Discourse-Building on Women-Centred Maternal Healthcare

CommonHealth

REPORT OF GRASSROOTS CONSULTATIONS WITH WOMEN FROM MARGINALIZED COMMUNITIES

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Layout Design: Sanskruti Designers, Pune

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Content

List of abbreviations

AAA	Amhi Amchya Arogyasathi
AWW	Anganwadi Worker
ANC	Antenatal Care
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
BP	Blood Pressure
CHC	Community Health Centre
COVID	Coronavirus Disease
DWT	Dead Women Talking
ECG	Electrocardiogram
ECHO	Echocardiogram
ECOSOC	United Nations Economic and Social Council
GH	Government Hospital
HSC	Health Subcentre
ICDS	Integrated Child Development Services
ICM	International Confederation of Midwives
IEC	Institutional Ethics Committee
IFA	Iron and Folic Acid
IUD	Intrauterine Device
IUCD	Intrauterine Contraceptive Device
JSSK	Janani Shishu Suraksha Karyakram
JSY	Janani Suraksha Yojana
KII	Key Informant Interview
LaQshya	Labour Room Quality Improvement Initiative
MMR	Maternal Mortality Ratio
PHC	Primary Health Centre
RMNCH+A	Reproductive, Maternal, Newborn, Child and Adolescent Health
SRHR	Sexual and Reproductive Health and Rights

TBA	Traditional Birth Attendant
THR	Take Home Rations
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund
VHND	Village Health and Nutrition Day
VHN	Village Health Nurse
VHSNC	Village Health, Sanitation, and Nutrition Committee
WHO	World Health Organization

1. BACKGROUND

Maternal health refers to women's health during pregnancy, childbirth and the postnatal period (WHO, 2019). Over the decades, much effort has been made to improve maternal health worldwide. However, maternal healthcare remains a significant challenge for the global public health system, especially in developing countries (Aliyu, 2018). Moreover, the gap in the risk of maternal deaths between developed and developing countries is considered the most significant health divide in the world (UNICEF, 2021). Since independence, the Indian government has also taken measures to address maternal health.

1.1 Maternal health policies in India

The major government flagship programmes for maternal health have been the Janani Suraksha Yojana (JSY, 2005) and the *Janani Shishu Suraksha Karyakram* (JSSK, 2011), both focusing on increasing institutional births. Under JSY, a conditional cash transfer program contingent on institutional delivery, eligible pregnant women are entitled to get JSY benefits directly into their bank accounts. ASHA workers, too, get a cash incentive to facilitate the provision of facility-based childbirth to pregnant women. JSSK entitles all pregnant women delivering in public health institutions to free deliveries, including caesarean sections. The JSSK initiative stipulates free drugs, diagnostics, blood, and diet and free transport from home to the institution and between facilities in case of a referral and drop back home.

The Government of India adopted the Reproductive, Maternal, Newborn, Child and Adolescent Health (RMNCH+A) framework 2013 to address the major causes of mortality and morbidity among women and children. The National Health Policy 2017 also endorses the same framework for addressing maternal health.

In 2016 and 2019, the government launched the Pradhan Mantri Surakshit Matritva Abhiyan and the Surakshit Matritva Aashwasan schemes, respectively. The former aims to provide comprehensive antenatal care to all pregnant women (in 2nd and 3rd trimesters) on the 9th of every month to detect high-risk pregnancies promptly. The latter aims to provide dignified, respectful, and quality healthcare at no cost and with zero tolerance for denial of services.

Whereas the initial thrust on institutional childbirths did lead to an increase in the rate of facility-based childbirths, it did not lead to any significant reduction in the MMR owing to the poor quality of intrapartum care (Randive et al., 2013). Hence, the Indian government also launched training programmes concerning maternal health to improve the quality of clinical care provided. The Dakshata Programme was introduced in 2015 to strengthen the competency of the providers

of the labour room through skill-based training and to improve the availability of essential supplies and commodities in the labour room and the postpartum wards. The LaQshya Labour Room Quality Improvement Initiative was launched in 2018 to strengthen key processes related to the labour rooms and maternity operation theatres and improve the quality of care around birth by organizing the infrastructure and protocol of labour rooms and maternity operation theatres.

1.2 Effectiveness of present maternal health policies in India

The key strategy of the Indian Government today to address maternal health revolves around institutionalizing childbirths – this approach hence encompasses the aspects of incentivizing facility births, skills training medical and nursing professionals, and providing free services. It again considers a narrow definition of maternal health, i.e., measuring the same through maternal mortality ratios. It fails to take aspects of quality of care, especially women's experiences of care, into its ambit. In its pursuit to optimize institutional births, it focuses on training the nursing staff as midwives, ignoring the already prevalent acute shortage of nursing staff in the country. Moreover, it ignores the role of traditional birth attendants (TBA), who have been supporting women during childbirth, especially in areas which are not well-resourced and do not stress enough on the role of ANMs in assisting births.

Many studies have concluded that institutional deliveries have increased following the introduction of the JSY scheme. However, there is also much evidence about the poor treatment women receive at the hands of healthcare providers when they visit public health facilities for maternal health services in India. For example, Ansari & Yeravdekar (2020), in their systematic review and meta-analysis of respectful maternity care during childbirth in India, found that the overall prevalence of disrespectful maternity care was 71.31%, ranging from 20.9% to 100% among individual studies. This disrespect comprised various forms of ill-treatment such as physical and verbal abuse, denial of confidentiality and privacy, demand for informal payments, and lack of basic infrastructure, hygiene, and sanitation. The study conducted by Khan et al. (2010) to assess the impact of Janani Suraksha Yojana in rural Uttar Pradesh found that more than half (56%) of women had experienced abusive practices such as being administered fundal pressure to hasten the delivery.

Further, after childbirth, 9% of the women were moved to cots without mattresses, 6% to the corridors, and 6% to the floors (Khan et al., 2010). In their 2015 study in Madhya Pradesh, Chaturvedi and colleagues explored whether the JSY ensured skilled birth attendance. They found that the delivery rooms were generally poorly maintained in terms of staffing, infrastructure, equipment and supplies,

and cleanliness. The hospital staff did not provide skilled care routinely; e.g., monitoring was limited to assessing cervical dilatation. The attendants took labouring women to the delivery room based on their judgements of increased severity of contractions. Hence, owing to an absence of professional monitoring of the progress of labour, deliveries often occurred unanticipated, leading to chaotic situations around the time of delivery. This study also found that hospital staff threatened, abused, or ignored women at the time of delivery (Chaturvedi et al., 2015).

1.3 State of Midwifery in India

Currently, India does not have a cadre of midwives educated to international standards (McFadden et al., 2020). There is a lack of national standards for midwifery education and accreditation systems to monitor the quality of education (Sharma et al., 2015). Maternity services are provided by obstetricians, general physicians, and staff nurses in hospitals in India. The midwifery scope of practice of staff nurses is not clearly defined but is "circumstance driven," depending on several factors, one of which is the availability of doctors (Sharma et al., 2013). The Government of India launched the Guidelines on Midwifery Services in December 2018, intending to create a cohort of Nurse Practitioners in Midwifery who are skilled per ICM (International Confederation of Midwives) competencies, capable of providing positive birth experiences to women by promoting physiological birth (thus reducing over-medicalization), providing respectful maternity care, and decongesting higher-level health facilities by providing services in midwife-led care units. This programme was piloted in Telangana, where the training programme was completed (Kumar, 2019).

However, this initiative fails to consider the severe shortage of nursing professionals in the country (Saikia, 2018). Hence, it overburdens the already overworked nurses who have to take on multiple roles within the hospital, including that of a doctor in the absence of one. Moreover, this model ignores the role of the traditional birth attendants who have been assisting in deliveries, especially in rural and under-resourced areas of the country. It also overlooks the potential contributions of auxiliary nurse midwives, who are already grappling with unclear roles within the hospital (UNFPA, 2021; Bhombe, 2019). Instead of being trained as nurses as laid down by the Guidelines on Midwifery Services, nurse practitioners can be trained to provide midwifery services

1.4 Rationale for the study

The current state of maternal healthcare in India and the prevailing policy scenario begs the following questions: *What is women-centred maternal healthcare? Do current maternal health policies and programmes provide for women-centred care? Do they meet the maternal health needs of women? What changes would be required to make maternal health policy and programmes women-centred?*

Hence, there was a need to understand what women experience, desire, and expect from maternal health services and what women-centred care would comprise from their perspectives. We sought to understand this through consultations with women, grassroots organizations working with women, and experts working to advance maternal health in India. The grassroots consultations were carried out with rural and urban women in different regions of the country comprising groups of women facing different issues of marginalization, such as Dalit women, women living in low-income settlements, women in unorganized labor, and tribal women. In-depth interviews were also conducted with frontline health workers in these same settings. CommonHealth's grassroots members conducted these consultations with women in their constituencies, with support from CommonHealth.

1.5 Objectives of the study

The study aimed to understand what women-centred maternal healthcare would entail and its different components and build a discourse around it.

The specific objectives of the study were:

i. To understand the perspectives of diverse groups of women in different communities on women-centred maternal health care

ii. To understand the perspectives of frontline healthcare workers on women-centred maternal healthcare

iii. To understand the perspectives of experts working on different aspects of women's health on women-centred maternal health care

iv. To develop a discourse on women-centred maternal health care and its different components

2. METHODOLOGY

The present discourse-building aimed to bring to the forefront the aspects constituting "women-centred" maternal healthcare. The research used qualitative methods to elicit women's narratives on the topic.

Data were collected in two phases:

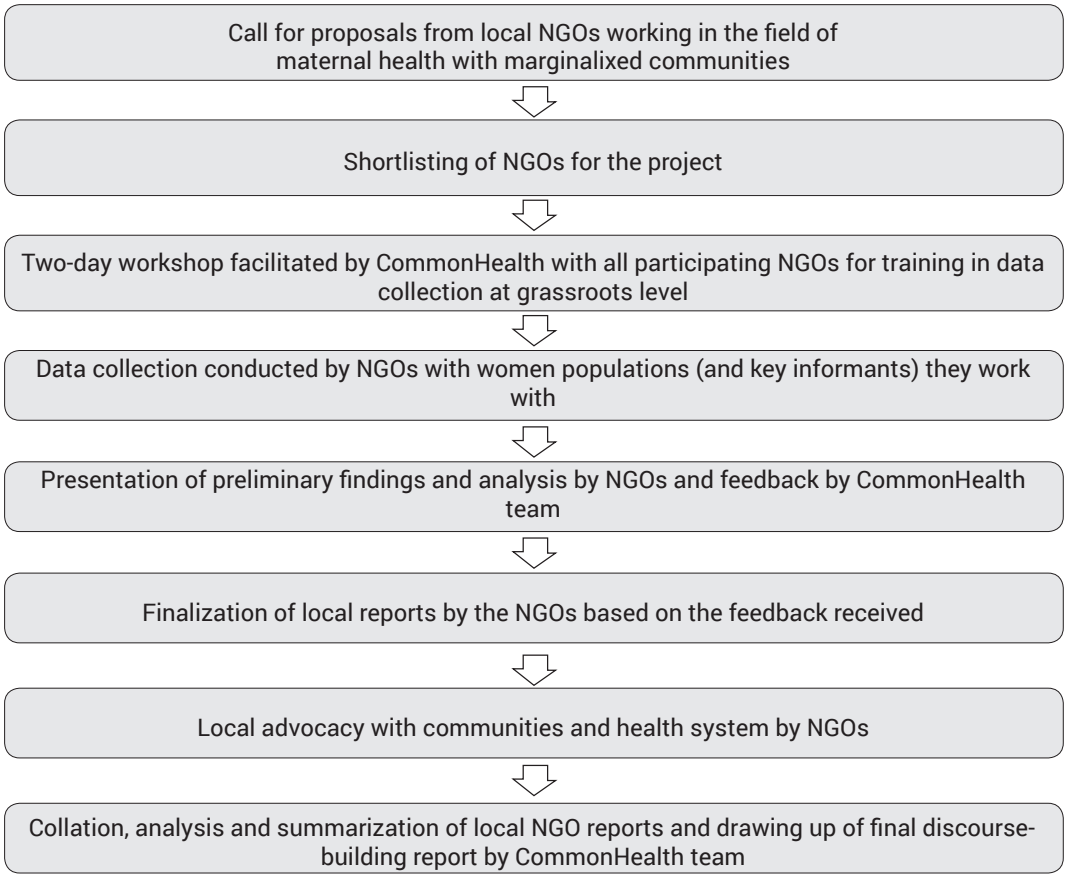
i. Phase I comprises data collection from women and key informants, such as frontline workers at the grassroots level

ii. Phase II comprises data collection from experts in the fields of sexual and reproductive health, medicine, and public health

2.1 Planning and implementation of Phase I

For Phase I of data collection, since the study's objective was to gather data at the national level and include representation of women from as many Indian states as possible, local non-government organizations working in the area of maternal health were partnered with as the link with the grassroots.

The following chart illustrates the various stages of data collection, which is elaborated upon further.



In February 2022, CommonHealth issued a call for proposals from organizations across the country which worked in the field of maternal healthcare, particularly with women from marginalized populations. The study also included financial support for data collection for participating organizations (contingent on selection). The discourse-building aimed to have heterogeneity in findings by including perspectives of women hailing from different marginalized communities and underscoring their unique experiences regarding childbirth. The proposals were evaluated based on the history of the organizations in maternal health care work, their long-standing association with the community, their ability to carry out research and data collection, and the geography and marginalized groups they work with. A total of 9 organizations were shortlisted through the process, which included Grameen PunarnirmanSansthan (GPS) and Shikhar PrashikshanSansthan(SPS), Uttar Pradesh from the north of India, Sahayog (Odisha) and Hashiya Socio-Legal Centre (Jharkhand) from east, RUWSEC and DEEPS from Tamil Nadu from the south, SAHAJ (Gujarat) and Amhi Amchya Arogyasathi (AAA) from the west, and SOCHARA from central India.

Following the selection, a two-day workshop with the organizations was convened in New Delhi, India, in September 2022. CommonHealth facilitated the workshop, and its primary focus was to orient the organizations to the research methodology and data collection methods they were expected to carry out. Two team members from each organization were nominated and present at the workshop. The team members were trained in holding grassroots consultations with women (Guidelines: Annexure 1), interviewing techniques while interacting with key informants (Guidelines: Annexure 2), i.e., frontline workers, and ethical considerations when conducting consultations. The representatives carried out mock consultations, wherein members took on the role of women, facilitators, and documenting team members. The facilitating and documentation processes were thus analyzed, and feedback was provided by CommonHealth team members on how they could be enhanced. Detailed documentation of the consultation process in the verbatim format, along with pertinent observations to accompany them, was stressed.

Following this two-day workshop, the participating organizations conducted grassroots consultations with women and frontline workers in their geographical areas of work. Following the consultations, a meeting was held in December 2022 in Mumbai, where the organizations presented their data and preliminary analysis findings. The organizations received feedback from the CommonHealth team on their presentations and data points that could be analyzed further. Based on this review and feedback, the organizations drew up their final reports of consultations, which were submitted to CommonHealth. The reports were then

collated, analyzed and summarized by the CommonHealth team to form the final report. This report thus collates the findings from all nine sites where the study was carried out.

In addition, each organization shared the study findings with the communities from which the data was collected and used the local-level reports for advocacy with the local health system.

2.1.1 Overview of data collection methods in Phase I

In the first phase, women and frontline workers were engaged through grassroots consultations by the selected local organizations to understand their perspectives on what they expected from maternal health care. Women at the grassroots included rural and urban women from different regions of the country and groups facing their unique issues arising from marginalization, e.g. Dalit women, tribal women, women from the unorganized sector, and women from urban poor settlements.

Prior consent was sought from all the participants before the consultations. First-level verbal consent was obtained from women by the collaborating organizations that contacted them, explained the purpose of the consultations, and sought their interest in participation. For the in-person consultation, a consent form was shared with women.

Diverse methods were used with different groups of women based on the context and their backgrounds, including participatory activities, role plays, and discussions on maternal healthcare.

a. **Use of the role-play method:** The facilitator asked for a participant to volunteer to play the role of a pregnant woman seeking care for childbirth and others to play the role of her family members. A few more women were asked to play the roles of different health care providers (ASHA, ANM, *dai*, nurse, doctor). They were asked to act out a typical scenario in their experience when they went to a health facility seeking childbirth services. The other participants were asked to observe. Once the participants finished acting out the scenario, the facilitator facilitated a discussion amongst all on what they saw, what they liked, what they would like to see change, and so on. Following this, the same group (or another) was asked to act out the same scenario but changed to represent the ideal way they want to receive care.

b. **Use of the free-listing method:** The facilitator asked the women what they wanted from maternal health care when pregnant, from pregnancy to delivery and the postpartum period. The facilitator encouraged them to include expectations from the family, the frontline health worker, the ICDS system, and the health facility. The facilitator then made a free listing. The women were then asked to rank the items in order of priority.

During these activities, a detailed process documentation was carried out to capture the nuances of women's responses. Video graphing was done only after consent from participants. Based on the data thus collected, an individual report of each consultation was prepared.

In addition, in-depth interviews were conducted by the participating organizations with frontline workers in their field area. These interviews mainly tried to capture frontline workers' perspectives on women-centred maternal healthcare and their suggestions.

2.2 Planning and Implementation of Phase II

The second phase of data collection included a consultation with experts from the fields of medicine, public health, sexual and reproductive health, and community health. The proceedings of the experts' meeting are presented as a separate report.

2.3 Ethical considerations in the study

The Institutional Ethics Committee of SAHAJ, Vadodara, reviewed the study. The study partners were trained on the ethical aspects of data collection and the overall research study and underwent a process of submission of ethical review guidelines to SAHAJ (Annexure 3). For the consultations with women, an information sheet (Annexure 4) in their respective local language detailing the purpose and methodology of consultations was provided to them. The consultation facilitator explained the content of the information sheet and sought verbal consent from women. A detailed informed consent form (Annexure 2)was developed for frontline workers, and written consent was sought before the key informant interviews. The researcher signed the consent form after explaining the purpose to the respondent. The team leader in the member organization countersigned the consent form after confirming that the researcher had explained the study purpose, assured confidentiality, and given the option of refusing participation (with no ad-

verse consequences for doing so) or withdrawing halfway or refusing to answer some questions, informed about non-availability of any amount for participation, provided contact number of the contact person in the organization, and offered to send a copy of the consent form for their record.

The women participants were identified by the participating organization in the course of their regular contact and work with them. The study was explained to them, their consent was sought, and their availability for consultation was requested. Once they got consent, a time slot suited to both the women and the researchers was fixed for conducting the consultation. Consultations were recorded only after consent from respondents.

Given the prevailing COVID-19 pandemic situation at the time, to safeguard the investigators and the respondents, the consultations were conducted in a well-ventilated space in the respondents' communities, where respondents could maintain social distancing while sharing their views. Training on COVID prevention and management was also included in the two-day training workshop.

FINDINGS

Expectations from the husband and marital family

The study highlighted clearly from women's narration of their experiences and the role plays they enacted that they expected support, nurturing and care from family members, especially their husbands, throughout the pregnancy and during birth. Most women lived in joint families and reported that decisions related to ANC utilization, delivery care, and place of delivery were made by mothers-in-law and husbands. Women wanted to have the freedom to make decisions about pregnancy and delivery-related care themselves. In addition, they wanted to have cash in their hands to spend on incidentals during visits to health facilities for pregnancy care and during hospital stays for delivery.

Women also expressed their desire for more involvement from their male partners during pregnancy and birth. In Tamil Nadu, women reported difficulty commuting via public transport during pregnancy and felt more comfortable visiting the health centre with their husbands on a two-wheeler. In Odisha and Tamil Nadu, women expected husbands' involvement as birth companions present at birth. They also wanted husbands to take responsibility for preventing pregnancy and the use of contraception.

Women reported feeling hugely pressured to conceive immediately after marriage and to have sons. They felt neglected and discriminated against at the birth of their daughters. These affected women's peace of mind. They expected care and support in all pregnancies, not limited to the first alone. They also expressed the desire for such care and support in the event of adverse pregnancy outcomes like miscarriage and stillbirth. Even when a healthy baby was born, women reported feeling neglected after childbirth because the care and support shifted to the baby, and they wanted care to continue in the postpartum period, too.

> *If we have money in our hands, we can have all food. The care from family members in giving fruits and vegetables is more for the first pregnancy only. Later, they do not show much interest. We need to take care of ourselves.*
>
> (Woman from Chengalpattu district, Tamil Nadu)

I already have four daughters and a son and have also had a miscarriage. My family wants another son, and I am getting pregnant again. After the tests done in the Anganwadi, I was told to be high risk. My weight is only 30 kgs, and my blood levels are also low at nine gms. I have been given five bottles of iron. I went a few days ago to the government hospital for a checkup, and I had to wait from 10 in the morning till 6 in the evening. There was nothing to eat or drink and a big crowd.

(Woman from Barod, MP)

Myths and misconceptions around pregnancy prevailed and dictated women's diet, nutrition, care and pregnancy-related practices. They complained about not getting adequate rest and sleep when needed and wanted the freedom to consume adequate food and satisfy food cravings. It was believed that pregnant women should work until delivery for normal delivery. Women reported working on farms and collecting firewood till the ninth month. They reported that sometimes their legs and faces would swell, and they had difficulty carrying out household chores. There were misconceptions about the consumption of iron and calcium tablets that these would increase the size of the foetus and create problems during childbirth.

The ANM has given me 100 iron tablets to take two tablets daily, but I wasn't allowed to consume all.

(Woman from Mirzapur, UP)

In Gadchiroli of Maharashtra, women reported their families preferred delivery at home because it was believed that childbirth in the hospital would result in infections and diseases. Everywhere, women wanted to adhere to their healthcare provider's advice and wanted no opposition from family members. In Jharkhand and Gujarat, women wanted pregnancy to be free from domestic violence.

I am currently 18 or 20 years old, and I am pregnant for the third time. My mother-in-law does not allow me to have my delivery in the hospital because she is afraid. I get medicines from the Anganwadi, but I have not received any benefits from any government scheme.

(Woman from Shankargarh, MP)

Expectations from the community

Women echoed similar expectations from their communities as from their families of not pressuring them to conceive immediately after marriage or to have sons. Women wanted physical and financial support from their communities in case of emergencies during pregnancy and/or delivery. One group of women in Maharashtra suggested that VHSNCs should be able to mobilize funds whenever there is a need for referral transport. Sometimes deliveries happen at home because no connecting roads to the hospitals exist. In Shankargarh, MP, most women participants shared having home deliveries because there was no motorable road. They felt the roads for ambulance and transport should be motorable.

Expectations from the frontline workers (AWW, ASHA, ANM)

Women agreed that it was helpful that the ANM stayed in the village, as they could avail themselves of the services at their convenience, which helped build trust. Women suggested that the ANM should conduct group sessions for pregnant women during her monthly visits on different topics related to care during pregnancy, such as rest, diet, schedule for checkups, danger signs, and mental and physical preparation for childbirth. She should also provide information on postpartum care, including postpartum contraception.

Women also felt the ANM's services should extend beyond specific days like the VHND and immunization day. When a woman repeatedly misses VHND attendance, the ANM should make a house visit and provide healthcare and advice as needed. The ANM should also send reminders for scans and checkups in PHCs via mobile phones. Women expected the ANM to respond to calls from pregnant women.

However, in many instances, ANMs and ASHAs could not be reached when needed. ASHAs in Mirzapur in UP mentioned that their mobile phones were without WhatsApp facilities, which created problems in communicating with women. ASHAs and ANMs interviewed at different sites also felt that the high workload, performance targets, low remuneration, and lack of public transport limited their mobility and ability to make home visits that cater to the needs of pregnant women.

> *I have to fill in the information in various registers, which is difficult and takes up most of my time.*
>
> (ASHA from Mirzapur, UP)

ASHAs' expectations from the public health system

ASHAs had several demands related to their remuneration. They demanded a fixed salary instead of the performance based incentives they currently receive, and some financial support after retirement. They also wanted to be reimbursed for recharging their mobile phones.

ASHAs also had suggestions for improving health facilities. They suggested that women should be able to get all services at one place. Ultrasound, HIV testing and drugs should be free and available at PHC level. They felt deliveries in health facilities should be safe and PHCs should have skilled doctors and nurses to manage complications of deliveries. They also suggested that PHCs should be staffed by paediatricians and equipped with intensive care units. Ambulance services should be easily available and free.

ASHAs also felt that both women and ASHAs should be treated with respect and dignity at health facilities. Women should be provided with free food during their stay as should their family members and ASHAs who accompany them. Arrangements for overnight stay of ASHAs and family members of women who seek care should be made at health facilities.

> *"We go to all the villages; some are interior without bus facility. We either go on a walk or ask for a lift from someone who goes on a two-wheeler to the village. We have targets - as mine are interior villages, I should see two antenatal mothers, two postnatal mothers and two adolescents per week – KII"*
>
> – Village Health Nurse (ANM) from Tamil Nadu

Women expected ASHAs and AWWs to be nurturing and provide moral and emotional support during pregnancy. They wanted health workers to treat them with respect and not harass them. In UP and Odisha, women said they preferred the ASHA to be from the same community as themselves so they could reach out to and trust her.

Women also wanted ASHAs to provide information about health insurance, free transportation for delivery and other government schemes. They wanted their husbands and family members to be counselled by the ASHA/AWW on care and support for the pregnant woman. They expected the ASHA to accompany them throughout their journey of pregnancy and childbirth.

The Anganwadi worker is expected to be present during VHND and Immunization Day. However, women felt they were not invested enough in the maternal health programme. Their role was limited to providing supplementary nutrition. Women expected the AWW to know about contraception and provide information and counselling.

Women reported feeling harassed by administrative procedures like filling in forms and providing documentary proof to avail themselves of cash transfer benefits schemes. They also reported frontline workers scolding them for not adhering to regimens and not attending follow-up visits. A few mentioned positive experiences. The woman in her community well respected a VHN in Tamil Nadu as she would visit homes and make efforts to ensure services like immunization. Similar experiences were echoed in UP, where women reported that the ASHA would help them financially. On the other hand, women from extremely marginalized groups like the Mushahar community in UP reported that the frontline workers did not visit their Basti/ tola – this led many women to not avail services till the sixth month of pregnancy.

FLWs' expectations from women and community

FLWs expected women to engage in good health behaviour – not marry early, limit to two children and use contraceptives. They wanted women to adhere to treatment guidelines, undergo ultrasound and all necessary checkups as directed and avoid homebirth.

A woman from the Musahar community shared her experience, which is as follows:

> *When I was pregnant and my labour pains started, I called the ASHA worker and went with her to the Primary Health Centre (PHC). Crying, I pleaded, 'Please have the ANM (Auxiliary Nurse Midwife) check me. I am in a lot of pain.' When the ASHA called the ANM, the ANM replied, 'Today is my Jitiya fast. I won't be conducting any checkups today.' I was in a lot of pain and felt very distressed. After some time, my baby was born just like that. No one came to help. I asked the ASHA worker to call an auto, and I went back home with the baby*
>
> (Woman from Mirzapur, UP)

Expectations from the public health system – During pregnancy

Nutrition and other Support - Women across all settings acknowledged receiving Home Rations, haemoglobin and BP testing, IFA and calcium tablets, weight measuring and abdominal checkups during the antenatal period. However, they wished nutritional support to be provided to pregnant women through the ICDS centres. In some places, irregular supplies or withdrawal of the scheme was a major challenge for women. In Tamil Nadu, women belonging to the Irula scheduled tribe did not have adequate financial status to meet the nutritional levels of pregnancy – they depended on the ICDS centre and PHCs for nutritional support. They would receive dates and eggs during ANC visits. Women were disappointed as the food distribution scheme was no longer operative. Across the board, the supplies of THR and IFA tablets were irregular, and women complained of not receiving them regularly.

In an interesting initiative in TN, a community-level baby shower ceremony ['Seemandam'] was also organized for pregnant women by the PHC, as many marginalized families could not afford such a function. Women expressed that their emotional health improved on such occasions.

Ambulance/ transport services – another major concern was the unavailability of timely ambulance services. The ambulance service was nominal, and the women complained that the ambulance never arrived on time. They could not depend upon it in emergencies. Therefore, women/ families were usually prepared to arrange their vehicles close to their delivery dates. Though supposed to be free of cost, the ambulance service was not so. Women were asked to pay for the service – they expected it to be available without any payment.

> *Now, ambulance drivers don't take 100 or agree to anything less than 200. We request the ambulance drivers, saying, 'Brother, our family can't afford more than 100,' but they don't agree. If they do, it's for 200, nothing less.*
>
> (Woman from Azamgarh, UP)

Sometimes, when the woman was very poor or had no support from her family, ASHAs arranged for their travel to the hospital. However, this came with costs. In Mirzapur, UP, ASHAs would arrange an autorickshaw for women from the extremely marginalized Mushahar community to reach the health facility. In return, the pregnant woman's family was expected to work at the ASHA's farm.

Overcrowding in government hospitals - Another challenge women spoke about was overcrowding in government hospitals, leading to the overstretched doctors scolding and abusing them. They felt their experience could be made better by reducing the crowds at government hospitals so they could get some care and attention. Women recommended that human resources in the PHCs be adequate to cater to the volume of pregnant women seeking care. The lack of human resources in public hospitals forced women to visit the facilities multiple times and compelled them to seek services from private hospitals. They also recounted instances of the PHC doctor leaving the PHC after 2 pm and seeing patients in their private clinic after that for a fee. There were suggestions for strengthening the primary health centre so they did not have to rush to the higher level hospitals for everything.

Drugs, diagnostics and supplies – Women demanded that PHCs have all the necessary equipment and supplies for routine investigations and care during pregnancy. Only immunization and blood testing happened at the VHND in some study sites. While women agreed that fixed days for antenatal care in PHCs were good, they pointed out that a woman coming on another day should not be turned away.

The need for ultrasound scanning in government health facilities was emphasized. In some settings, government-funded ultrasound facilities were reported to be missing entirely. Women were expected to pay approximately 1000 rupees to get an ultrasound from private facilities. The non-availability of ultrasonography in government health facilities resulted not only in the patient missing out on a critical examination during pregnancy but in problems even at the time of delivery, as government hospitals insisted on an ultrasound report being produced at the time of admission. The ASHAs in Jharkhand especially mentioned being scolded by the hospital administration if they brought women for delivery without an ultrasound report. The ASHAs stated in their interviews that they felt awkward asking the extremely poor patients to get an ultrasound, especially since they knew that this service should be free but was not available.

In Tamil Nadu, women shared that four scans were normally recommended during the pregnancy and blood investigations were done four times. Women from marginalized communities reported finding it very difficult to mobilize the funds for doing these scans and tests in the private sector. Women also reported that sometimes they were asked to have additional tests like ECHO and ECG - the women expressed that they undergo these in the government hospital as these tests are very expensive in the private sector. However, the waiting time in the government hospital is very long, even though the tests are free. Women felt that the PHC should be equipped for testing for gestational diabetes, hepatitis infection and thyroid status. All drugs, including essential medicines like iron sucrose injections, should be made available free of cost. Buying from a private pharmacy was not affordable.

> *We go to the private sector for scan. We could not go to C… (town) GH as we could not stand in the line for a long time, so we save money for this… when we go to work, we save money little by little ['siruga siruga'] and go to the private facility.*
>
> (Woman from Tamil Nadu)

Services in the private sector in some states seemed to be perceived to be better than the ones in the public sector. Women who sought services from private health facilities in Gujarat shared that sonography is done in the same facility, and they were immediately informed of the foetus's status; they do not have to wait long. Other children are cared for during the visit, and only one doctor follows up with the woman throughout her pregnancy.

Infrastructural facilities - Women recommended that PHCs and higher-level health facilities should have adequate infrastructural facilities for checkups for pregnant women - enough places to sit, fans, drinking water, and clean toilets at a minimum. In some settings, where lunch used to be provided to pregnant women coming for monthly checkups, women regretted the withdrawal of this scheme. In some places, women expected lunch and clean water arrangements, especially when they spent the whole day sitting at the PHC for ANC checkups and filling out forms for cash transfer schemes and certificates. Procedures for filling out forms should be easy and simple and should not require too much documentation. Women reported that in government facilities, they had to spend a whole day for tests and scans. It was much quicker in the private sector.

Contraceptive services - Women in all settings felt that reversible contraceptive methods should be provided at the community level regularly. There should be no pressure of targets on the ANM to insert IUCD (Copper T). Such pressures led to consent procedures not being followed.

Respectful care for all women - Women across the board expressed that pregnant women should be attended to and treated with due care and respect. They shouldn't be yelled at and scolded for coming late and not adhering to schedule.

> *I delivered both my children in the GH. When I went for ANC care, the nurse asked me to bend and stretch my legs and even slapped me while doing the examination. I felt very bad and explained to my husband, and then he took me to a private hospital in (Thirukazhukundram) for ANC care. I had to go to GH for delivery as they told me it would be a C-section, and we could not afford the costs of delivery in the private hospital.*
>
> (Woman from Chengalpattu, Tamil Nadu)

Expectations from the public health system - delivery of care

Mixed responses were received regarding delivery-related care at public hospitals. There were some good experiences, but simultaneously, women reported facing challenges.

Two issues mentioned across the board repeatedly were:

Demands for informal payments - Informal payments were reportedly demanded by hospital workers at all levels, from the watchman and sanitary worker to the nurses. More worryingly, withholding of services and care when payment was not made was one of the biggest problems that women faced. Families paid money expecting good treatment from the staff. There were reportedly fixed rates for each service. The extent of informal payment expected

also varied according to the baby's sex. Women were coerced to pay for the baby to be shown to the family, for cutting the umbilical cord, for cleaning the newborn and the woman, for birth certificates, and for getting entitlements under various schemes. Services were withheld in case of non-payment. In addition to the informal payment, families were asked to arrange to pay out of pocket for sanitary napkins, blades, soap, syringes, and other items. They were given prescriptions for medicines unavailable at hospitals, and families had to procure them outside.

> *If we stay there for 10 days, we should allocate at least Rs. 10,000. For example, visitors are supposed to be allowed between 12 Noon and 1 PM. Even so, the person at the entrance will demand Rs. 10 or Rs.50 or Rs.100 from whoever enters the ward. They almost grab the money from us. If we do not pay, attenders will not be allowed in, and they will also talk in an abusive manner. After my delivery, I was in the GH for 10 days, and my husband spent Rs. 10,000 on these extra expenses.*
>
> (Woman from Chengalpattu, Tamil Nadu)

A range of other issues were mentioned.

Availability of Caesarean sections - In many places, women reported that caesarean sections are not available in public facilities. Women recounted various instances of being referred to higher facilities for caesarean section. Women also doubted the need for caesarean section in many instances, saying the delivery would be conducted normally (vaginal birth) if they paid up money.

> *Often, when a woman comes to the Community Health Centre (CHC) for delivery, the staff nurse immediately refers her to the district hospital. However, if someone recommends the case or gives a bribe, the normal delivery is done there. Alternatively, if she goes to a nearby private hospital, the normal delivery happens without issues.*
>
> (Woman from Azamgarh, UP)

Women demanded that unnecessary caesarean sections should be avoided. When caesarean sections are performed, a clear explanation should be provided to the woman on the need for surgery.

Ambulance services - A key demand from women was for free ambulance service to transport the woman and the baby after delivery.

A supportive environment in health facilities - Women recommended that delivery wards have good infrastructure, such as adequate clean beds, protection from mosquitoes and pests, clean toilets, and fans. Free food should be provided to all women admitted for delivery. Women should receive support from nurses to initiate breastfeeding.

Respectful Maternity Care – Women wanted their childbirth experience to be free from violence, abuse, neglect and apathy. They didn't want to go to private hospitals because it was expensive, but they shared that they were paying for dignified behaviour in private hospitals.

Women were very keen that they should not be abused, humiliated or treated with disrespect during childbirth. Women at all study sites reported grave and extensive physical violence and verbal abuse at the time of delivery. They recounted being shamed, slapped, and manhandled by the health staff in government hospitals.

Physical violence and shaming by medical staff - Many women narrated experiences of being hit and shamed at the time of delivery. They said they were slapped hard, yelled at and humiliated.

> सोते वक़्त दर्द नहीं होता है? अब क्यों चिल्ला रही है? *(Does it not hurt when you have sex! Why are you screaming now?)*

This sentence was reported as a common form of verbal abuse in almost every setting.

Women reported that when they screamed in pain during labour, they were mistreated and abused. One woman in Jharkhand shared a horrifying incident of being beaten and humiliated to the extent that she ran away from the hospital during her labour. She began to bleed soon after and delivered twins at home with the help of a traditional midwife. Only one of the twins survived.

Apathy, Discrimination - Across different sites, women complained of instances where the doctors did not want to touch them and made this very obvious. The doctors and nurses were reportedly also rough with them while suturing tears, and reports of no anaesthetics being used during suturing were also recounted.

> नीचे कपड़ा जैसा सिलाई कर देती है सुन्न करने का दवा भी नहीं देती*. (They stitch our genitals like one would stitch clothes. They don't even numb the area with anaesthesia.*
>
> (Woman from Jharkhand)

Neglect: While the presence of a birth companion along with the woman is now mandated in the programme, this was often not the case for women. Women demanded that no woman should be left unattended when she is in labour. There should be provision for a birth companion, and a nurse and doctor should be on call. No woman in labour should be left to the care of a trainee doctor alone.

When my labour pains started, my mother-in-law informed ASHA Didi. Since it was late at night, 108 ambulance didn't arrive. We hired an autorickshaw to reach the hospital. I was left alone to fend for myself. No one was with me. My mother-in-law was not allowed to be with me. My throat was dry, and I was thirsty and asked for water. I was in pain. Everything was blurry, and I felt I was going to die. I was scared. I went to the next room, and my mother-in-law gave me water. The nurse then arrived and scolded me for going to the next room and scolded my mother-in-law for giving me water. My mother-in-law requested the nurse to attend to me. She, however, ignored this, and I felt she was enjoying my suffering.

(Woman from Odisha)

Emergency obstetric care at sub-district and district hospitals - Women felt that taluk and district hospitals should be equipped to provide care for any emergency during delivery, including blood transfusion, and should not refer patients to higher-level facilities or the private sector.

Referrals - Women demanded that unnecessary referrals by nurses from CHCs and PHCs of women in labour to higher-level facilities should stop. Nurses threaten to refer to higher-level facilities if they don't give informal payments. Such practices discourage women from using services at public hospitals and push them to use private hospitals.

Once, we went to a government hospital, and when the staff nurse asked for money, we refused to give it. She angrily said, "People spend lakhs of rupees, and here people hesitate to give even 10 or 5 rupees." We responded by saying that in government hospitals, there are no charges. The staff nurse replied, "If we refer you from here, what can anyone do to us?" She directly threatened us like this. If doctors and staff nurses threaten people in this way, what is the point of going to a government hospital? It's better to have the delivery at home. The entire system is a stain on the name of government healthcare—it's full of people who are just there to make money.

(Woman from Azamgarh, UP)

Accountability of private hospitals - Most of the women who accessed services in private hospitals did so because services were not available in the government setting, or even if available, subjected them to corrupt practices, mistreatment, or abuse. The private services included antenatal care, ultrasonography, blood investigations and other diagnostics, and caesarean section deliveries.

Women acknowledged dignified behaviour at private hospitals but were overcharged and felt there should be accountability in private hospitals.

A woman in Odisha gave birth to her third child one day before tropical cyclone Fani at a Private hospital because the government district hospital referred them as a complicated case. The woman had to undergo two more operations after her caesarean section delivery. Even after spending more than two lakh rupees, she could not pay the whole amount and had to escape sneakily in the night.

Postnatal care - Women were keen that there should be care post-delivery. The focus in the postnatal period is shifted to care for the baby, and the woman's needs are ignored. There should be sensitivity towards women who undergo operative procedures like caesareans. Women said they were expected to get up immediately and walk around even after a caesarean. Women also emphasized the need for privacy in health facilities and during postnatal care. Women also felt that due entitlements should be provided even if the woman delivers at home.

> *We had a home delivery, but no one came to our house afterwards—not the ASHA or Anganwadi workers. The baby's weight was measured only later, and we did not receive any financial assistance.*
>
> (Woman from Shankargarh, MP)

Consent for contraceptives - Women reported being fearful of insertion of Copper-T without consent in public facilities - this forced them to go to private facilities. Insertion of IUD postpartum, without the woman's knowledge or consent, should stop. Failure to seek women's consent for IUD insertion creates mistrust between ASHAs and women and discourages women from utilizing services in the public sector.

Expectations requiring policy and programmatic changes

In addition to the above, several of women's expectations would require policy and programmatic changes. We list them here:

- Every facility should have a woman doctor providing antenatal care and delivery care. Adequate human resources to cater to the needs of pregnant women should be available in all facilities. The number of nurses in the delivery wards should be planned to ensure that no woman will be left unattended.
- The capacities of AWW and ASHA should be enhanced to provide appropriate information and support to pregnant women, including contraception and government schemes.
- Tribal women who participated in the study preferred delivering close to their homes, in health subcentres. HSCs in tribal areas should have experienced ANMs who are skilled midwives.
- There should be a cap on the charges for services provided in private health facilities.
- There should be systems to ensure that private health facilities provide good maternal health care and do not carry out unnecessary procedures or investigations.
- There should be systems for complaints and their redressal at all public health facilities and regular monitoring of the quality of maternal health services.

DISCUSSION

This study results from CommonHealth setting out to build a discourse on women-centred maternal health care. It seems oxymoronic that maternal health care has to be defined specifically to be women-centred when all care during pregnancy and birth should ideally revolve around the pregnant woman and her needs. However, policies and programmes nationally, and to some extent globally, have largely been technocentric and focused on efficiency. Globally, the push for skilled birth attendance has translated into institutional births without simultaneous investments in health systems to improve the quality of care. The focus on the technical quality of care has almost erased the role of traditional birth attendants who were culturally attuned to women's needs. Although maternal mortality has decreased globally, women's morbidities are left inadequately addressed, and women survive pregnancies while continuing to experience ill health.

In India, skilled birth attendance has been interpreted by policy and programmes as institutional births, with cash incentives being offered to women to promote the "good behaviour" of adopting institutional births. Unsurprisingly, this did not translate into reductions in maternal mortality until efforts were made to improve institutions to provide better quality of care. Even the more recent programmes of the Government of India, like the midwifery programme, while ostensibly promoting a woman-friendly midwifery philosophy, are by design not meant to address women's specific needs of culturally sensitive care with dignity close to home. In such a scenario, we felt the need to showcase "women-centred maternal health care."

We, therefore, documented the experiences and expectations of women during pregnancy and birth, especially those from marginalized communities. We felt this capturing of women's voices was important so that any discourse on what women-centredness is would be informed by the women themselves who are experiencing pregnancy and birth. Foregrounding the voices of marginalized women is also a reflection of CommonHealth's key values of participation and accountability, where all our initiatives are guided by and are accountable to those most impacted by them.

Capturing women's voices, however, required the use of innovative methods. Multiple consultations across diverse contexts engaged women in role plays, discussions through vignette scenarios, and ranking and prioritization exercises. Using these methods required preparation and training of the facilitators, and it was challenging to fit into the schedules of women's everyday lives, which were filled with responsibilities for childcare and earning livelihoods. We see this experience as a key learning point on the efforts that need to be made to ensure the meaningful participation of women in designing policies and programmes.

The women who participated in this study articulated their expectations with clarity– from their homes and families, the communities they lived in, and the health system. These are detailed in the results section.

CommonHealth had carried out a similar exercise more than a decade ago to understand from women what they meant by "safe delivery". What has changed for women in the ensuing years? Unlike a couple of decades earlier, most women reported giving birth in health facilities, not because they were asked to, but because they saw this as a better choice for themselves and their babies. Despite this and improvements in many areas of health facilities over the years, women's experiences highlighted the continued presence of gaps in the health system preventing women from being able to receive sensitive, dignified and respectful care. These gaps include the almost routine experience of violence and abuse in health facilities, regular demands for informal payments for various services, overcrowded facilities, difficulty in accessing ambulance services, giving births at home in the absence of motorable roads, missing postpartum care for women and the shifting focus onto the newborn after birth at family and health system levels. It is concerning that many of these gaps are similar to what was reported over a decade ago with little improvement. The pandemic compounded many of these gaps by resulting in the withdrawal of regular services, some of which, e.g. free food during antenatal visits, had still not been reinstituted during our consultations with women.

Another issue that seemed to remain unchanged, or had even seemingly become worse, was the coercion by health care providers for the use of contraception by women. Women recounted from diverse settings the non-consensual insertion of postpartum IUCD – the continued practice of such human rights violating behaviours is ironic, especially since most states have reached the stated demographic goal of replacement level fertility.

This study also went beyond a health system focus to understand what roles communities and families could play in putting women at the centre of maternal healthcare. Our findings reiterated the strong contribution of social determinants to maternal health. Women's experiences highlighted the role gender continues to play as a determinant of their health. Women recounted gender discrimination in their homes, lack of agency to make decisions about their health, and even expressed seemingly small desires that were unfulfilled, such as having control over a small amount of money to spend on themselves. Their expectations from their families focused on relief from their gender-determined household and caregiving responsibilities during pregnancy and the postpartum period. They also wanted a sensitive, violence-free environment at home. Son preference was seen as a continued issue in many communities, placing mental stress on women.

These experiences of gender intersected with other axes of marginalization, like caste and poverty. This was starkly visible in their interactions with frontline healthcare workers. Women from marginalized communities narrated experiences of caste discrimination at the hands of ASHAs and ANMs. Poverty was compounded by the lack of specific services like ultrasound scans in the public sector, adding additional burden on poor women who were forced to spend on these services in the private sector or miss availing them altogether.

Another key contribution of this study is to foreground what frontline health workers saw as women-centred care and the challenges in providing such care. Interviews with frontline workers revealed that as women, often from marginalized communities or poor households, they had to tackle several problems to sustain a means of livelihood. They faced multiple challenges in addressing the needs of women, burdened as they were by poor pay and high workload, including large amounts of paperwork. The work conditions of frontline workers were not sensitive to their needs. They reported a lack of transportation to carry out home visits and an absence of overnight stay arrangements at hospitals when they accompanied women for care. Any discourse on women-centred maternal health care will also need to acknowledge and address the needs of these women.

What do these findings mean for making maternal health care more women-centred? How can programmes and policies ensure their services go beyond the technical issues to truly address women's needs?

It must be acknowledged that there have been efforts and investments in improving the quality of care in public sector facilities. However, women's experiences in this study highlight that while these may have improved the very important technical quality of care, this alone is insufficient to improve women's experiences of care. Sustained efforts must ensure healthcare providers are trained and sensitized to always provide respectful care for women. However, this needs to be accompanied by measures to improve the working conditions for healthcare providers on the ground. Hence, they function in an enabling environment to provide such care. Health systems also need to be designed with women's needs in mind – the midwifery programme that results in the centralization of services is a case in point where well-intentioned programmes end up being unable to address women's core needs.

Thus, a key intervention that emerges from the findings of this study is the need to invest in improving the governance of health systems. Women's voices need to inform policies and programmes designed for them, and special efforts need to be made to ensure meaningful participation by women. There have been several efforts at establishing community accountability mechanisms for health in different states – lessons from these need to be incorporated into processes that ensure participation.

Better governance would also mean addressing the pervasive corruption in health systems that women and their families report facing regularly. It is well documented that corruption in health systems causes lack of trust, substandard quality of care and poor health outcomes. Concerted efforts need to be made to address corruption at all levels.

This study also shows that women-centred maternal healthcare needs investments beyond the health system. Gender, caste and poverty are key social determinants that affect women's access to and experience of care. Women from marginalized communities are even more

vulnerable to the effects of these determinants. Women-centred maternal healthcare will need actions beyond the health system to address gender-based inequalities within the household, the community, and wider social structures. At the same time, health systems need to recognize the gendered challenges women face and mitigate these by providing services that meet women's needs.

ANNEXURE-1

Women's experiences and expectations from maternal healthcare

Tool for discussion with women (administered by a facilitator)

- *The facilitatorwill provide the information sheet of the study to the participants, explain it to them and willanswer all their questions and concerns.*
- *After this she will seek their verbal consent for participation and for videography of the consultation (if possible) and then proceed with the consultation.*

I. Introduction/rapport building

Facilitator asks a few women to volunteer on the following:

1. Please introduce yourself by telling a bit about yourself – your name, where you stay, your family members, and how many children you have.
2. Where did you have your last delivery? (Probes: public hospital, private hospital, traditional birth attendant) *(Ask few volunteers who could provide this information)*
3. Who all were present with you at the time? *(Ask few volunteers who could provide this information)*

Facilitator will explain:

- *To get your views on the issues of Maternal healthcare, we would be using participatory methodology such as enacting a situation and then asking questions on the same about what your views are.*
- *The facilitator will explain the activities and process.*

Activity I:

Role play

Request a few volunteers from the group (4-5) to do a role play. You can also choose a few active participants and ask them if they are willing to do the role play.

Give clear instructions to the volunteers – ask them to enact a scene depicting their best experiences with care during pregnancy and childbirth. Tell them to show scenes within the family, during check up and during childbirth. Do NOT give details of what they have to enact – let the participants decide this. Ask the participants to take on different roles like pregnant woman, family member, ASHA, ANM, nurse in the hospital etc. Once they decide the roles, you can help them pin a badge on their dress with the name of the role in order that they can be easily identified. Ask the rest of the participants to keenly observe the role play. Ensure that the role play does not go beyond 10-15 min.

Once the role play is finished, facilitate a discussion with the group that enacted the role play and the others as follows.

Questions to the group that enacted:

1. Ask each person in each role, e.g. the woman, the family, the health care provider, how they felt with the overall pregnancy and childbirth experience. What were the emotions going through them, what were the reasons behind their actions?
2. What would they have liked to be done differently in the scene?

Questions to the observersgroup:

1. What did you observe in the scene?
2. Who has carried out the pregnancy check-up? Is this usually the case? Who usually carries out the check-up? Do they come to your house or to a place in your village, e.g. anganwadi centre, or do you travel to the health centre? Please elaborate.
3. How much time is spent during each ANC check-up? How many check-ups are conducted/are you able to attend usually? Why?
4. What are your recommendations at the time of ANC check-ups? (Probes: time spent, travel and transportation, care provided, etc.)
5. What did you observe in the childbirth scene? What did you like in what you saw and what did you not like?

6. Does this happen? In what settings? Which parts of this seen have you experienced/ heard of happening?

7. What are your comments about the care provided, about the medical healthcare provider's behaviour?

8. What is the ideal setting for a delivery to take place? (Probes: public hospital, private hospital, home) Why?

9. What are your recommendations for ideal care during delivery? (Probes: transportation, birth companion, provider-patient interactions, different procedures carried out, consent for the procedures, post-natal care)

10. What would you like to change in what you saw? How do you think this experience could have been made better for the woman? Do you have any concluding remarks you would like to share?

Activity II:

The facilitator asks the women what are the things they would want in an ideal scenario in terms of maternal health care if they themselves were pregnant – starting from in pregnancy, at the time of birth, postpartum period, newborn care etc. The facilitator encourages them to include things in the family, from the health care provider, the ICDS system etc. A free listing will be made by the facilitator. The documenters helps the facilitator list these on a board/ chart paper.

The women will then be asked to rank the items in order of priority. For eg. a few bindis are given to the women and they are asked to stick a bindi each on the top three things in the list that they feel are most important.

Process documentation

Ensure that a detailed process documentation is done all through these activities – please refer to the documentation checklist to ensure completeness of documentation.

ANNEXURE-2

(Interview Field Guide)

(Key Informant Interviews)

Informed Consent

Basic information

Namaste. My name is _____. I am from *****. The study is conducted by CommonHealth, a rights-based, multi-state coalition of organizations and individuals that advocates for increased access to sexual and reproductive health services to improve health conditions of women and marginalized communities.

The purpose of this study is to systematically document women'sperspectives and opinions on what would constitute a women centred maternal healthcare in order to develop a discourse on women centred maternal healthcare. You being a health worker providing these services and a crucial support to women and link between the women and health systems, your views on this subject matter are very important.

For this, I would like to have your permission to discuss these issues. The information you provide us has the potential to help improve these services in your area during this period as well as in future health crisis situations. The interview would require around 30-45 minutes of your time.

All the data that we gather will be used for research purposes and as data for policy recommendations. Your identity will not be revealed anywhere. Only our research team will have access to the information you provide us. You can take your time to decide whether you want to participate or not in the study. If you decide to participate, you can withdraw from the study at any time, without assigning any reasons. The data collected from you till the point of withdrawal will not be used in the final analysis.You have the right to refuse to discuss any question if you feel uncomfortable about it. This will be without any consequences for you now or in the future and there is no penalty for refusing to take part. However, I do hope that you will give me permission for this good cause. You may ask me at any given point if you have any questions related to this issue. Even post interview, ifyou have questions, you can also contact: ******, Study team lead, Organisation **** (Contact number ****).

Do I have your consent to proceed?Please let me know. I will register your consent in the consent form. I will provide you with a copy of the signed form if you want.

Participant consent

I, _____, have understood the purpose of and topics to be covered during the interview. All of my questions have been answered. I understand that my participation is voluntary and that if I choose to refuse to participate, I understand that my refusal will not affect me or my career in any adverse manner, and there will be no adverse impact whatsoever to me for my refusal to participate. I also understand that I may withdraw my consent at any time, and I do not have to provide a reason to withdraw. I voluntarily agree to participate in this study.

Verification of Consent

The benefits, risks, and procedures for the research study have been explained to the respondent. Her questions have been answered. Oral consent of the participant is taken on ..... (date) in person/ telephonic conversation. She has agreed to participate.

_____Signature of interviewer

_____Date (dd/mm/yyyy)

May I begin the interview?

Note: The interview should be conducted as a conversation / discussion, with each (sub) question flowing from the answer to the previous one. Each of the questions listed are the types of information that is to be collected, but how the questions are asked will depend on how the conversation is going. The questions are there as examples. They are not meant to limit the interview, but rather keep the interview on track.

Frontline workers' experiences and perceptions of maternal healthcare

Tool for discussion with frontline workers (administered by a facilitator)

Profile of FLW

1. Age
2. Educational qualification
3. Designation
4. Place of posting
5. Total population covered
6. Years of service

Questions

1. What do your roles and responsibilities comprise? (Probes: general roles and responsibilities, those with regard to childbirth services)
2. What are your specific duties with regard to caring for pregnant women during their pregnancy (ante-natal care)? Please elaborate.
3. What are your specific duties with regard to care during childbirth? Please elaborate.
4. What are your specific duties with regard to care after childbirth and care of the newborn (post-natal and neonatal care)? Please elaborate.
5. What is your best rewarding experience while working till now? Can you share any such example?
6. What are the challenges and barriers you face in performing these pregnancy and childbirth-related duties?
7. What are your recommendations for overcoming these barriers?
8. In your experience, what are the difficulties women and families face with regard to pregnancy and childbirth-related care? (Probes: difficulties during ANC, delivery, PNC)
9. What are your recommendations for overcoming these barriers?
10. In your experience, what expectations do women voice with regard to childbirth-related care? (Probes: expectations during ANC, delivery, PNC)
11. What are your recommendations for improving childbirth-related care and services? How can maternal healthcare be made more women-centred.i.e. It fulfills the specific needs and expectations of women ('woman-centred' to be translated into Hindi/local language)?
12. Concluding remarks, if any.

ANNEXURE-3

SAHAJ ETHICS GUIDELINES 2018

Part 1: For Ethics Committee members

a. Expected benefits and risks (Non-negotiable)

b. What are the expected benefits of the interventions/research to

A. The community groups/subjects of intervention/research

B. SAHAJ (CommonHealth)

C. Others – please specify?

c. What are the perceived risks? Risks to the –

A. The community groups/subjects of intervention/research

B. SAHAJ and organization teams?

C. Data collected (ex. storage, consideration of privacy, quality)?

D. Project partners

E. Funders?

F. Others?

d. What strategies have been designed to maximize the benefits to each of the above?

e. What safeguards have been made to minimize the risks to each of the above?

Risk to the respondents-

Risk to the researchers-

f. Are there any key technical issues regarding interventions? If so how are relevant experts going to be consulted on this?

g. Does the overall assessment of benefits versus risks justify the intervention/ research efforts? If no, why?

h. Informed Consent process (Non-Negotiable)

i. Have you considered consent of participants while getting any information from them? And in which form- oral, written?

j. Whose consent will you seek in case of minors? Those not able to give their own consent? Process of seeking consent?

k. What were the ways of ensuring informed consent?

l. Did participants have any question/s and whether they were responded to?

m. Does the consent form contain all required information? (aim of the project, how long it will take to collect information, the participant is informed that it is voluntary, why collecting the information etc. See example at the end of the checklist)

n. Was remuneration/incentive status for the participation clarified at the time of the consent?

o. If your intervention/research changes, how will consent be re-negotiated?

ANY OTHER IMPORTANT ETHICAL ISSUE/S NOT COVERED ABOVE THAT YOU FEEL SHOULD BE MENTIONED.

Part 2: For SAHAJ team

1. **Partners and consultative process (Non-negotiable)**

    a. Which are the main partners and what is the consultative process?

    b. How will you ensure transparency in the process of ongoing communication with these partners?

    c. What is the planned MoU? Does the MoU follow the ethics guidelines? Are guideline attached to the MoU? Does the MoU cover legal and ethical aspects and training with partners for clarity on ethics guidelines throughout the mentioned period of the intervention/research?

    d. What are the measures planned to reduce power inequalities between partners? And for power sharing between partners?

2. **Relationships (Negotiable/Desirable)**

    a. Define all relationships for the intervention/research?

    b. How would it be ensured that the relationships are based on transparency, fairness and overall mutual beneficence? (whether it exists within the team, team and participants, team and local organisation)

    c. How would decisions be taken within the team and how would differences be resolved?

    d. How would the confidentiality of persons approaching the team be maintained and how would confidential information be shared within the team?

1. **Broader relationships (Desirable)**

    a. How will the activity be communicated to society at large?

    b. How it will be ensured that commitments to funding agencies are respected?

    c. What mechanism of regular communication with the community/respondents will be adopted?

    d. How will the conflicts between commitment to funders and to the community be resolved?

2. Processes for empowerment and sustainability (Non-negotiable)

a. Will the Principal Investigator/Project Coordinator monitor the ethics aspects of the intervention/research throughout the course? When? And How?

b. How will the Principal Investigator/Project Coordinator ensure training of the researchers and team associated with this intervention/research to develop their skills and capability to follow the ethical guidelines? Also by providing regular external inputs over the entire period?

c. How will the project/research enhance 'voice' of those addressed/studied?

d. What is the withdrawal strategy (at the end of the project) keeping in mind the ethics perspective? (share report with them or take some action or not do anything)

e. What are the sustainability processes initiated by the project?

3. Crises and unforeseen situations (Non-negotiable)

a. What is the broad 'Contingency plan' for crisis situation specially regarding how decision making will be done, how responsibilities will be shared and what is organisation's commitment? (The Coordinator can take a call keeping the organizational values in mind and informing the organization's senior members. If required, they can contact the Ethics Committee members for guidance.)

b. What are the safety plans for persons who may face problems because of involvement in project initiated processes?

c. What are the mechanisms to ensure the personal safety of organisation staff and other persons directly related to the project activities?

ANY OTHER IMPORTANT ETHICAL ISSUE/S NOT COVERED ABOVE THAT YOU FEEL SHOULD BE MENTIONED.

ANNEXURE-4

Information sheet

Discourse building on women centred Maternal Healthcare

Warm greetings from CommonHealth!

CommonHealth is a rights-based, multi-state coalition of organization and individuals. CommonHealth has been working in the field of reproductive health for many years, and advocates for increased access to sexual and reproductive health care and services to improve health conditions of women and marginalized communities.

We have currently undertaken the project Discourse building on women-centred maternal health care. The purpose of this project is to understand from women what they expect in terms of a good quality, respectful and women centred maternal health care.In order to do this, CommonHealth will hold a series of consultations with grassroots women and frontline workers in different parts of the country with the support of our members.

As someone who has experience with pregnancy and childbirth and have used maternal health care services for the same, we would like to hear from you your experiences around this and also your expectations from such services. We therefore would like you to participate in a consultation on the same where a group of women from your own community will participate to share these experiences.

Your participation in this consultation is completely voluntary. This meeting may require a few hours of your time. Your participation would add valuable insights to this exercise, and we truly hope you shall participate. In case you decide to not participate, there would not be any adverse implications of this.

We hope you shall be able to support us in this endeavour and add much value to this discourse on maternal health with your contribution.

You are free to ask any questions/convey your concerns, we will be happy to answer those. We seek your verbal consent and if you agree, we shall proceed with the consultation.

Please sign the registration sheet to indicate your consent. Also, mark yes /no in the column to indicate consent for videography in the registration sheet.

Name of facilitator:

Contact:

About SAHAJ

Since its inception in 1984, **Society for Health Alternatives - SAHAJ** has focussed on comprehensive development of children, adolescents, young persons and women especially from 30 bastis from urban Vadodara. Additionally, through its partner organisations, SAHAJ has been working in Anand, Dahod and Mahisagar districts of Gujarat for Adolescent/Youth Rights, Reproductive Health and Community Development; and in the state of Punjab and Assam for localising SDGs 2030.

About CommonHealth

CommonHealth - Coalition for Reproductive Health and Safe Abortion, constituted in 2006, is a rights-based, multi-state coalition of organisations and individuals that advocates for increased access to sexual and reproductive health care and services to improve health conditions of women and marginalized communities in India. Within sexual and reproductive health and rights, CommonHealth concentrates its efforts largely on maternal health and safe abortion. The coalition draws its membership from diverse disciplines, thematic areas and geographies within the country.

Sahaj

towards alternatives in health and development

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