Beyond Health Literacy: Navigating Boundaries and Relationships During High-risk Pregnancies

Challenges and Opportunities for Digital Health in North-West India

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ABSTRACT

Few studies in HCI4D have examined the lived experiences of women with pregnancy complications. We conducted a qualitative study with 15 pregnant women to gain an in-depth understanding of the context in which pregnancy takes place and everyday experiences living with complications in rural North-West India. To complement our interviews, we conducted six focus groups with three pregnant women, three community health workers and three members of an NGO. Our study reveals insights about the challenges and experiences of the pregnant women with complications while navigating the physical, spatial, social and emotional aspects of antenatal care as part of complex and contradictory structures and settings of their everyday life. We argue that the design of digital health in support of pregnancy care for the Global South must center around supporting the navigational work done by the pregnant women and their families.We summarize research in two areas including an overview of public health strategies and challenges to improve maternal health in India, and digital health in the Global South, with focus on the Indian context.

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CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Empirical studies in HCI.

KEYWORDS

Pregnancy complications, Maternal health, Digital health, Global health, HCI4D, ICT4D, Pregnancy Care

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1 INTRODUCTION

Maternal and neonatal mortality constitute one of the major global health problems that exceptionally affect women and infants in developing countries (LMICs) [74, 87]. The situation is alarming in Southern Asia and Sub-Saharan African countries, with India appearing first in the top-ten list, above Nigeria and Pakistan, with the most stillbirths, maternal and neonatal deaths worldwide [74, 120]. At the beginning of the pregnancy, more than 40% of Indian pregnant women are underweight [24] putting them at high risk to develop anemia [18, 139] and other pregnancy complications such as gestational diabetes [90, 99] and pregnancy-induce hypertensive disorders (preeclampsia) [52, 64]. These complications together with the increasing prevalence of obesity and overweight [69, 118], make the self-care management of Indian pregnant women more challenging. In addition, women's low utilization of maternal and reproductive healthcare services [126, 127] and the exacerbating

socio-cultural and economic inequalities in India [122] are jeopardizing women's health especially in urban slums and rural communities [29, 84]. Despite decades of efforts of the Indian government trying to improve maternal and child health indicators through various schemes increasing maternal surveillance, financial incentives, providing iron and food supplementation and nutrition education [63, 68], malnutrition among pregnant and lactating women is alarmingly high [72, 91, 93] and India is lagging behind in achieving the Sustainable Development Goal (SDG) 3's targets to improve health and wellbeing [124].

Previous research in Human-Computer Interaction (HCI) and Computer Supported Collaborative Work (CSCW) has explored the use of information and communication technologies for health, digital health [146], before, during and after pregnancy [11, 26, 31, 56, 91, 111]. While digital health has explored the needs and lived experiences of pregnancy [43] including managing physical and mental pregnancy complications [15, 34, 50], most research on maternal health has been done in developed countries with few exceptions from HCI for Development (HCI4D) research in LMICs [16, 17, 86, 93, 109, 110, 137]. In India, for example, digital health initiatives have focused on promoting women's health literacy and supporting women's information seeking practices [60, 147] targeting maternal behaviors and supporting data collection, work performance, communication and training of healthcare providers [28, 92, 116, 138]. However, there is limited research understanding women's experiences managing complications in the Global South [16].

In this paper, we report a qualitative study with 15 pregnant women with pregnancy complications combining semi-structured interviews with storytelling and visual activities to investigate women's lived experiences, perceptions and challenges managing pregnancy complications in North-West India. To complement our interviews, we also conducted three focus groups with three pregnant women, two focus groups with three frontline health workers, and one focus group with three members of an NGO to further unpack sociocultural and structural challenges that influence pregnancy care. Our studies highlight key physical, social and emotional challenges influencing women's experiences with pregnancy complications in North-West India. Our work makes multiple contributions to HCI in maternal health with a particular focus on the Global South: First, our findings reveal that digital health should account for the different ways' women get access and make sense of medical procedures, prescriptions and norms across the distributed and fragmented healthcare services and existing resources including governmental schemes. Second, our findings show how socio-cultural practices and traditional belief systems and norms within the community and households about food influence the care of pregnant women, women's agency and the overall pregnancy experience. Third, our findings present women's perceptions and desires for better care and the potential role of household caregivers and the use of technology within these contexts. We argue that the design of digital health in support of pregnancy care for the Global South must go beyond the focus on increasing awareness and health literacy to center around making visible and supporting the navigation of pregnant women and their families across complex settings, relationships and situations.

2 BACKGROUND

2.1 Pregnancy Complications in India: Initiatives and Challenges

According to the World Health Organization [145] around 295,000 women died from causes related to pregnancy and childbirth around the world, 94% of these occurred in low and middle-income countries [145]. Complications during pregnancy or within 42 days after birth are the major contributors to poor maternal outcomes including severe hemorrhage, maternal infections as well as other non-communicable diseases such as diabetes and anemia [145]. In India, the double and triple burden of malnutrition (undernutrition, overnutrition, and micronutrient deficiencies) are challenging the health of adolescents, women and their infants throughout the life course in urban and rural areas, increasing the risk of diet-related non-communicable diseases and pregnancy complications before, during and after birth [30, 69, 88, 118]. For example, anemia in India is a silent killer that accounts for 80% of maternal deaths in South Asia [97]. Iron deficiency is the major cause of anemia; however, it can also result from other nutritional deficiencies (e.g., folate, Zinc, vitamins A and B12), parasitic infections, acute and chronic inflammation and other disorders that affect hemoglobin synthesis [97, 144]. Nutritional-related anemias are often caused by strict vegetarian and iron poor diets, short interpregnancy intervals, lactation, chronic blood loss during menstrual periods or pregnancy, malabsorption of iron, etc. [6, 97]. If untreated it can have detrimental consequences such as perinatal, neonatal and maternal mortality and mild mental retardation for the baby [97, 132, 141]. In addition, women's nutritional deprivation in early life increases the susceptibility for overweight and obesity in later life [35]. Obesity increases the risk of complications such as pregnancy-induced hypertensive disorders, gestational diabetes, stillbirth, cesarean, preterm deliveries, low birth weight, and etc. [27, 41, 69, 99].

The Indian government has recognized the need to improve maternal and child health through its National Health Mission by launching a number of public health initiatives including the reproductive, maternal, newborn child and adolescents health (RMNCH+A) strategy to enhance health coverage and increasing maternal surveillance and pregnancy monitoring using the government issued mother and child protection card (Thayi card) [72, 119, 142]. Additional strategies included nutritional prophylaxis programmes (iron and folic acid supplementation) [80, 97] and various governmental schemes such as Janani Suraksha Yojna [68, 76, 81, 113] and Pradhana Manthri Matritva Yojana [63, 128]. These schemes aim to support maternal health by introducing frontline health workers (called Accredited Social Health Activists) to encourage women to use antenatal and postnatal care services and seek institutional delivery [68], providing supplementary nutritional services (take home ration) and nutritional education at the Anganwadi centers [143]. Although these initiatives have proven to be slightly effective in reducing anemia and has increased the use of antenatal care and the number of institutional deliveries in various Indian states [45, 76, 81, 97, 113], no significant changes have been reported. The prevalence of anemia among women of reproductive age (15-49 years old) has only decreased from 53.2% in 2005 to 51.4% in 2016 [39] and the maternal mortality rate (MMR) in India is still quite high (174 deaths/100,000 live births) [83].

There are many challenges that negatively impact the uptake of the governmental schemes. For example, lack of adherence to iron supplements is a major concern due to the acrid smell, bad taste, and additional side effects (e.g., cramps, diarrhea, constipation) [97, 125]. In addition, sociocultural practices and norms ("fat" as a sign of beauty), food habits and community beliefs (e.g., too much iron may cause a difficult birth or a large baby or the use of ghee as "healthy") play a major role influencing the uptake of public health strategies [18, 42, 69, 80, 125, 133]. Practices such as serving men food first or "eating last" or "eating whatever is leftover" can lead to women not getting enough food [42], putting them and their unborn infants at risk of malnutrition (e.g., low birth weight) [24] and other pregnancy complications [24, 84, 90]. Sedentary lifestyle behaviors, imbalanced diets and frequent snack (e.g., sweets, fats) foods are also contributors to obesity and overweight in adolescents and women [23, 69, 133]. Also, women do not seek help until symptoms become severe or they might be discouraged to go the doctor by husbands or family members [42].

Existing healthcare infrastructure inequalities including the lack of physical and human resources and the fragmented and distributed nature of healthcare services also challenge the implementation of governmental schemes [10, 57, 68, 104, 117, 123]. In addition, everyday environmental factors such as unhygienic housing, poor sanitation practices (e.g., open defecation and lack of toilets) and indoor air pollution from cooking and space heating practices also increase the risks of anemia, gestational hypertension and preeclampsia [1, 61, 95, 103]. Women living in complex socio-cultural and economic circumstances from rural and urban areas are amongst those who are particularly at risk of poor access and uptake of antenatal care services, lack of social and healthcare professional support and serious complications during pregnancy [2, 44, 62, 65, 68, 126]. Although community-based (health education, financial incentives, home visits) and lifestyle (exercise, diet, yoga) interventions have shown their potential in increasing the uptake of antenatal care [68, 143], birth preparedness [71], preventing gestational weight gain [106, 107] and pregnancy-induced hypertensive complications [114] in Indian pregnant women, there is still limited evidence on the long-term effects to reduce adverse outcomes [85, 102, 108]. Thus, providing supplementation, making nutritious food available or providing health education are not sufficient for impacting nutrition and maternal outcomes [46, 68, 143].

2.2 Digital Health Strategies for Maternal Health in the Global South

The digital transformation in healthcare is opening up several opportunities for supporting citizens and healthcare providers [146] to for example enhance maternal health by promoting healthy behaviors and mental health during pregnancy through technology in developed countries [8, 15, 33, 34]. However, there is still limited evidence on the impact of technology-supported interventions in reducing the risk of poor maternal outcomes in both developed and developing countries [5, 101]. Previous work on digital health in LMIC contexts has explored the potential use of mobile and digital technologies to enhance maternal health by tracking pregnancies, enhancing communication, supporting data collection and serving as educational tool for the provision of care services [5, 94, 109, 136]. In South Africa (SA), a study has explored how women use pregnancy-related applications as information sources to support their information seeking practices [94]. Similarly, mobile phone text messages are providing women with pregnancy-related information (e.g., diet advice, warning signs, fetus development, reminders, etc.) depending on the stage of the pregnancy across five SA provinces [129]. In addition, an antenatal care system has been implemented to help nurses to perform risk assessments, make referrals, schedule interventions and improve the compliance to maternal care guidelines [55]. In Lebanon, community radio shows have been explored to enable refugee women to get access to antenatal care services through telephone conversations [136]. In Kenya, a hybrid computer-human SMS system has been implemented to engage pregnant women in health-related conversations with healthcare providers [109] and semi-automated bidirectional messages have been used to engage women and their partners in family planning conversations [110]. In Ghana, electronic fetal monitoring including cardiotocography has been introduced to the hospital setting to improve birth outcomes among women with preeclampsia [75]. In Pakistan, informational messages (e.g., follow-up visits, adherence to iron and calcium supplementation, tests, diet advice, delivery preparation, high risk indications, etc.) have been provided to women by SMS and automated voice calls [16].

In India, the governmental pregnancy registration initiative has implemented the mother-and-child tracking system (MCTS) that gathers information from the Thayi card (antennal registration booklet, also referred as Mamta Card in Hindi speaking states) to monitor and store pregnancy information and events, ensure accountability, and receive reminders for both health workers and pregnant women [72]. Mobile phones are also facilitating access to information and services to both women and frontline health workers to get assistant, advice, and reminders from frontline health workers in case of emergency, where to get medications, antenatal visits, lab tests and family planning [92]. Text messages are used to promote maternal health initiatives [116] and support lifestyle interventions (dietary advice) [106], video-based health education material to engage women in dialogue [115, 140] and an interactive radio-show to enable sharing experiences with others [66]. Digital health is enabling healthcare professionals to remotely monitor pregnant women, analyze their progress, get motivation and training support to improve their performance [115, 138], support the communication between frontline health workers about delivery and birth, send reminders to co-workers, make referrals, call mothers and ambulances services, and send SMS to the MCTS system [92].

Most of these maternal health interventions in the Global South (technologically supported or not) have been implemented to promote society and global health ideals of maternal behaviors, overlooking women's experiences living with complications and the sociocultural and environmental contexts where pregnancy takes place [3, 38, 54]. Digital health has mostly focused on the communication and data collection needs of frontline health workers and on providing access to information and health education to women expecting them to take informed decisions [67]. However, most of these interventions have overlooked the wider context including

the situated network of community actors and power dynamics, sociocultural (family structures, traditions, norms, beliefs), material and spatial aspects of everyday settings and health infrastructures that influence women's experience before, during and after pregnancy, limiting the effect of existing strategies [68, 98, 143]. Digital health for the Global South needs to get an in-depth understanding of the everyday context, infrastructures of care, and women's lived experiences to design sociocultural contextualized interventions to enhance maternal health beyond focusing on health literacy.

3 METHODS

Our study was situated in an interpretivist paradigm taking a practice-oriented research approach [19, 25, 37] and aligned to the more-than-human approach to digital health [79] seeking to investigate the sociocultural practices, material and spatial elements that influence the everyday experiences of women with pregnancy complications rather than viewing pregnancy complications as a result of women's individual behaviors.

3.1 Research Context.

Our study took place in Kuraj, a village located in the Railmagra block of the Rajsamand district of Rajasthan state in northwestern side of India. Kuraj is located 266.2 Km away from the city of Jaipur (the state's capital city) and around 96 Km from the city of Udaipur. Kuraj village is well connected by public bus transport. The healthcare services in Rajasthan are conformed by a network of sub-health centres (SHCs), primary health centres (PHCs), and community health centres (CHCs) [9]. In total the Rajsamand district has 38 PHCs [96], 5 of these located in the Railmagra block and one of these is located in Kuraj, which is the most preferable primary health center, called "Adarsha [ideal]" PHC and covers other five villages in this area including Khandel, Lapsya, Junda, Jitacas, Bamaniya kala.

3.2 Participant Recruitment

Participant recruitment was facilitated by a collaborator, Jatan Sansthan, a grassroots Indian non-governmental organization (NGO) working with rural and resource poor communities located in the state of Rajasthan [59]. Jatan Sansthan's grassroots workers work closely with the local self-government (named Panchayati raj) of villages in rural India and its local task force that consists of frontline health workers (ASHA and Anganwadi workers) of the locality. Hence Jatan Sansthan has a close and trusted connection developed over the years working on local issues of the villages by empowering a dialogue between the women of the villages and the taskforce of the Panchayati raj. The study received ethical approvals from the Srishti Institute of Art, Design, and Technology (India) and the University of Leicester (UK).

Before recruitment began, we met with 6 community health workers through a Jatan's grassroots worker. These community health workers covered three different Anganwadi centers (named Kendras) in Kuraj and connected us to the families of pregnant women experiencing pregnancy complications. Jatan Sansthan's grassroots worker accompanied us to women's homes to make the first introduction, explained the purpose of the study, provided the information sheet, gathered the informed consent and helped us respond questions if any. We recruited 15 women who were more than 28 weeks pregnant at the time of the household's interviews. All women were over 18 years old, experiencing some sort of pregnancy complications and in particular anemia that means that women's hemoglobin (Hb) levels were below 11gm/dl [97]. Participants were all housewives with an average of 10th grade education. Each participant was given a code denoted as KXPWY, where X is the number (1-3) of the Anganwadi Kendra and Y the number given to each pregnant woman. While the experiences of pregnant women are deeply situated in the particular social and cultural circumstances, even as our findings show, in the project we focus explicitly on capturing this from the perspective of the pregnant women. Inclusion of mothers and mother-in-law and husbands as explicit participants was not in the scope of this project but is planned as future work.

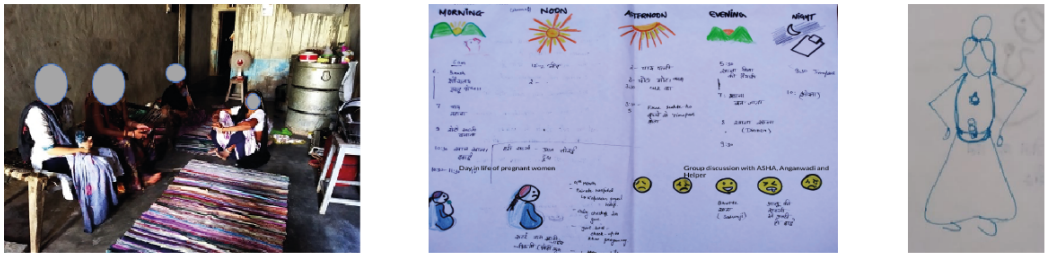
We also conducted six focus groups with three frontline health workers, three Jatan grassroots workers, and pregnant women. All interviews and focus groups were conducted in Hindi. Although we were prepared to compensate participants appreciating their time and efforts [73], after discussing with Jatan's workers about the local culture and customs we followed their advice as they considered it inappropriate for the area.

3.3 Data Collection and Data Analysis

The study took place between July to September 2019 and we conducted two phases.

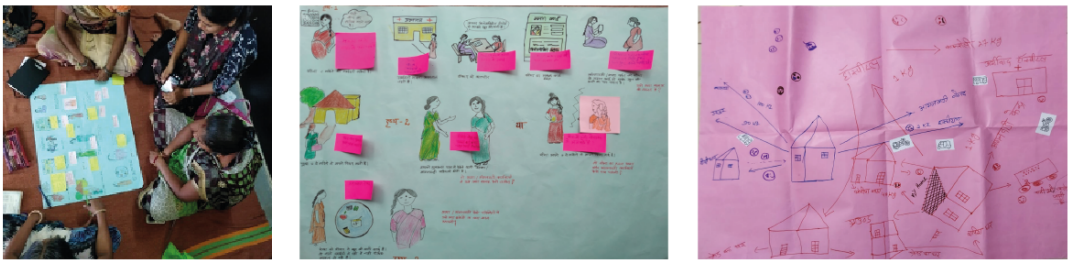
3.3.1 Interviews and Visual Methods. We conducted semi-structured interviews in pregnant women's home, see Figure 1 (a), combined with visual methods not only to make it more interactive but also to help capturing the lived experiences characterized by complex conditions when language and words are not enough [22]. In addition, visual methods can favor women with low literacy skills, providing a depth understanding of participant's pregnancy experiences [82]. Embracing interviews as interactions [21], we performed a day in life storytelling activity to help pregnant women to visualize their everyday embodied experiences [36] with pregnancy complications. Figure 1 (b) illustrates the layout of the activity focusing on women's daily routines (morning, noon, afternoon, evening and night –top of Figure 1 (b), feelings around their pregnancy (happy, sad, worried, etc.)—bottom right of Figure 1 (b), and traditions and beliefs during pregnancy—bottom left of Figure 1 (b). This was followed by an activity where the pregnant women indicated the level of awareness of her body parts such as stomach, uterus, and heart on a silhouette drawn by the researchers, see Figure 1 (c).

3.3.2 Focus groups activities. To follow up on the interviews and further unpack sociocultural and structural challenges that influence pregnancy care experiences, we additionally conducted six focus groups with frontline health workers, pregnant women and Jatan's grassroots workers. In contrast to the visual activity during the interviews, in the focus groups we facilitated the participants to collaboratively engage on visual activities and we used the resulting visual representations to foster discussion within the groups. Two focus groups with frontline health workers aimed to explore frontline health workers' role in women's pregnancy journey through



(a) (b) (c)

Figure 1: (a) A pregnant woman's home, (b) a day in life visual activity, (c) identifying body parts activity.



(a) (b) (c)

Figure 2: (a) A focus group with frontline health workers at the Anganwadi, (b) a storyboard annotated by frontline health workers, (c) a map of the physical, social, and emotional aspects of pregnancy care by women.

storyboarding with different scenarios constructed from the previous interviews, see Figure 2 (b). For example, a scenario explored the following: "If a pregnant woman went to her mother's place in the 7th month of pregnancy then how frontline health workers will be able to help the pregnant woman". For every scenario, participants write comments on post-its and discuss their thoughts and concerns. These focus groups took place at two different Kendras (1 and 3) and lasted for one hour considering participants' time availability. Each focus group included an ASHA (AW), an Anganwadi worker (AWW) and an ASW helper (known as Sahyogini helper), see Figure 2 (a). We assigned a number for each of the participants.

To further investigate and confirm the social structures both in public and private spaces of pregnancy, we conducted three focus groups with pregnant women to map their social navigation across public and private spaces (e.g., farm, public and private health services, vegetable markers, friends, mother's place, Anganwadi center, etc.) and lasted an hour in average. Participants were encouraged to create a map, see Figure 2 (c) freely and by the end of the discussions they also got the opportunity to edit or remove anything they would like to change. The first focus group took place at the Anganwadi Kendra (#1) taking advantage of the "tikakaran" day where women visit the Kendra to get vaccinations during pregnancy. The remaining focus groups took place at pregnant women's homes with participants who know each other and were either friends or relatives to execute the mapping activities. The second focus group happened in one of the interview participant families. Two sisters, one in her last months of pregnancy and one recent nursing mother who just came back from the hospital and one of her sisters in law (their brother's wife) that was in her 5th month of her pregnancy. All of them discussed the pregnancy journey of the women who just delivered and experienced Anemia in pregnancy. The third focus group took place in a pregnant woman's house and included four participants. Two pregnant women who were friends and had moved to their mother's house for the delivery, and two participants who were their sisters-in-law who were mothers but not pregnant during the activity. In particular, the sisters in law shared their pregnancy experiences that helped to enact participation and discussion among the pregnant women. The last focus group included three members of the Jatan's team (JT) who had worked in the field on similar issues related to women's and child health and took place at the Jatan's office in Railmagra. We discussed and validated early findings and got their perspectives on food beliefs and cultural aspects about "bashfulness and shyness" among pregnant women. Validating our observations and interpretations with Jatan's team was informally performed throughout the project, as the researchers were staying with one of the field members and had dinner discussions about the research findings. Furthermore Dr Murthy from JT, who has been working with the communities in the area for three decades visited the site and conducted a debriefing and feedback session mid-way during the project.

3.3.3 Observations: Visits to the Anganwadi's Kendras and the PHC in Kuraj. During the interviews and focus groups, we also did observations of the three Anganwadi Kendras in Kuraj which are located approximately 2Km apart from each other looking at their physical infrastructures, routines and interactions between women and community health workers. The Anganwadi Kendras were open from 8am to 12:30pm. The Anganwadi worker and the Sahayika helper

arrive to the Kendras in the morning to clean up the space. During the morning, kids arrived at the Kendra, prayers and exercises are performed under the Anganwadi's instructions. The ASHA worker also reaches the Kendra and while the Sahayika helper serves food to the kids, the ASHA and Anganwadi worker fill in and maintain registers (mostly copying information from one register to another). In addition, we visited the only primary health centre (PHC) of village Kuraj that is situated at the outskirts of the city. The campus is quite big, and it has a huge compound where the ambulance and vehicles can be parked. There is one Medical officer (MO) assigned to the PHC who takes care of all the cases. The hospital is well ventilated and there is a separate segment within the hospital with a ward and a labor room dedicated for maternity care and childbirth.

3.3.4 Data Analysis. Data analysis was conducted concurrently with emerging themes being explored in subsequent interviews and focus groups. The visual representations generated throughout the activities were used as tools to not only to enact discussions but were also used to support the analysis. All audio recordings from interviews and focus groups were transcribed in Hindi and thematically analyzed [20]. We started the analysis by first checking the visual representations to help us guide our first round of analysis and then reading the transcripts and labeling concepts and themes as they develop. The generated visual representations were also used for clarifications. Examples of initial codes include desires and feelings, food practices, decision making, healthcare access, technology use, and distances and modes of travel. Codes were refined iteratively relating and joining codes into themes and the most prominent findings are below.

4 FINDINGS

Our findings provided rich insights on the challenges and experiences of the pregnant women navigating: a) community perceptions, relationships and norms while accessing the distributed antenatal care services, and b) the sociocultural norms, beliefs, practices and information about food and care of pregnant bodies at home.

4.1 Navigating Community Perceptions, Relationships and Norms While Accessing Distributed Antenatal Care

Many patients experience navigational challenges while accessing and using healthcare services [4, 51] that often requires navigational assistance [47, 58, 130]. This navigation work [32] outside the hospital setting includes seeking and integrating knowledge, making decisions, encountering and repairing breakdowns [51], mobilization of practical resources (e.g., transport) and making arrangements to integrate it into everyday life [32, 40, 48]. In India, this navigation work becomes even more complex in the presence of fragmented and distributed healthcare systems [10, 57]. For instance, pregnant women have to travel long distances ranging from a couple of kilometers to 90 Km to get access to healthcare services periodically during pregnancy and birth. Throughout the pregnancy journey participants visit the PHC or a private clinic for monthly camps for high-risk pregnant women, visit either private or public hospitals for testing and sonography in Railmagra (about 7 Km away) or in Kankorli (about 30 Km away) or in Udaipur (90 Km away). Our study shows how women's experiences and navigational efforts are shaped by a range of interconnected aspects beyond distances between healthcare providers and the home and means of transport to also consider who they travel with, practices related to the management of complications, socio-cultural beliefs and norms, past experiences of self, family and friends, and their own expectations for care.

4.1.1 Navigating Culturally Imbibed Sense of Bashfulness and Disclosure in Public. The pregnancy journey for most of our participants began when they missed their periods for a month or two, tested at home with off-the-shelf pregnancy-test kits, and then visited the nearest PHC to get their pregnancy confirmed. It is interesting to note that almost all of the pregnant women first visited a doctor either at the PHC or a private clinic to get their pregnancy confirmed rather than going to the Anganwadi center, which is very close to their home and is intended to be the immediate point of care. Participants visited the Anganwadi Kendras for the first time in most cases when the doctor suggested to register on the MCTS for the Mamta Card. In many interviews the perceptions of one's self by others emerged, especially with older men and women, and was linked to feelings of *sharam*, a combination of shyness and bashfulness. We found that this was not an individual trait, but a sort of a cultural norm that was ingrained in the behaviors of the pregnant women and the social hierarchy within the community, and beyond the inherently patriarchal family structure [70]. For example, a participant (K1PW8) commented that when she missed her period for the first month, she used the home-test to confirm and went to the PHC with her husband. She did not go to the Anganwadi center, as she mentioned, "*sharam ati hein* [I get bashful]" to let the Anganwadi workers know that she became pregnant. This participant (K1PW8) got married at the age of 13 and had her first child when she was 16-year-old and was 8 months pregnant with her second child at the age of 19. Her lower level of education and getting married at a young age may have contributed to the developing the sense of bashful and embarrassment in sharing the news about pregnancy in public. However, it does not explain the case of another participant, (K2PW1), who got married at the age of 21. She was five months pregnant with her second child at the age of 32 (first child was 8 years). She kept her pregnancy as a secret from her extended family and relatives. Only her immediate family knew and the close friends around the neighborhood.

More importantly, the social risks (being chided or stigmatized) from the environment arising from feelings of bashfulness influenced the access to healthcare services and exacerbate the clinical risks. A pregnant woman (K3PW1) hesitated to use the free public ambulance service while going to hospitals, even during major complications (e.g., bleeding) as she felt shy due to the social stigma attached to being at the center of the neighborhood's attention. Our observation was validated by a frontline health worker (AWW1) who expressed, "*Pregnant women do not call for ambulance services as they know that people around will become aware that something is wrong with them when the ambulance arrives with its lights and sirens*".

4.1.2 The role of Husbands as Caregivers and the Unintended Consequences. In contrast to other patriarchal societies [93, 137], participants in our study were far more comfortable to disclose their

missed periods and suspicion of pregnancy to their husbands, who then shared the news to their close family after the medical confirmation. A participant (K1PW1) mentioned, "*unse kya sharmana?* [why should I be shy with him?] *I tell him everything*". Another participant (K3PW1) recalled how when they came back from the PHC with the confirmed pregnancy, it was her husband who called her mother on the phone to break the news. Such cultural settings [110, 115], where a pregnant woman is more comfortable in sharing the possibility of her pregnancy with her husband than with her mother, enables an active role of the husband in the care of the pregnant woman. For example, a participant's (K2PW1) husband helped her to read the reports and monitor her hemoglobin levels. In the case of another participant (K3PW1), her husband took care of their joint family when she had to be hospitalized for blood transfusion in the 4th month of her pregnancy. We also found that almost all women visited clinics (whether the PHC, the Community Health Center or private clinics in Kankorli, Railmagra, or Udaipur) with their husbands. For example, every 15 days an anemic participant (K2PW1) goes to a private clinic in Kankorli for checkups with her husband by motorbike. As she mentioned, "*the doctor told us not to travel by motorbike, but my husband rides it very slowly, so it's okay*". Another participant (K3PW1) shared that she went to the monthly camp for high-risk pregnancies at the PHC with her husband on a 10-minute motorbike ride. Aligned with [32, 40], mobility, transport and the flexibility and support of husbands influenced the attendance of periodic checkups. However, husbands did not enter the consultation, "*only I go inside* [to the consultation room]" (K1PW4).

Women's dependence on husbands can bring unintended consequences that might delay access to antenatal care or even increase the clinical risk. In addition, time constraints and phone availability can also impact the navigational practices of pregnant women. For example, a participant (K2PW4) stated that she always preferred to go with her husband to the hospital for regular checkups, and if her husband would not be available then she would wait for him. Another participant (K2PW1) mentioned how she prefers to visit the clinic for checkups on Sundays as her husband is available only on that day, and only he can book the doctor's appointments over the phone. But this overt dependency to wait for husbands led to breakdowns in antenatal care. For example, a participant (K1PW3) did not visit the hospital for the fifth month sonography as her husband was busy. Another participant (K2PW1) did not visit the PHC during the 3rd month of pregnancy because her husband could not find time and could not get her blood pressure and hemoglobin levels checked. During the 4th month's visit, she was diagnosed with low hemoglobin levels increasing the clinical risk.

4.1.3 Previous Experiences and Emotional Distress Navigating the Healthcare System. Previous research in Lebanon has reported both positive and negative experiences of women navigating antenatal care services [137]. In our study, a participant (K3PW1)'s case highlights how previous experiences influence women's navigation through the healthcare system. This participant was 21-year-old and was in the 6th month of her first pregnancy during the interview. She got married when she was 15 years old. Since then she has been living with her husband, his elder brother who is separated from his wife, and a widower father. She is mildly anemic, with her Hb level at 8. In the fourth month of pregnancy she started bleeding. She and her husband went to the PHC and to the community health center in Kankorli, where she had to undergo blood transfusion, one pint per week for four weeks. As explained above, her husband took her to the hospital every week on the motorbike and did domestic chores at home, as she was very weak and could not move much. Now, the couple visits the PHC monthly for the high-risk pregnancy camp and her Hb levels have improved. Due to this experience, her fear of blood and needles has increased, and she gets anxious at the hospital, "*I don't feel like going, I am very scared. I have to close my eyes every time they draw my blood*".

Fear and anxiety related to blood or mistreatment or too many people around, mostly rooted in bad prior experiences, influenced some pregnant women to choose private clinics in Kankorli, and even in Udaipur, which is 90 Km away, despite the practical troubles to periodically visit the clinics. For instance, a participant (K1PW5), did not have a good experience when she sought relief from symptoms due to anemia "*I had visited the government hospital* [CHC at Kankorli] *once but the pain did not go away so now I visit a private hospital*". This private clinic is in Udaipur, which she visited once a month, and twice if she felt very weak or her back-pain returned. She and her husband take the bus, which take up an entire day. Similarly, some participants (K2PW2 and K1PW1) trust private doctors and facilities because they had good experiences in previous pregnancies. Participant (K1PW1) was living in Udaipur during the first two pregnancies, the first of which ended in a miscarriage. She liked the care provided by the private clinic, and now in her third pregnancy she has moved to a village, and yet she visits the Udaipur clinic to help manage complications due to anemia. However, she missed her monthly visits in the early part of second trimester and her Hb levels dropped severely. In the 6th month she started bleeding and had to be hospitalized in Udaipur for blood transfusion. The doctor mentioned that her Hb level was 7 and asked her, "*Why did you miss the visits in between?*" K1PW1 told us she was scared and could not sleep properly at night due to her anxiety.

In contrast to previous research [93, 135], our study shows how a woman can for example visit the local PHC alone and the private clinic in Kankorli periodically with her husband by motorbike as in the case of a participant (K1PW7) who experienced mild anemia (Hb levels ~ 8). While she did not find any difference between public and private services as she trusted doctors, her family insisted that she access the private clinic and comply with prescribed medication. Family members believe that her previous miscarriage was a result of bad quality of care at the PHC, and the private clinic is perceived to have better quality.

4.2 Navigating Sociocultural Practices and Information at Home

Sociocultural practices, norms and information influence the use of antenatal care services in the Global South [60, 93, 105, 115, 137]. In our study, the care management of pregnancy complications is enmeshed and entangled in a range of socio-cultural practices and information outside the clinic. We found that pregnant women as part of caring for themselves, have to navigate across norms, beliefs and practices about food and nourishment, and the body and its care, medical knowledge and know-how about care they access

through multiple channels, increasing the sense of responsibilities they carry as domestic 'care-givers'.

4.2.1 Navigating Food Beliefs and Desires, Norms, Practices, Expectations, and Emotions. Previous research has described the patriarchal family structure and the role of older female relatives and in particular the considerable influence of mothers-in-law in pregnancy care [70, 93, 115]. In our study, we found specific community's beliefs about foods and diet for pregnant women, which have been normalized and passed on over generations. These beliefs and norms were often perpetuated by the older women in the family, and in the neighborhood. The mapping of pregnancy journeys consistently brought forward culturally rooted beliefs, mostly about what food the pregnant women should avoid, in contrast to medical advice to have a balanced diet (eat as much fruit and vegetables) without explicitly avoiding anything. Our study shows the ways pregnant women navigate within these beliefs and the medical advice as part of their self-care.

A common pattern that emerged across the mapping of pregnancy journeys was the belief that pregnant women should not eat food that is '*chiknapan'* which translates to fatty and oily. These are commonly available in potentially nutritious food such as milk, curd, yoghurt, buttermilk, ghee (clarified butter), etc. The common reason justifying this belief was captured by a participant (K2PW4) who expressed, "*the fat in these foods gets settled on the head of the fetus*" However, the mother-in-law of another participant (K1PW4), had a different reason, which she stated while interrupting the interview, "*We used to work a lot when we were pregnant. But nowadays the younger women are weak. They just eat and sleep, and all the fat gets settled down. Hence they should avoid ghee and curds*" This statement reflects how pregnant women are considered as primary domestic workers, performing households chores such as cooking, cleaning, managing food needs of the family and of domesticated animals and of the farm, even when they are dealing with anemia and the related weakness and pain. Pregnant women often perceived such comments given by older women as quite reasonable and adopted them as part of their care, and some of them actively sought the advice of their mother or mother-in-law for food. For example, a participant (K1PW6) shared how she always consulted her mother when she had any doubt about diet. Even if pregnant women are aware that there is a discrepancy in what their doctor advice is (eat everything) and the culturally evolved beliefs around fatty foods they accept ongoing practices at home, without attempting to subvert or push-back. For instance, a participant (K1PW1) mentioned, "*the family says to avoid a few things, and the doctor says eat everything. But ultimately, I have to listen to the family*" Similarly, another participant (K1PW7), whose family appeared to be more open to allow her to decide what to eat, mentioned, "*my family doesn't say much about what to eat and what not to. I mostly listen to what the doctor says. One should take care of one's own health*" However, she also avoided milk, curds, ghee and buttermilk. This shows how food beliefs are not just rooted at home but are more communal, where an entire set of communities come to believe and practice over time.

We observed another interesting tension between food beliefs and medical advice. One of the grassroots workers (JT2) stated, as per her observations, women are less likely to eat red lentils and beetroot because of their color, as local communities associate red color with bad luck. This can be detrimental to the health of pregnant women with anemia, as doctors suggest eating beetroot, pomegranate and apples on daily basis. While the mapping of food habits showed that some women did consume apples and pomegranates, many participants did not consume beetroots, except for a participant (K1PW7), who belonged to another religion. In our interpretation the association of red color to bad luck is aligned to religious beliefs of the community.

Patriarchal practices further influenced food practices as our study shows that usually women eat food after the whole family finishes their meal even during pregnancy. An ASHA worker (AW1) during the focus group session pointed out that pregnant women usually eat last in the family, and if the vegetable and lentils are not left after the family eats, then they just eat pickles with the rotis (flat bread), or eat whatever is left in the kitchen. For pregnant women it is a part of their '*responsibility to the family*', as a caregiver, and they do not push-back this practice overtly. For example, a participant (K3PW2) mentioned, "*it's my duty to feed my husband and child first then only I can eat*". A participant (K2PW1) has to perform all the household chores even when she is weak from bleeding as her mother-in-law is too old and cannot carry out these chores.

The sense of responsibility for caring for the household, was foregrounded clearly when the pregnant women talked about their desires to be at their mother's place during pregnancy but could not go or were planning to delay the relocation due to responsibilities and work at their 'husband's homes'. During the mapping activity, see Figure 2 (c), were women sketched out the places they visit during the months of pregnancy and externalized their emotions while visiting those places, participants put forward happy emotions while marking the path to their mothers' house and said, "*we feel happy visiting mother's house and when coming back we feel sad*". One of the Anganwadi workers (AWW1), mentioned during the focus group session that "*when she* [a pregnant woman] *is at her mother's place she can demand food of her own choice. She doesn't have to feel shy or hesitate to ask for it.*" In contrast to previous research [93, 115], we also observed that both the pregnant woman and the husband and his family prefer that the delivery happens at her mother's place. This is essentially due to the comfort of the woman with her family members and the postnatal care, which is an extra responsibility and cost, and is generally expected to be taken care of by her side of the family. The decision of going to mother's place is generally taken either in the 7th month or the 9th month. The time of going to the mother's place partly depends on a belief that pregnant women should not travel in the 8th month. However, one of the participants (K2PW1) exemplifies the sense of responsibility, "*If I go now* [to her mother's place], *who will do the household chores*" Another woman (K1PW7) showed concerns about her elder son's education if she goes to her mother's place and is waiting for the school vacations.

We also found that pregnant women have to deal with a sense of loneliness. In some cases, pregnant women felt lonely because their husbands had migrated to a town for work. For example, a participant (K2PW1), whose husband is a teacher in Chittor, which is about 85 Km away, commented that her husband only comes home during the weekend. In other cases, there was a tension within the joint family and other family members as they had

separated kitchens. In this case pregnant women miss the company of other women in the family, as in the case of a 7-month pregnant participant (K1PW1). Although she stays in a joint family, due to a dispute in the family, the members are not in good terms with each other. There is no one at home whom she could talk to once her husband leaves to work. To deal with feelings of loneliness, she visits the Anganwadi center daily for 3 hours with her daughter so that she can meet and interact with people. Among other things, being lonely has a direct influence on food habits. For example, a pregnant woman (K3PW1) who is the sole woman in a joint family, is alone during the day as her husband and his brother go to work. Due to patriarchal norms she cannot converse with her father-in-law nor eat food along with him and she eats after he finishes. When asked about what she eats she replied, "*I don't feel like eating when I am alone*."

We also found that the pregnant women tried to change their food habits to accommodate the healthy foods suggested by doctors. For example, three participants (K2PW5, K2PW4 and K2PW2) consumed fresh coconut water regularly and one participant (K2PW2) in fact replaced her daily consumption of milk-tea with coconut water. However, coconut water is not easily available and someone, usually husbands, had to go to Railmagra or Kankorli to get it. A participant (K1PW8) expressed, "*I know I need to drink coconut water, but it's not easily available*" as her husband is a farmer and does not commute much to the town. The lack of availability of some food in the village influenced the desires of some pregnant women for a life in the cities. For example, when a participant (K1PW1) was asked about the food that she craves for, she replied, "*this is a village, there is hardly any choice and variety. It would have been different if I was in a city.*" Another participant (K2PW3) expressed similar desires*, "everything is available in the city, but you do not get many options in the village"* We found such desires expressed by women who had experienced a city life before.

Family planning was another area a pregnant woman navigates across sociocultural norms and expectations from life, sometimes successfully and other times not so much. We found that conceiving very soon after marrying was a social norm, as there is a pressure on women to bear children, and this sometimes led to complications. For example, a participant (K1PW3) was still emotionally suffering from her last miscarriage and was not ready to get pregnant again. She wanted to work for some time but the pressure from her family was to conceive as "*Every married woman has to have a child otherwise people will start questioning her*". In contrast, a participant (K2PW4) who was working as a high-school teacher before marriage and has two boys (aged 9 and 5 years), desired a daughter and became pregnant for the third time, despite her husband not in favor, "*Boys must have a sister. My husband was not ready, but I decided this pregnancy. . . this is my last chance. After this I will go for an* [sterilization] *operation. I wanted to get operated after my second pregnancy, but it was a boy.*" The contrasting examples show how pregnant women navigate the common social norms of having children post marriage, and while some are able to push back and claim their own agency and decision making, aided by factors such as education, employment, as well as an understanding husband, others without such socio-economic supporting factors are not able to do so.

4.2.2 Navigating Multiple Sources of Information, Knowledge and Strategies. Aligned with previous research [60, 78, 93], our study shows how pregnant women engage with multiple sources of information and knowledge related to their pregnancy care. Women have to strategically navigate the tensions and conflicts across the medical information and the community knowledge, traditional norms and beliefs, socio-cultural practices, and also multimedia on digital smartphones.

Pregnant women trusted their mothers, mothers-in-law and other older women and the communal knowledge that has evolved culturally over generations, as discussed before. This also shaped how women understood the changes in their bodies during pregnancy. For example, when a participant (K2PW4) was asked during the interview to point in a silhouette of a pregnant woman, see Figure 1 (c), where the fetus was growing, her mother-in-law answered, pointing it next to the stomach area, and the woman agreed. Their understanding of the body is different from the medical one, misplacing the baby at the stomach rather than the uterus, *bacchadani* in Hindi, which literally means a bag that holds a baby. The already introduced food belief about fatty food is also connected to the understanding of the body, as women believed that fatty food would settle on the head of the fetus making birth more difficult. Another example was participant (K1PW3), who was a mother of two children, who also located the uterus in the same position as the stomach.

However, we found out that such understanding cannot be entirely framed as "lack of awareness" or "lack of knowledge" of pregnant women as presented in previous research [93]. Women were aware of many aspects of their body and its care, in ways that mattered to their everyday care practices. Medical information in their reports was one such aspect. While the majority of the pregnant women did not understand what an Hb level of 7 or 8 meant, they did however understand the body signs and experiences of feeling weak, bleeding and the troubles they and their family had to undergo to get blood transfusions. Some pregnant women in fact took a more active role in reading their reports and understanding the implications of the numbers reported in their periodic tests. For example, a participant (K2PW1) who is educated till the 12th grade reads all her medical reports with the help of her husband. The doctor at the PHC suspected that she had Rubella virus and had performed the "torch test" and had suggested that this could be harmful for the 'baby', increasing her anxieties. She looked at on the Internet through her smartphone and also consulted a private doctor in Udaipur. She understood that there are two values IgM (Immunoglobulin M) and IgG (Immunoglobulin G) and the report showed only IgG values, and she confirmed she was not under any harm. Another participant (K3PW1) who is educated till 9th grade reads all her reports by herself as her husband is not literate. She knows that she should increase her weight and also her Hb levels should not go below 9-10 (it was 8 during the time of the interview) as she has had a bad experience with bleeding in the fourth month of pregnancy.

Besides the understanding of reports and test values, women are also aware of the government schemes for maternal health, in particular the 'poshahar' scheme (nutrition package) from the Anganwadi center. For example, a participant (K2PW2) is aware of all the insurance schemes and its benefits with the help of the ASHA

worker who visited her home for the periodic vaccination in the third month of her pregnancy. Another participant (K1PW7) also mentioned that the ASHA worker visits her diligently and updates her about all the insurance and nutrition schemes, helping her track vaccinations. She avails and consumes the nutrition package provided by the Anganwadi center. However, an Anganwadi worker (AWW1) stated that while the Anganwadi center provides vaccination services, pregnant women often hesitated to visit the center, due to the cultural norms of young married women to be bashful and shy, along with some family's issues constraining women's movements in public. Hence the ASHA and Anganwadi workers have to visit the pregnant women for vaccination, including delivering the nutrition package. In another example, we observed K2PW5 following a unique practice of keeping her iron and other supplements near the water pot to remind her to take them every morning when she goes to drink water.

Pregnant women also developed an understanding of their bodies based on their previous experiences. For example, a participant (K2PW4) who has two children followed her intuition as she can feel her body, "*During my first two pregnancies I did not like onion and garlic, and now I can't have enough of them. Also, now I have morning sickness, unlike the last two ones. So, I feel this time it will be a girl*".

As mentioned above, the Internet was a source of information, and women mentioned using YouTube on Android smartphones to get informed about food, diet and recipes during pregnancy. Aligned with [93], women's access to a smartphone was often mediated by someone else. A participant (K1PW1) accessed the YouTube App on her husband's smartphone after he came back home from work and watched videos about recipes and food for pregnant women. In contrast, another participant (K2PW5) owned her own smartphone but found no time during the day to watch videos or be on social media.

We also found some participants regulating their access to Internet based on previous experiences. A participant (K1PW5) mentioned that she only watches videos for recipes and food, as she is scared to watch videos about pregnancy and birth. Another participant (K2PW3), who is educated till the 6th grade, watched a video about food during pregnancy and how "*it influences the skin color and gender of the baby*". She was confused after watching it and stopped watching videos. She said, "*I once watched a video, it said if you eat so and so, your kid will have darker skin, if you eat so and so the complexion will be fair, and eat this to get twins. . . So it got into my head. After that I stopped watching. Not everything is true on YouTube*" Women developed an ability to decide what information to take or not, as expressed by participant (K2PW4) that watched a video suggesting pregnant women not to eat grapes, "*I am educated, was a government teacher. I can decide what to eat and what not. I just watch* [the videos], *let 'time pass' on it, whenever I get time.*"

5 DISCUSSION AND CONCLUSION

In this section we discuss what our findings mean for the design of digital health in support of antenatal care in the context of pregnancy complications in India and Global South, and broadly for the maternal health.

5.1 Designing Beyond Health Awareness

Previous work on the design of digital health technologies for maternal health in India has mostly focused on providing access to information and services, promoting health literacy and awareness aiming to educate pregnant women and their families, enabling the share of experiences, providing advice and reminders and supporting the work of community health workers home visits [66, 70, 106, 115, 116, 138, 140]. However, our findings point to a need for design initiatives that go beyond the focus on educating and raising awareness, particularly dealing with pregnancy complications and for those who belong to socio-economically marginalized communities. The underlying assumption has been that by raising awareness and educating pregnant women about their bodies, rights, and public health services, digital health is empowering them and enabling them to be more autonomous in making informed decisions, to persuade them to take responsible action about their care [60, 115]. However, aligned with recent important HCI4D research in Bangladesh and Pakistan [93, 135], our findings bring attention to the complexities of living in a patriarchal society, and contradictory ways in which women become aware of different aspects of their care.

Aligned with previous research highlighting women's lack of awareness and knowledge in maternal health [93], we also found participants 'unaware' of other aspects of their care such as the governmental schemes they are entitled to. For example, the same pregnant woman who figured out the difference between IgM and IgG values when tested for Rubella virus, which resulted in taking an informed decision of going to a second opinion, was not aware of the nutrition package she was entitled to and yet followed the traditional beliefs about fatty foods. In addition, some participants could not relate and make sense of the numeric value of the Hb levels and most women were not aware of the biology of the women's body, for example, with respect of where the uterus lies in their body. However, our findings describe how this is not merely a 'lack of awareness' as our participants are acutely aware of aspects that directly shape their pregnancy care based on their lived experiences. For example, women were aware of the weakness and pains in their bodies and its changing nature in an experiential manner, often relying on past experiences of self and of the collective. In addition, some pregnant women were aware of their medical information, used and tracked test reports through a range of means including the Internet or by asking their husbands to help them interpret as well as trying multiple doctor's opinions. We also found out how some pregnant women are in control actively discerning what information to check through smartphone apps such as YouTube. With the help of family as well as their own intuitions, pregnant women could figure out what is okay for them to watch and learn, and what could be potentially harmful and hence avoided. In this case, Digital Health should explore how medical terminology can be presented and visualized [60] and provide collaborative interpretation [7] to help women not only to become aware but to construct their experiential knowledge about their health and their bodies.

As women's behaviors are shaped by socio-cultural and material practices that are embedded into their everyday life, it is important that digital health design interventions carefully consider this embeddedness and experiential knowledge to explore the design

space on how to support pregnant women in their ongoing efforts navigating social relationships, information and advice at different levels and by multiple sources. For example, taking inspiration from the way a pregnant woman (K2PW5) kept her supplements near the drinking water pot, design could explore how to support pregnant women to develop practices of remembering and habit formation [131]. An opportunity could be to design a flexible reminder system that can leverage women's own strategies (spatial, temporal, social, material) and relying on the intimate care network (husband, mother, mother in law) to help them better integrate the supplements into everyday routines. Indeed, our study shows a healthy relationship and an increased involvement of partners in pregnancy care offering great potential for digital health to encourage them [110] to continuously engage in pregnancy care decision-making and support care activities and household's chores beyond driving a motorbike.

We argue that the challenge is not so much to design to inform the pregnant women in better ways, but to help them make sense of the information, which they currently think is not important or relevant for their care and management of complications, as an integral part of their complex and contradicting everyday life. Design should attempt to make the complex connections across information sources and forms—the medical information from the reports, the traditional beliefs, norms and care practices, as well as their own intuitions built over past experiences—more visible for the pregnant women as part of their everyday care practices. As cultural norms are socially transmitted [53], our study revealed that in particular food beliefs can play a role in women's decisions around food practices. Here, digital health can explore how to disentangle these beliefs through cross-cultural participation of multiple community stakeholders to promote healthy eating practices and nutrition during pregnancy by for example enabling the community to craft stories, share memories and construct and reconfigure the community experiential knowledge about eating healthfully [49].

5.2 Navigation as an Expression of Agency

There is a growing body of work within HCI4D [70, 93, 121, 135] that focused on examining the agency of women (or lack of it) particularly in the Global South and within the patriarchal and other socio-cultural and economic structures of marginalization. These studies have reported how women's autonomy and agency are influenced by many different factors impacting women's decision making in pregnancy care.

Agency in healthcare is often defined as the patient's ability to contribute, influence, and decide on treatment that might contribute to a shared decision making [100] and it is often linked to notions of empowerment [13] and autonomy [89]. While autonomy implies independence and enables women to willingly act as they want (e.g., decision-making, freedom of movement and gender role attitude), women's agency is an important constituent of empowerment and socially shaped by the living experiences and circumstances [89]. Indeed, Suchman [134] describes human agency as inevitably tied to a particular context and their specific sociomaterial arrangements. Barad [12] argues that "agency is not an attribute but the ongoing reconfiguring of the world" and brings attention to different forms of (human and non-human) agency as "the enactment of iterative changes to particular practices through the dynamics of intra-activity", so it is "not a thing but a doing" [12]. In contrast to previous studies showing women with little autonomy and lack of agency [93, 135], our study shows how women feel themselves to be autonomous not only by the freedom to move to go alone to do antenatal checks but by also following their desires to for example become pregnant. Some women showed a larger level of control and participation in decision making practices around pregnancy care either by themselves looking at information over the Internet or YouTube or together with their husbands by deciding to relocate to their mother's home. However, some decisions were influenced by extended family and older female relatives in the households. This ongoing navigation across multiple, often conflicting and contradictory aspects (physical, spatial, socio-cultural and emotional) of pregnancy care, can be characterized as an expression of agency iteratively performed by women towards shaping their pregnancy experiences.

In addition, we also found that most pregnant women were seemingly okay with delaying their access to healthcare services taking 'clinical risks' to avoid 'social risks' [14]. They did not avail the free ambulance service due to the fear of social embarrassment and gossip and delayed going to the Anganwadi center to avoid disclosing their pregnancy publicly and not being chided and teased. Women have learnt over time how the public and private spaces shape their pregnancy journeys and built on their innate and intuitive awareness to figure out ways to enhance their care as the case of a pregnant woman (K2PW2) successfully replacing her tea with fresh coconut water. Family dynamics and patriarchal structures [89] also influenced the autonomy and agency of some women who took the responsibility of caregivers, against their own desires to be taken care of at their mother's homes. Women dealt with their loneliness by attending the Anganwadi center or watching videos to minimize emotional distress. Digital health should explore the design of collective interventions to provide social support [112] within their communities and avoid social stigma.

Configuring agency as an ongoing navigation across the multiple, often conflicting and contradictory, structures and circumstances brings attention to the sociocultural, material and infrastructural arrangements embedded in their care: the clinical advice, vaccinations, Hb levels and supplements, frequent tests and travel across towns to manage complications, multiple beliefs and norms socially transmitted by communal and collective wisdom for care at home, and their own desires, expectations, and emotions that are shaped by past experiences, friends and family, and the Internet and YouTube videos. The navigation done by pregnant women is not only a result of their acknowledgement of how both the medical and socio-cultural structures often lie in conflict with each other and with their desires and expectations, but also as actions that showcase their ongoing navigation work in living with, reconfiguring, adapting and finding alignments and adjustments, and making the best of the circumstances to enhance their care. We are not attempting to romanticize and idealize the lives and struggles of our participants, but to highlight the immense amount of physical and emotional work done in such complex navigation. Digital health aimed at supporting pregnant women with complications should center and foreground this navigation work taking a women-centered approach to minimize both the social and clinical risks and

enhance women's wellbeing. Future work should also explore the affective atmospheres [77] and emotions that are generated through this complex navigation across distributed human and non-human actors in pregnancy care settings, and investigate the intended and unintended consequences and forms of agency promoted by digital health practices [13].

One of the limitations of our study is the class and caste positionality of the research team vis-a-vis the communities we engaged in the study. The members of the research team on the Indian side belong to a middle socio-economic class and belong to caste communities that are deemed 'upper' in the socio-cultural hierarchy that pervades India. This position has influenced the framing of the study and our analysis. We have followed the best practices and standards of research including the community in iterative feedback loops to validate the data and its interpretation. Furthermore, we are also working on making the research results available to the communities in a form and language that is appropriate working with Jatan. Given our positionality we could have engaged the communities, particularly the pregnant women more directly throughout the research project, from defining the research questions to publication and engagement with the results and outcomes. We could not do this due to the limitations of funding. As a future step we plan to engage with multiple community stakeholders through our research insights to collaboratively explore if and how digital interventions could be designed to enhance their navigation work on pregnancy care.

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