women had three divisions of natal care provided as follows:

Ante-natal Period:

It was an incentive based approach. These incentives were based on number of factors such as number of patients treated, deliveries. Having no other choice, the mothers were stuck to the procedures and treatments provided with a no option- belief towards the mid-wives. There is a credibility of the investigations carried out and lack of ultra-sonography techniques. High risk detection.

Intra-natal Period:

Amongst, all the three periods, this is where the women experience the major interactions and actions with the treatments. There is a prevalence of bribery. Apart from this, the patients are verbally abused and it creates a height of stress at that point of time to the women delivering the baby. In case of emergencies, there is lack of credible referral doctors available to treat the patients. For Multi-gravidas, neo-natal resuscitation there is still no proper referral available in this district.

Post-natal Period:

The role of women does not stop just by giving birth to the baby but more, after that. Her health has to be monitored and awareness about reproductive health becomes important. Medical Management, Immediate postpartum and intrapartum IUCDs without consent and education is a common practice.

Dr Sangeetha further explained in detail about the present scenario of safe deliveries versus institutional deliveries and the gynaecological problems of non-pregnant women. She also highlighted about the emerging issues such as alcoholism, domestic abuse, migration, suicidal intentions and a shift towards urban life, concluding the discussion with informative messages.

Shen mentioned that, in the recent past the organisation has made initiatives to help the community in expanding their source for food and livelihood, since nutrition and food are important aspects for sustaining good health

Discussion

Following the above five presentations, the floor was chaired by Rakhal.

Some of the key points emerged were:

1. There may be different problems across south, however issues faced by women is similar. The government mentality/logic whether in TN or Kerala ignores women's needs and only seeks to implement the state's vision be it fertility reduction or others.
2. The second is privatisation, role of market, commercialisation are also factors influencing and affecting women's autonomy. It questions how doctors can be so compassionless be it private or public? There is a complete failure of public healthcare system and women are going to private and are further marginalised.
3. Ameer added that it is not only lack of implementation capacity of the public sector but also the presentations clearly brought the role of economy's unorganised sector which is not streamlined/regulated.
4. Sundari raised the role of gender play in the issues of Hysterectomies. She asked if we need bring gender, patriarchy and class in the background while foregrounding privatisation.
5. She also added how in Tamil Nadu, issues of dalit children are emerging. When children go for education to colleges – the first generation of dalit college goers from the family, the love tangle that emerges during these new situations between different caste teens become a problem in the communities leading to honour killing of the girls/boys.
6. Kousalya added that the marginalised communities issues are not prioritized and due to which gender budgets are compromised. She added that unless HIV issues pertinent to SRHR is documented, it is not possible to track how different are marginalised populations' gender issues.
7. The policy and programme lack of gender sensitivity: where husbands get HIV, there are programs for post care, prevention of child HIV. But as a woman my gender issues of sexual negotiation, my husband contraceptive negotiation all that although falls within gender domain are never discussed or taken up anywhere when programmes are designed.
8. Dr. Sangeeta's presentation emphasised that pregnancy is being looked at as if a disease. Respecting the women and their feelings, emotion, experiences and preserving their dignity in the process of reduction in MMR is very important. The discussion also brought out the consequences of over medication for anaemia in many instances and the total neglect of social factors in the present health systems.

9. Ameer emphasised that the community needs to be central to planning and policy- breaking the medical intelligence is essential. Why is it that the words “rights” always treated with aversion by the government?

PLHIV and RH

Kousalya along with Veena and Bindu orally presented the issues pertinent to their groups.

Problems within the programme

- Pregnancy and sex work alone is considered as data, nothing else is recognised or information collected on.
- Condoms is seen to prevent HIV during mother to child transmission and to sex partners in sex work, primarily to protect -*the* men
- None of the prevention programme is planned based on data or evidences. Even in the fifth NACO programme, it is not considered.
- The primary prevention as a important public health need is globally missing…except a undocumented effort in Kenya; gender is manipulated as transgender included ness; policy, funding initiatives are compromising women’s issues and now gives importance only to transgender issues.
- Delivery services are not provided to positive women, where there is no ART centre – PPTCT and ART centres are only available at the district hospital based on national guidelines.
- HIV is a corporate driven programme - to the extent donor based where medical supply and choices are determined.
- Women’s infection are increasing but none of the mid-term reviews consider our voices. Now the situation is there is no fund to add to it, is what we often hear
- ART medicines causes side effects and government is unresponsive to it. And even doctors are unaware. There are lack of studies to support these issues.
- Documentation of maternal and child death – due to cause of HIV are not properly documented; adolescent education, primary prevention of STI/HIV is missing in the government’s public health agenda; consequence of long term medicines, long term diseases, changes in body due to ART medication needs more documentation and future research studies;
- Positive women’s children’s future about marriage, addressing teen education, consequences of marriages of positive children, separated women due to this, the possible pregnancy conditions are all unexplored and grey areas.

Discussion

HIV positive people are forced to take the onus and the stigma associated to it (this is pitting 20 lakhs people, against 1 billion people).

Subhasri raised if women have control over their bodies and decisions? How important is lived experiences and their participation in planning and implementation? The various marginalised groups, and their gender issues is yet another dimension interlaced.

The macro forces is taking advantage of private health facilities, pharmaceuticals and public health systems themselves are pushing private sector, and other patriarchal forces, denying the women's right to their own bodies.

Subhasri concluded the day saying: "We are trying to influence SRHR and in the given political situation, the spaces are still declining. Until we join together as a collective, could we move ahead is the reality..we are consciously trying to build alliances with other women and marginalised groups to take the issue of SRHR forward."

Day 2

The second day started with two presentations from the floor – one from Karnataka and the second from Tamil Nadu.

Campaign to improve quality of maternal care in Manvi and Sindanoor taluks of Raichur district,

Karnataka, Jagrutha Mahila Sanghatane, Pothnal

- JMS has been one of the few women's collectives with a clear articulation on health rights issues and has been tracking dalit women's access to health care services in Sindanoor and Manvi taluks of Raichur district
- JMS is one of the core constituents of KJC and has been constantly intervening and raising issues of maternal care issues in Raichur district:
    - Shortage of IFA tablets and Iron sucrose injections

  - Lack of robust emergency referral transport services
  - Predatory private clinics and hospitals
  - Dysfunctional taluk hospitals
- A survey formed the basis of the campaign - Survey focusing on 234 dalit women and women daily wage agricultural workers from 36 villages (delivered in the past 1 year) to assess:
  - Quality of AN care women in government health facilities
  - The extent and reasons why women were forced to seek AN care in the private sector
  - The out of pocket expenses incurred by pregnant women and their families in the private sector
  - Various kinds of health problems suffered by pregnant women
  - Issues related to newborn care
  - Survey undertaken by JMS women using survey tool with pictorial cues
- Key findings from the survey were presented.
  - Poor quality of AN care in government facilities pushing 80% women to seek AN care in private
  - PHC was the only functional facility in the public health system.
    - 73% of all women and 69% of women with risk factors had delivered in government facilities
    - 45% of all women and 38% of women with risk had delivered in PHCs, mostly attended only by staff nurses
    - PHC seemed to be the only functional facility:
    - Only 21% of all women and 22% of women with risk had delivered in taluk hospitals
    - Only 2% of all women and 3% of women with risk had delivered in CHCs

- Only 2% of the women including women with risk had delivered in district hospitals
- As a consequence 24% of all women and 29% of women with risk had delivered in private hospitals

– Catastrophic cost of maternal care in private sector

- An average of Rs.11,114 for antenatal care services for on an average of 4 visits (consultation, average 2 scans, medicines and tests)
- An average of Rs.4338 for treatment of complications during pregnancy
- An average of RS.13279 for normal delivery
- An average of Rs.48145 for c-section
- An average of Rs. 6808 for 'treatment' of newborn

– Based on these findings, a Campaign was held. Jatha was undertaken to 36 villages from 26th December 2017 to 4th Jan 2018 during which 'Report cards' of 5 PHCs presented in public meetings. A pictorial representation of a woman's story "Mallamma's story" that captured catastrophic maternal expenditure was also shared in these meetings. The report card was also presented to the PHC Medical officer.

– A protest march to the block headquarters, Manvi Chalo, was also organized. Women took to the streets demanding good quality maternal care in Public health system and as the culmination of the march, presented a memorandum to the local MLA and DHO.

Community Action for Health in Tamil Nadu

Ameer Khan from SOCHARA and MNI presented the experience of the CAH project in TN specifically focusing on the efforts to document inequity.

- He shared that specific efforts had been made by the project to capture inequity in the provision of services. He presented the tools used during the project and focused on how

disaggregated information was sought to be documented on services received by specific marginalized subgroups (Arundhathiyars) even within dalits, and minorities.

- He highlighted the need for such disaggregated documentation to be planned even from the design stage of a project in order for inequities to not be excluded.

Discussion

The discussion following these presentations was facilitated by Ameer.

- Ameer pointed out that monitoring in the CAH project had specifically been focused on entitlements as it was a part of the NHM programme. On the other hand, the JMS presentation had framed maternal health more broadly as rights.
- He also spoke about the differences in strategies of confrontation and dialogue with the health system each bringing its own set of advantages and disadvantages.
- He also pointed out how neoliberal economic policies had led to commercialization and privatization of health services.

Way forward

The last session was to discuss ways forward.

Subhasri presented the proceedings from the tool development meeting in July 2017 for comprehensive monitoring of RH services.

In the plenary, some of the following points were discussed.

- Kausalya from PWN shared that PWN had done similar documentation of stories of positive women in ’93, but this had not been focused on health. She said that PWN would be happy to document the RH pathways of positive women.
- She also shared that primary prevention of HIV in other marginalized groups was a neglected area. PWN would be interested in working on this.
- Sangeetha from THI expressed interest in conducting qualitative studies in tribal women who had recently delivered to understand their experiences.
- It was also felt in the group that there was a need to rehumanize the very dehumanized medical education and dialogues with health care providers needed to be initiated.

- Selvi from RUWSEC highlighted the high prevalence of prolapsed and the need to document some of these RH issues.
- Another issue brought up was the need for sexuality education for young women who lived in institutionalized settings.

Following this, the participants broke into small groups to discuss what they could concretely do in terms of RH monitoring in the next few months. The following groups were formed to work with specific marginalized communities.

- Positive women
- Adivasi women
- Dalit women

Each group presented a work plan in the plenary. This is summarized here.

- Positive women
    - This group planned to document the RH narratives of positive women. As an initial pilot, stories of 2 women each in five districts each of three states – TN, Karnataka, Kerala – would be done. Specifically, positive women from marginalized groups, eg. dalits, adivasis, would be purposively selected.
    - This group also planned to develop modules for comprehensive sexuality education – this would be focused on general women (not specifically HIV +ve), specifically dealing with how to prevent HIV infection, both before and after sexual experience. These modules will be used not just for conducting workshops, but also for advocacy.
- Adivasi women
    - The participants in this group planned to document SRH life stories of women in two geographical areas and specific adivasi groups.
        - Amongst the Irula tribe in Kancheepuram district
        - Amongst both valley and hill tribes in Sittilingi
    - The stories would aim to capture beyond just the biomedical factors in these women.
- Dalit women
    - RUWSEC agreed to document RH narratives from young dalit factory workers in Kancheepuram district.
    - The following domains would be covered.

        - Rules of the factory and infrastructure as related to their influence on RH
        - Social media influence
        - Sexual expressions and sexual behaviours
        - Problems related with increasing consumerism
        - Freedoms and threats as related to class/caste dynamics
    - The following specific sub groups would be focused on
        - Shift vs non shift workers
        - Married vs unmarried
        - Within those married, those who have had a pregnancy and those who have not

Following the presentation of these plans, some timelines were also discussed. It was felt that the subgroups could meet once or twice by July and share preliminary documentations following which further steps can be planned.

With this, the meeting drew to a close.

Participants

Subha Sri – A gynaecologist by profession and associated for the last 8 years with CommonHealth. Also associated with RUWSEC, Tamil Nadu

Mukhil: Representing the Tirunelvell Positive women Network. Involved with PPTCT project with an NGO called Arikiayam, in Coimabatore – Worked for the last 15 years with +ve women. And helping women voluntarily. She networks with other positive women networks and shares information at her field level.

Anandi Yuvaraj – A positive herself and has engaged at different capacities, since the last 20 years in the area of HIV/AIDS. Since last three years engaged as a gender consultant with UNAIDS. Continues to be part of guidelines committee. Earlier involved with ICMR studies on awareness in 4 states of India. positive for the last 20 years.

Jamuna. Bai, representative from RUWSEC on adolescent reproductive health issues.

Satya – representative from RUWSEC and also member of the public health committee.

Sundari Ravindran – A professor from Sree chitra Tirunal Institue of Public Health, Trivandrum. Both associated with RUWSEC and CommonHeakth.

Bhuvaneswari Sunil – Associated with CommonHealth for the last six years as a listserv coordinator, then as member, and now also an SC member.

Selvi – Representative from RUWSEC working for the promotion of rights of SRH in the community

About RUWSEC – Along with 12 dalit women and Sundari Ravindran, we started the organisation called Rural Women's Social Education Centre. The organisation works with women, children, men and adolescent girls in schools, villages

Amudha – Representative from RUWSEC working since 1997 and engages at the community level on adolescent education

Radha –Representative from RUWSEC – working as a part time worker in the community

Sangeetha – A medical doctor by profession since last two years is engaged with THI – a Tribal Health Initiative in Dharmapuri district. THI works on mother and child health in around 22 villages and is also recently working on organic farming craft initiative with the tribal population for their livelihood opportunities, along with a school.

Kousalya – Representative of Tamil Nadu Positive Women's Network – for HIV women. "We started in 98, to mend the differences among HIV women to lend support amidst ourselves. Now we are striving to make changes. In 13 districts our presence exists. However only in seven districts it is active. We also work for children of our children. We conducted studies among some positive women who have had more chances of getting cancer, in 2005. We did another study about what knowledge we have and what we need and availability of services at the Tamil Nadu State level. We also did some advocacy based on that. There are several issues that are not implemented although guidelines exist or contradictory practices against

the guidelines. Mother and child deaths due to HIV and denial of care also leads to this, but we have no data on these, inspite of voicing it for years now".

Bindu – Representative from PWHN, Kerala. Worked earlier on a UNICEF project, in PPTCT program and violence against women project.

Reena – Representative from PWHN, Kerala.

Reena – In 2009, associated with PWN and started working on issue of women in the regions of Raichur, Ballari in Karnataka, in the absence of presence of women's groups. At present working as warden at the freedom formation.

Mary – Representative from PWN, Karanataka. Ever since removed she was removed from work due to her positive status, she started helping positive women.

Chinnamma – Representative and a grassroot worker from, JMS, Raichur district. She engages with the community on child marriage, dowry, restricted women's mobility – 20 years of work experience working with groups of women, home visits, bringing family issues to groups. She also enaged in identifying maternal deaths. In the absence of women's organisation in the dalit community her and the organisation's presence made a difference

Sunanda – A representative and a grassroot worker from JMS, Karnataka.

Sister Teena – A representative from JMS, works since 2001 at the grassroot level in the northern Karnataka region. Works with people's health. One and half years engaged in chasing maternal deaths in Raichur and Vadgir regions

Kariappa – Representative from JMS. He is a karyakarta working for the last 3 years. He brought 520 dalit children into education system, through alternative education. Of these 100 of them have gone for jobs. Landless dalit families were analysed and initiatives for government land redistribution were implemented and NREGA. Atrocities against women were also addressed in the area of his work.

Rakhal – A Public health expert and at present pursuing his PhD. Also a member of medico friends circle.

Sam Thomas – A representative from pwn network, Chennai

Shruti – An MBBS doctor.

Sumati – Representative from PWN, Chennai working on positive women's issues.

Kalavathi – Representative from RUWSEC, with 32 years of field experience. Presently a coordinator at RUWSEC's clinic where services are offered and reproductive health is prioritised.