Towards Enhancing Everyday Pregnancy Care: Reflections from Community Stakeholders in South India

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ABSTRACT

We need a deeper understanding of the everyday challenges of pregnancy care in lower socio-economic settings in India. This paper reports reflections from three workshops involving multiple stakeholders, conducted as part of a larger project exploring the role of digital technology in enhancing everyday practices of pregnancy care. In particular, this paper only reports our initial engagement with community stakeholders in pregnancy care, including the local public and third-sector network of care-workers. Based on the findings, we present three reflections namely, a) tensions between traditional and everyday care practices versus requirements of modern pregnancy care, b) tensions in coordination between multiple stakeholders in pregnancy care, and c) the role of physical and digital infrastructures in pregnancy care. These reflections are introduced as concerns and highlight opportunities to further inform technology design to enhance everyday care of pregnant women in semi-urban and rural India, and beyond.

Author Keywords

Pregnancy care; maternal health; digital health; ICT4D.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION

Maternal health is one of the foremost public health challenges in India. A set of complex issues make the care and management of pregnancy more challenging, especially in urban slums and rural communities [3]. In addition, the low utilization of maternal and reproductive healthcare services [8] together with the exacerbating socio-cultural and

economic inequalities have jeopardised women's health especially at the lower levels of the socio-economic system in India [7]. Hence, a holistic approach is needed to address and account for diverse stakeholder's perspectives that goes beyond the individual pregnant woman.

The use of Information and Communication Technologies (ICTs) is creating opportunities to support community based pregnancy care in India [2, 5, 6, 9]. However, large existing ICT-driven interventions have not focused on accounting for how community everyday settings and households influence pregnancy care. While designing health ICTs for everyday settings poses new challenges [1], it also creates opportunities to support the situated nature of care [4] and potentially help reinforce healthy practices and help lessen the impact of unhealthy practices. In particular, design needs to consider how existing household and community power dynamics challenge technological interventions [5, 6], and understand the existing challenges beyond the home setting that might be exacerbated in resource-constrained settings.

In this paper, we report on synthesized insights across three workshops with community stakeholders in pregnancy care, to highlight the challenges and potential opportunities towards enhancing the everyday aspects of pregnancy care beyond the household and at the community level. Each workshop was with a varying set of participants including multidisciplinary academics and researchers with different backgrounds including public and population health, nursing, and human computer interaction (HCI) as well as other community stakeholders including community health workers, and a group of Auxiliary Nurses and Midwives (ANMs). We use the multiple perspectives voiced by these diverse stakeholders as material for analysis. Reflecting on these discussions we bring three themes. The themes open up a space for further research with an explicit focus on how everyday practices, routines and activities in and beyond the household of pregnant women shape pregnancy care, and how care practices can be enhanced through the design of digital technology in low and middle income countries.

BACKGROUND: RESEARCH SITE

This study is part of our project entitled Healthy Crossroads in Pregnancy Care (HCPC), where the aim is to co-inquire

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what roles ICTs might play in enhancing and shaping (individual and community-based) socio-cultural practices around pregnancy care in India. As part of the project we have chosen the district of Channapatna, which is a town in the Ramanagara district, of Karnataka state in India with 145 villages (Census of India 2011). The main reason to choose this site is the fact that one of our local collaborators, MAYA Health, works in this region. MAYA Health trains and supports women health workers, termed as Health Navigators (HNs), in 90 of the 145 villages in Channapatna.

WORKSHOPS WITH DIVERSE STAKEHOLDERS

We engaged in three different workshops with diverse stakeholders. Though we visited and talked to one pregnant woman, we did not explicitly include pregnant women or their families in the discussion at this stage. We aim to understand the existing care networks and issues around care-work across the community stakeholders in pregnancy care before we engage closely with the primary stakeholders.

Figure 1: Workshops with community stakeholders.

In the first workshop, participants included academics and researchers from different backgrounds including public and population health (1), social science applied to health (1), nursing (3), and HCI and digital health (2) as well as 3 members of third-sector organization (MAYA Health). The participants listed challenges and opportunities present in the existing pregnancy care infrastructures and everyday practices (see figure 1, left side). In the second workshop, participants were twelve representatives of a self-organised group (SHG) of community health workers, the Health Navigators. The HNs mapped out the different stakeholders they interact with during their work and the positives and negatives experiences faced during their course of work (see figure 1, right side). In the third workshop at one of the urban primary health ‘sub-center’, participants included the medical officer, the staff nurse, a lab technician and the 9 Auxiliary Nurse Midwives (ANMs). We discussed about the day to day activities carried out in the field and the role they play in the care of the pregnant women.

REFLECTIONS

The discussions, the post its, and the stakeholder maps were used by the research team to reflect on the existing challenges and the opportunities in pregnancy care. We used the method of affinity analysis, by manually discussing each observation written on a post-it and finding affinity patterns across others to formulate the themes. The themes emerged from the most relevant topics discussed across the

workshops. We synthesize our findings across these three groups, and cluster them in the following themes.

Traditional & Everyday Practices Versus Modern Medical Care Requirements

One of the foremost concerns raised was the tension between the traditional belief systems and everyday practices of the households, and the requirements of care as defined by the modern medical standards.

Nursing academics brought forward how practices rooted in religious beliefs interfered with care of both the mother and infants even in hospital births, where monitoring and supervision is possible. Examples of such practices include feeding infants drops of honey, oil or ghee, along with non-feeding of colostrum. Despite counselling by the nursing team, the mothers or mothers-in-law of the pregnant women and young mothers continue to practice this form of feeding as they believe this helps the infant’s immunity. Another example was how during pregnancy most women did not eat their full requirement of food as they believed that this will increase the weight of the baby, which in turns is perceived to lead to a lot of pain during labour and birthing problems.

Another tension arose not from religious beliefs, but from practices that have evolved over time and are facilitated through the patriarchal systems of living in joint families. The discussions revealed that in most households, pregnant women eat the same food that gets prepared for all members; there is usually no extra nutritionally rich food prepared for them. Furthermore, the ANMs discussed how they have to always counsel not just the pregnant women, but also their mothers or mothers-in-law about nutrition as in most households the food is prepared under their supervision.

However, the presence of mothers and mothers-in-law does not always negatively influence care. Our discussions also brought forward how they support care, including food preparation, offering advice and guidance from experience on pregnancy and labour and child rearing, and support for other activities of daily living. We also found that the informal peer-to-peer network of women in and around the neighbourhood also plays a major role in influencing care through social activities and sharing of stories, experiences and general know-how. We did learn that some women are more connected to these networks than others depending on household norms for female mobility outside the home.

Tensions in Care Coordination Between Diverse Stakeholders

While the pregnant woman and her household are of course the primary stakeholders in pregnancy care, diverse community stakeholders are involved and influence care practices beyond the household. There is not always a cohesion and coordination between them.

One group of stakeholders is the network of Accredited Social Health Activists (ASHAs) and the ANMs who deliver the ‘last-mile’ connect to the public health system. Our discussion with the ANMs highlighted how between the 9

ANMs, they cover a population of 90,000 people. As part of the Maternal Care program under the National Rural Health Mission, the ANMs go door to door to monitor, record data, and counsel pregnant women and young mothers and their families about all aspects around family planning, pregnancy and childbirth such as nutrition, vaccinations, clinic visits, and hospital birth. Underlying this network is the sub-centre, which has the facilities for minor emergencies, pathology lab testing, vaccination and consultation, and the Primary Health Centre (PHC), which has additional facilities of a labour theatre and ward. The private clinics, labs, and ‘nursing homes’ (20-50 bedded hospitals with a labour theatre funded by private investment) form another external network of care-givers. This network offers mostly tertiary care focusing on diagnostic and monitoring tests and birthing.

Our discussions brought forward how there is not much cohesion and coordination between the networks that the pregnant women and their families interface with. They register for the government scheme of maternal care¹ and have the ASHAs and ANMs visit their house (three to four times during pregnancy) for counselling and data recording. However, in most cases the women and their families go to private health clinics for consultation, intermediate tests and scans, and finally birth, as there is a perception that private care is of better quality than public facilities. The perception is driven by the fact that the public health infrastructure of India is resource-poor given the heavy demands placed on the system by a large and growing population.

The shifting across two networks of care leads to gaps in the experience of care. For example, the ANMs described how some pregnant women are encouraged to go for expensive diagnostic tests such as ultrasound scans by the private clinics, even when they do not require it. When the ANMs suggest women limit the number of tests, their suggestions are not taken seriously because of the existing perception of them being ‘less trained’. In general, it takes a lot of effort and work for the ANMs to gain the trust of the family.

Furthermore, the nursing academics highlighted that the tertiary care units most often receive pregnant women with high risk conditions without proper history and documents from the referred health centers. This leads to lost time in offering specific care. This is especially pertinent because by the time women reach these facilities they are often in an emergency situation and experiencing complications. The cause is rooted in the distributed nature of pregnancy care as it shifts back and forth from the home, to private clinics, to private diagnostic labs, and the public health infrastructure.

The Important Role of Physical & Digital Infrastructures

Both physical and digital infrastructures influence pregnancy care in multiple ways. Distance from the clinic and community or tertiary hospitals is one of the biggest

influencers of pregnancy care, in particular the more periodic care offered by the ANMs. The ANMs we met discussed how they have to cover a distance ranging from 2 to 10 kilometres during their home visits, and mostly do it through walking to save money, while carrying heavy boxes of informative materials and vaccine storage boxes. This physical labour influences their ability to counsel the community including pregnant women and their families as they often end up at their homes tired. It is a similar case with the HNs and their work. While the semi-urban HNs did not have much distance to travel, the rural HNs travelled for a distance ranging from 2 to 15 kilometres. To address this challenge, MAYA is now offering them bicycles and scooters as mode of transport through a co-ownership model.

Living spaces was another form of physical infrastructure that shaped pregnancy care. Most of the urban families live in very small spaces, densely laid out and populated. For example, the HNs described how sometimes a family of four lived in a 50-squaremeters home, as they wanted a separate home than the in-laws, but yet wanted to live in proximity to their extended family. One of the implications of this was that these homes do not have much space for counselling, and the HNs and ANMs have to do group counselling in a larger house in the neighbourhood. While group counselling and sharing is nurturing, some of the sensitive issues (related to sexual and reproductive health, for example) are not shared and discussed due to perceived notions of privacy and shame associated with such topics.

Digital infrastructure is an emerging influencer of pregnancy care. Firstly, the care work by the ANMs is increasingly about data collection and digitalization of the data for monitoring at the district and state levels. The ANMs use the physical mother’s card (Thayi Card²), that has a unique identity number of the pregnant woman, and all the details are captured, including the counselling done, vaccination, iron and folic acid supplements prescribed, tests recommended, and post birth tracking of vaccines and immunization. When the ANMs go back to the sub-center after the visits, a data entry operator enters the data from the pages and uploads it to a central server. The ANMs do have access to this data, but through a rigid and rather unusable web-based interface.

Secondly, cell phones and smartphones have increasingly pervaded the Indian families (India has about 530 million smartphone users³). The ANMs send text messages, about reminders for tests, vaccines, counselling about generic nutrition and other practices, government schemes, etc., to the phones of the pregnant women registered on the Mother’s card. However, the challenge here is the skewed ownership of cell phones, as in India 114 million more men than women have cell phones⁴. During the discussion, ANMs did mention

¹ http://www.karnataka.gov.in/hfw/nhm/pages/maternal_health.aspx

² <https://unicefstories.files.wordpress.com/2014/02/12-mcts.pdf>

³ <https://indianexpress.com/article/technology/india-set-to-have-530-million-smartphone-users-in-2018-study-4893159/>

⁴ <https://www.wsj.com/articles/why-the-vast-majority-of-women-in-india-will-never-own-a-smartphone-1476351001>

that most of the registered phone numbers belong to the husbands. The woman is therefore dependent on the husband to convey the messages they receive to their pregnant wives.

Another aspect of smartphone ownership is the pervasive use of social media, in particular WhatsApp, which has emerged as an easy way to share information often unverified and sometimes false⁵. One of the ANMs shared how she was threatened by the community members during a vaccination drive alleging mal-intentions, as they believed that vaccines would drive them toward infertility. Here, religious beliefs in combination with open and easily shared, but unverified information, conflicts with the care networks and their work.

CONCLUDING REMARKS

In this paper, we reported our reflections from the three workshops with community stakeholders of pregnancy care in rural and semi-urban India. Based on these reflections we present three areas of further research as follows.

Unpacking the tensions between traditional practices and modern clinical requirements. One of the key insights from all three discussions was that any ICT intervention needs to understand and work with the tension between the traditional ways of pregnancy care, whether they are rooted in religion or cultural practices, and requirements of modern medical care. A way forward is to further understand the specific religious-cultural practices of the communities and collaboratively explore if and how ICT can not only bridge the gap, but leverage the everyday practices to enhance the uptake of medical prescriptions and services of care.

Collaborative design for developing trust, and support coordination across multiple stakeholders. During the discussions, we saw a potential advantage of training and support of the HNs expanding their roles to provide support for pregnancy care in collaboration with ANMs. However, the discussion with the HNs brought forward the challenges of developing trust between the HNs and both the private and public networks. The way forward is to collaboratively explore the role of digital technology to help develop trust across the stakeholders specifically and broadly to facilitate the collaboration and coordination across these networks.

Exploring current and future roles of physical and digital infrastructures in shaping everyday pregnancy care. Based on our reflections, another research path is to unpack and understand the ways everyday physical spaces shape pregnancy care in-depth. Additionally, there is a need to unpack the relationship between social media usage, gender and more equitable access to digital technology, and how pervasiveness of unverified information could possibly be addressed at the community levels. Furthermore, during the analysis post the discussion with the ANMs we speculated on, what if the ANMs had the historic data more readily available during the visit? In particular, tracking data about the mundane aspects of the day-to-day care, such as food

eaten and exercises done, medication adherence, etc. was discussed as valuable to help the HNs and ANMs to contextualise their counselling in more specific ways.

In conclusion, we position the above opportunities for future research as a call for an explicit focus on how everyday practices, routines and activities within and beyond the household of pregnant women shape pregnancy care, and how it can be enhanced through the design of digital technology in low and middle income countries.

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