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# Embodied Negotiations, Practices and Experiences Interacting with Pregnancy Care Infrastructures in South India

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Behavior change and improving health literacy based on normative ideals of motherhood is a dominant paradigm to address maternal health challenges. However, these ideals often remove women's control over their bodies overlooking how the bodily experiences of pregnancy are socially and culturally constructed. We report on 27 interviews with pregnant women and nursing mothers in rural and semi-urban areas of South India, and six focus groups with 23 frontline health workers as secondary data. We explore how the embodied pregnancy experiences are influenced and negotiated by the socio-cultural context and existing care infrastructures. Our findings highlight how the ways of seeing, knowing, and caring for a body of a

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pregnant woman through often conflicting norms, beliefs and practices of medicine, nourishment and care actively shape the experiences of pregnancy. We open up a space for novel opportunities for digital health technologies to enhance women's embodied experiences and pregnancy care infrastructures in the Global South.

# CCS CONCEPTS • Human-centered computing • Human computer interaction (HCI) • Empirical studies in HCI

Additional Keywords and Phrases: Maternal health, digital health, pregnancy care, care infrastructures, challenges, embodied experiences, negotiation, HCI4D, South India

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#### **1 INTRODUCTION**

Poor maternal health is one of the major global health challenges that exceptionally affect women and infants in low-and-middle-income (LMIC) countries [117, 135]. It has been estimated that between 1990 and 2015 about 10.7 million women died worldwide due to maternal causes [5]. Major risk factors contributing to maternal and neonatal mortality are young or old maternal age, non-communicable diseases, under and overnutrition, and other pregnancy-related disorders before, during and after birth [51, 117, 169]. In India, for example more than 40% of women are underweight at the beginning of the pregnancy [39], and the prevalence of anemia in women is still high [20, 147, 206], and the prevalence of obesity and overweight is rapidly expanding [107, 166]. Together with additional pregnancy-related complications such as diabetes [140, 148] and pre-eclampsia [44, 136] are severely impacting women's and infant's health and the overall Indian healthcare system. Although a number of public health initiatives for pregnant and nursing mothers exist (e.g., Pradhan Mantri Surakshit, Matritva Abhiyan, Thayi Bhagya, Janani Suraksha Yojana) to improve maternal health in India [38, 128, 147], no significant changes have been reported as the maternal mortality rate is still quite high, 174 female deaths per 100000 live births in 2015 [133]. Unavailability, inadequate, and low utilization of antenatal health services [169, 181], traditional care practices and everyday living spaces [13] together with existing socio-economic inequalities [173], challenge pregnancy care in India [50, 134].

Human-Computer Interaction (HCI) and Computer-Supported Cooperative Work (CSCW) research on maternal health and digital health—the use of information and communication technologies (ICTs) for health [221]—have explored the use of digital health throughout the maternity journey including conception [40, 90, 174], pregnancy [18, 55, 72, 82, 91, 156, 185, 217] and postnatal period [52, 88, 160, 200, 214, 222] with focus on digital motherhood [14, 15, 77, 141, 192]. However, most of this research has been done in developed countries, often reinforcing normative ideals of an efficient, intensive and good motherhood [7, 63, 122, 170], that might alienate women from pregnancy bodily experiences [103, 132, 170]. Although there is a growing interest to understand the lived experiences and challenges women face while interacting with pregnancy care infrastructures in the Global South [12, 143, 196, 213], there is limited understanding of the embodied experiences and negotiations that take place during pregnancy while interacting with the normative ideals of medical care infrastructures [103, 161].

Through a number of workshops with community stakeholders [13], we became aware of the societal structures and challenges faced by women and their caregivers as well as the potential role of physical and digital infrastructures in shaping pregnancy care practices in South India. In this article, we seek to further understand women's embodied experiences of pregnancy, their everyday challenges, their embodied interactions with care infrastructures bringing attention to the physical, social and cultural aspects that influence the embodied caring practices that women undertake during pregnancy. To gain this understanding, we conducted a qualitative study with 27 households in semi-urban and rural areas of South India including women of reproductive age (19 pregnant women, and 8 nursing mothers) and six focus groups with 23 front-line health workers. The findings reported in this paper are derived mostly from the household interviews, while data from focus groups are used to offer additional context to the findings. We take a "care infrastructure" lens [216] to devote attention to its multiple human and non-human assemblages women interact to during pregnancy and while seeking and receiving care and how these shape women's experiences as well as highlight their importance in the design of digital health technologies [125].

Our research makes multiple contributions to HCI, CSCW, and healthcare research. First, we provide a detailed account of the multiple embodied experiences of pregnant women while negotiating pregnancy care infrastructures: knowing about, responding to and nurturing their changing bodies as well as traversing the spatial and socio-cultural dimensions of accessing healthcare facilities. This complements research investigating care infrastructures in practice in the Global South [13, 31, 92, 152, 193] with particular focus on the sociocultural situatedness of pregnancy care practices and how these are influenced by the physical, social, and cultural dimensions of pregnancy care infrastructures [12, 103, 143, 156, 157, 196]. Second, based on our findings, we provide design opportunities to enhance and support women's embodied experiences of pregnancy care as a rich practice situated in diverse and yet fragmented and distributed care infrastructures in the Global South. This adds to a growing body of work within the HCI for Development (HCI4D) community that highlights the importance of understanding the sociocultural practices of the local context to inform the design of digital health technologies for maternal health [108, 143, 150, 205] with particular focus on pregnancy care [12, 98, 196, 213]. Lastly, by contextualizing our findings at the intersection of HCI and women's health, our work contributes to recent calls to get a broader understanding of women's health and wellbeing [103, 110] to design technology to enhance women's health going beyond the ideals of changing women's behaviors [83, 101, 106].

#### 2 RELATED WORK

To situate our work, we consider relevant research in human-computer interaction, social sciences, and public health. We describe the embodied experiences during pregnancy, existing challenges of pregnancy care infrastructures, and digital health technologies that support and shape pregnancy experiences, especially in the Global South.

#### 2.1 Embodied Experiences during Pregnancy: Beyond the Changes in Women's Bodies

Pregnancy is a life-changing experience that can be both exciting and pleasurable as well as physically, emotionally, and socially demanding [7, 156, 157]. The experiences of pregnancy and reproduction are socially and culturally constructed [145] going beyond biological changes in women's bodies [7, 63, 145]. Women's experiences of pregnancy are embodied and negotiated by constantly "learning, adapting and performing" [145] daily practices of care for their bodies and shaped by the sociocultural context [25, 145]. For example,

Neiterman describes pregnant embodiment as a process that involves learning how to be pregnant by reading about it, listening other's advice [145], and listening to their bodies [146]. Women would "repeatedly reconstruct their bodies as pregnant through modified physical activity and consumption" [146] while adjusting what they eat, how much exercise they need to do, what supplements to take as well as avoiding alcohol, sugar, caffeine, smoking and drugs [7, 30, 79, 82, 121, 145]. Making these daily decisions also facilitates personal reflection of their embodied experiences helping women to understand their bodies [146], fostering their embodied knowledge of pregnancy [87]. In contrast, the experience of fathers and other family members (e.g., grandmothers) is disembodied as they do not directly experience body changes or symptoms but they rather acquire this knowledge through other means [58, 87, 184]. For example, body-mediated moments [58] such as touching the women's abdomen to feel the baby's movements and technology-mediated moments [57] using ultrasound scans can provide indirect embodied knowledge (disembodied knowledge) of pregnancy to caregivers [87].

Parents and in particular mothers share not only food but also their mood and social environment [146] developing a strong and intimate relation with their unborn child [122] who is usually perceived as vulnerable and dependent on the mother [122, 126]. Women (and partners) are subjected to increased surveillance not only by medical professionals [7, 170] but also by the media and general public [79, 129, 184] and expected to take responsibility and discipline their pregnant body [7, 126]. As a result, women are increasingly engaging in self-management and monitoring practices [121] not only as an expression of caring and love [120] but also as a way to control and carefully manage their own bodies [121] to ensure 'successful' outcomes [7, 63, 121, 122]. However, the overemphasis on surveillance and monitoring practices is increasingly pushing women and partners into normative ideals of good motherhood and intensive parenting [7, 63, 126, 170] contributing to the "institutionalization of motherhood" and medicalization of pregnancy [87, 170], increasing parental anxiety [63, 121, 122], and social stigma [79, 97, 130, 218]. These ideals treat women as self-conscious, vigilant, and highly reflexive [63], with increased parental accountability and responsibility and believing that more information will help women to make informed decisions [63, 121], even if they do not want to [11, 30, 56]. These ideals render a woman and her body as an important risk factor for the unborn child [121, 122, 126], increasing feelings of guilt [11] and downplaying women's agency, embodied knowledge and removing control over their bodies [80, 87, 132, 170].

The ideal of becoming good and efficient parents [63] also take for granted all the "invisible" [189, 191, 208] work (physical, social, emotional) that women and caregivers do during pregnancy to adjust bodily practices (e.g., morning sickness, fatigue, change in size, posture, sleeping position, etc.) [145] that goes beyond the clinical encounters [11, 82, 84, 96, 127]. For example, Gui and Chen [84] reported the infrastructuring work, as invisible labor, that women and caregivers do to fix infrastructural breakdowns (by checking policies or calling the hospital, etc.) and their efforts to circumvent spatial (lack of equipment in clinics) and temporal (long waiting times) infrastructural constraints to get access to healthcare services. A recent narrative review [127] shows a variety of invisible work parents engage in during pregnancy while seeking advice and searching information from different sources (information work) [32], managing emotions and uncertainties especially during complications (emotion work) [12, 32, 116], operating different self-monitoring devices at home (machine work) [34, 82], and reflecting on their self-care data (interpretative work) [2, 78, 82]. The aforementioned ideals also contribute to the asymmetric power-dynamics in antenatal care with multiple, often conflicting, stakeholders with diverse agendas, perspectives, values, and responsibilities [13, 53] and women's resistance to the offer of

maternity services [127]. Women living in complex socio-economic circumstances are most likely affected by societal expectations, "appropriate" health behaviors, stigma, and discrimination [11, 71, 79, 130].

Turner describes embodiment as "... not a static entity but a series of social processes taking place in the life course. Embodiment is a life process that requires the learning of body techniques such as walking, sitting, dancing, and eating. It is the ensemble of such corporal practices, which produce and give a body its place in everyday life... Embodiment is the mode by which human beings practically engage with and apprehend the world" [207]. Bearing all of this in mind, these ideals exert a powerful influence on women's experiences of pregnancy and it is critical to move away from the objectification of the pregnant body that gradually disembody women from their perspectives, knowledge and embodied experiences [59, 113, 145, 146, 184]. Thus, it is important to further understand the embodied experiences of pregnancy and the sociocultural and material dimensions that shape women's embodied experiences [87, 122, 145, 170] as bodies "cannot be separated from the spaces, objects and other bodies with they interact" [122] and are constantly reconstructed through complex negotiations with oneself and with the sociocultural context [45, 145].

## 2.2 Care Infrastructures and the Sociocultural, and Material Dimensions that Influence Pregnancy Care

Existing infrastructures of care and the materiality of everyday living spaces (home, work, maternity wards, restaurants, etc.) including physical and digital artefacts also influence women's experiences during pregnancy and birth [1, 2, 41, 74, 129]. Star and Ruhleder [188] define an infrastructure as a "fundamentally relational concept, becoming real infrastructure in relation to organized practices" [187, 188] and as "part of human organization" [187] bringing attention to the socio-material arrangements and practices that sustain infrastructures in practice [95, 187]. In healthcare, care infrastructures do not only involve the "structures, functions, and resources required" [183] to provide public and private healthcare services but also all the physical, social and structural arrangements of dynamic human and non-human elements that support and sustain care practices within and across different care settings [92, 152, 193, 212].

HCI and CSCW research in healthcare has used infrastructural inversion [187] and examined the sociotechnical and material arrangements of care infrastructures with particular focus on the hospital setting [24, 67, 190, 198]. At the hospital, the configuration of care infrastructures involves a collection of multiple assembling (human and nonhuman) entities such as people (e.g., clinicians, patients, secretaries, hospital orderlies, etc.), places (within and beyond hospital departments), routines, and physical and digital artefacts (e.g., plans, procedures, standards, schedules, patient record, technologies, etc.) that are temporally and spatially arranged, coordinated and sustained by different visible and less visible work arrangements to support the continuity of patient care [3, 16, 21, 24, 67, 159, 198, 199]. Care infrastructures reaches far beyond the boundaries of the hospital including the home setting accounting for the efforts of people and caregivers in supporting care by dealing with health conditions, adapting healthcare services, and reconfiguring infrastructural breakdowns [1, 26, 84, 104, 197]. At home, care infrastructures also involves the configuration and arrangements of multiple human and non-human entities e.g., people, spaces, physical and digital objects, routines, etc. [43, 114, 216]. Yet there has been limited HCI and CSCW research investigating the existing formal and informal care infrastructures in the Global South [31, 92, 93, 193, 194] especially around pregnancy care [12, 143, 196].

In LMIC settings, pregnancy care is influenced by complex socio-economic circumstances and exacerbating inequalities [64, 65, 173, 175, 177, 196]. Socio-cultural factors such as community beliefs [102, 150, 196], family

structures [196], community power dynamics [111] and societal expectations [79, 130] have a strong effect in pregnancy care and women's health and wellbeing. In India, for example, navigating community perceptions, relationships, beliefs and norms within and beyond the home pose challenges to pregnant women [12]. In particular, the social environment can negatively influence pregnancy care as women often find themselves in subordinate positions [64, 179, 180] and are discouraged to visit the clinic by husbands or family members [70]. severely impacting their agency and autonomy towards their health [22, 64, 177, 179]. Community beliefs and cultural practices such as considering food that "cool the body" as beneficial and food that "produce heat" as harmful or considering the delivery process as "impure" impact women physically and emotionally [70, 102]. Even birth and the immediate postnatal period are influenced by existing beliefs when engaging in unhealthy practices such as unhygienic cord cutting, delayed breastfeeding or early bathing [70, 102]. In addition, the fragmented and distributed nature of healthcare services [13, 182], lack of sanitation [4], low utilization of maternal and reproductive health services [181], lack of adequate physical and human infrastructure, training and resources [4, 144, 165, 172, 182], lack of adequate motivation and incentives for health staff [155] challenge pregnancy care practices and infrastructures [46]. Additional contextual factors that indirectly affect pregnancy care include for example, urbanization, economic situation, existing policies, education, access and use of ICTs [4, 46]. Thus, there is a need to further understand how the sociocultural, material, and institutional dimensions of care infrastructures shape women's embodied experiences during pregnancy going beyond behavioral approaches.

#### 2.3 Digital Health for Pregnancy

The use of information and communication technologies (ICTs) for health or, in other terms digital health, [221] is creating opportunities to support pregnancy care for both women and caregivers by facilitating access to pregnancy-related information [61, 124, 156, 157], giving translation support of care services [185], receiving recommendations, reminders and alarms [96, 219], getting a preview of the baby (e.g., sex, size, etc.) [138], simulating pregnancy experiences (e.g., fetal movement, weight and heartbeat) [105], recreating real life experiences [119], playing with pregnancy and its physical appearance [201]. Digital health technologies are also supporting lifestyle coaching [210], self-monitoring of lifestyle activities and health parameters [42, 82, 217, 219], facilitating self-report of psychological well-being [54, 55], managing nausea and vomiting [118], sharing experiences, concerns, measurements, and promoting self-reflection [2, 61, 82, 91, 219, 224]. Digital health technologies provide help establishing and sustaining social connections [123, 124, 202], receiving and negotiating peer support [9, 85, 176], creating stories to foster self-expression [9], encouraging partners to be attentive and supportive with the expectant mother [203], socializing the unborn baby [96] and enabling disclosure [8, 9]. Digital tools have shown the potential to reach women at risk of pregnancy complications and receiving lower quality of care, in particular the ones living in complex living circumstances [73, 86] by facilitating anonymity, providing additional pathways to receive care as well as information and reassurance through discussion forums, blogs, chatbots and virtual communities [124, 209]. In clinical settings, technology is facilitating alternative ways for storage, communication and monitoring between the home and the hospital [2, 61, 82, 178], providing healthcare professionals with personalized advice and feedback [10, 53], learning of pregnancy and childbirth pathologies [75], enabling video consultations [2], prenatal screening [11] and collection of health data that women could check and "act on" [2, 53, 82].

#### 2.4 Digital Health for Pregnancy in the Global South

In the Global South, digital health technologies are also creating opportunities to support both health providers and pregnant women's care practices [35, 37, 47, 111]. Pregnant women and partners are engaging in healthrelated conversations through personalized SMS in Kenya [153, 154], or engaging with community health workers through health education and feedback using mobile multimedia resources in Lesotho, southern Africa [139]. In Ecuador, research has explored how to support paramedics to register pregnancy information and estimate time of arrival during the women's transport to the hospital through mobile technology [204]. In addition, women have received information in connection to the prevention of transmission of HIV during pregnancy through the website of the VIHDA Foundation in Ecuador [171]. In Pakistan short SMS messages and automatic voice calls have been used to provide reminders and information during and after pregnancy [19]. In addition, videos have been used to support the learning of hypertensive disorders (e.g., causes, diagnosis, management, medication, and emergency referrals) in pregnancy to Pakistani community health workers [94]. In Indonesia, mobile technologies are facilitating communication and better access to medication information to midwifes [35, 36]. In India, mobile phones and videos [98, 108, 211] and interactive radio shows [100] are supporting women's information seeking practices and access to government healthcare facilities [205], giving them the opportunity to share experiences, as well as receiving support from their communities. For instance, pregnant women are using WhatsApp groups to ask questions and discuss health issues with medical practitioners [99]. Community health workers (e.g., accredited social health activists - ASHAs) are also using mobile phones and videos [111] to support postnatal care examinations [66], the registration and monitoring of pregnant women [47], selftracking of household visits through voice-based feedback and web visualizations [48, 49]. Community health workers can timely communicate between them about delivery and birth notifications through mobile phones [142] as well as to SMS [163] and create videos to engage women in dialogue, enhancing their motivation and learning during visits [162].

#### 2.5 Existing Challenges in Maternal Digital Health

While there is a potential for digital health to improve maternal health, existing interventions aimed at pregnant women and their families have mostly focused on investigating and supporting health literacy and informationseeking practices through text and voice messages and video-based health education, and basic visualization. As a result, there are negative consequences of using ICTs as mediation of risk and uncertainty by pregnant women, especially when increasing women's choices [56] or when insufficient or ambiguous information is received [32]. False positive diagnosis through ultrasound [56, 76] as well as wrong information from a Google search given to pregnant women [156], can generate anxiety or stress. In addition, too much information can overload women making them feel "frightened" and "paranoid" [112] and social media can cause stress, discomfort and fear [224]. Mobile apps are promoting norms, social rules and assumptions that provide a gendered stereotyped and patronizing view of pregnancy [96, 201, 219], contributing to disciplining of parents and pushing responsibilities on the women's shoulders [96]. Interestingly the role of partners and other caregivers in pregnancy care has been overlooked [96, 168, 203] with few apps simplifying the role of fathers through the "ludification" of pregnancy [203].

Moreover, these technologies often tend to endorse the normative ideals of 'good' and data-driven parenthood [69, 96, 120, 186] characterizing women's bodies as "a site of risk" that requires close monitoring and surveillance [202]. These technologies are often presented as a tool to discipline the woman's body [89,

202] and expecting them to perform the ideal mother and informed patient roles [186], disregarding the social context and women's embodied experiences during pregnancy [7, 81]. Given the current public health goal to improve maternal health in LMIC countries through technology, it is crucial to understand women's experiences during pregnancy and how their embodied caring practices are negotiated and shaped by the sociocultural context, the normativity ideals and the existing arrangements of care infrastructures in low-resource settings to inform the design of locally situated digital health tools for the Global South.

# **3 A CASE STUDY OF PREGNANCY CARE IN INDIA**

We engaged in an exploratory case study to investigate women's everyday challenges and experiences during pregnancy and the individual and contextual factors that influence pregnancy care in rural and semi-urban areas of South India. A case study approach is well suited for providing an in-depth understanding of real-life contexts, issues and how they unfold in practice [151, 223]. This study is part of a multidisciplinary project entitled Healthy Crossroads in Pregnancy Care (HCPC). We align with recent calls from human-computer interaction [68], practice-based approaches to public health research [23, 101], sociology of health and science and technology studies [89] and take a more-than-human approach to digital health [125], seeking to investigate pregnancy care practices through the socio-technical lens of care infrastructures [114, 216]. As explained above, adopting this lens enabled us to unpack and map the relation between women's experiences and existing care infrastructures by devoting attention to the wider network of actors (human and non-human assemblages) including people (e.g., women, partners, families, health workers, etc.), socio-cultural practices and norms, traditional beliefs as well as temporal (e.g., routines), material (e.g., physical and digital objects), and spatial (e.g., within and beyond the home and care centers) arrangements that influence pregnancy care practices. A care infrastructure lens helped us to shift away from focusing on individual behaviors [101] to take a more ecological [156] and socio-technical approach to pregnancy care bringing attention to multiple human and nonhuman assemblages of care infrastructures and highlighting their importance in the design of digital health interventions [125].

#### 3.1 Research Context

The fieldwork for this project was conducted in rural and semi-urban areas of Channapatna town located in the Ramanagara district of Karnataka state in South India. Channapatna is located around 80 Km away the city of Mysore and 55 Km away from the city of Bangalore, capital city of Karnataka. The district consists of 145 villages [225] and we reached a number of these areas in Channapatna with the help of a local collaborator, MAYA Health<sup>1</sup>. MAYA provides training to micro-entrepreneur women who promote preventive health services in the communities, known as Health Navigators. Three main levels described the public health infrastructure in Karnataka. The primary level of healthcare services is formed by a network of 2346 primary health centres (PHCs), 326 community health centres (CHCs), and 8871 sub-centres (SHCs). The secondary level includes the district hospitals, and the tertiary level includes the medical colleges and specialized hospitals<sup>2</sup>. Additional health programmes and government-supported public health schemes are also provided including reproductive and child health services such as Janani Suraksha Yojana, Madilu, Prasuti Araike<sup>3</sup>. A key aspect of these

<sup>&</sup>lt;sup>1</sup> <u>http://mayahealth.net/</u>

<sup>&</sup>lt;sup>2</sup> https://www.karnataka.com/govt/health/

<sup>&</sup>lt;sup>3</sup> <u>https://www.bankbazaar.com/health-insurance/karnataka-govt-health-schemes-and-programmes.html</u>

services is the Web-based mother and child tracking system (MCTS) that includes the 'Thayi Card', that is a '*comprehensive mother and child registration booklet*' used as a 'person-centered' artifact to document, track and promote care services for pregnant women, and infants [38].

#### 3.2 Participant Recruitment



Figure 1: Discussing and finalizing the recruitment of households for the study with Health Navigators and field coordinators of MAYA

Six (3 from rural and 3 semi-urban areas) of the Health Navigators (HNs) and two field coordinators supported by MAYA, working in Channapatna became a core part of the research team, helping to define the scope of research, recruitment, conducting research and engaging with data analysis and presentation. Over two meetings with the HNs we discussed the research agenda and the exclusion and inclusion criteria and decided that we wanted a wider representation of pregnant women across rural and urban, religion and caste, and varying socio-economic contexts, as this was a scoping study (see Figure 1). The HNs as part of their work serve about 300-400 households within their neighborhood. As part of their regular visits the HNs, who were familiar with baseline survey methods, gathered information from the households (e.g., where there was a pregnant woman or a nursing mother). The information included age, current trimester of pregnancy, type of family (nuclear or joint families), occupation of pregnant woman, partner or family to be able to record the socioeconomic status, geographical location and type of area (rural or semi-urban). The HNs informed the pregnant women from whom this data was collected about the study and took their verbal consent, and their potential interest of a follow-up detailed interview. All the households agreed, mostly as the HNs were very familiar and trusted members of their own communities. We had a pre-recruitment list with 81 households, 69 collected by the HNs and 12 additional households added through word of mouth via the networks of the HNs. We used the information collected to inform the sampling for the interviews aiming for a stratified sample and select representatives across the different spectrum of possibilities. We purposefully [151, 223] decided to keep a spread of 8 households with pregnant women or a nursing mother per locality, giving us a total number of 48 households with a fair spread across religion and socio-economic contexts. We decided to also interview households with nursing mothers as they would have had the complete experience of pregnancy, from

conception to birth, and a retrospective mapping of their pregnancy journey would be very valuable; a point foregrounded by the HNs.

Due to practical limitations (time, resources, long distances, etc.), we managed to conduct 27 household interviews during the summer of 2018, 15 from semi-urban areas and 12 from rural areas. Each participant household was given a code denoted as RxPWy or UxPWy, where R stand for rural village and U stands for a semi-urban locality, *x* is the code of the area and *y* is the number given to each participant (see Table 1). Upon the recommendation of the HNs, we did not compensate participants as it was considered inappropriate [115] as paying the participants would set a precedent and given the scarce funding that the HNs get for their work, they would not be able to meet this demand in subsequent work once it is set. Instead, we utilized the funds to prepare and print information booklets for the communities that the HNs use to educate their communities towards healthier practices. The study received ethical approvals from HCPC project partner's institutional review boards including the Srishti Institute of Art, Design and Technology, Bangalore (India), the University of Leicester and Loughborough University (UK).

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NO.	Area	#Housenoids	Participant Codes
R1	Kenchainadoddi	3	R1PW1-R1PW3
R2	Hunasanahalli	1	R2PW1
R3	Nagapura	2	R3PW1 – R3PW2
R4	SM Halli	4	R4PW1 – R4PW4
R5	SM Dodde	2	R5PW1 – R5PW3ª
U1	Islampura	6	U1PW1 – U1PW6
U2	Jevanpura	3	U2PW1 – U2PW3
U3	St Michael School	1	U3PW1
U4	Kotte	2	U4PW1 – U4PW2
U5	Tamil Colony	3	U5PW1 – U5PW3

<sup>a</sup> Two pregnant women in one household

#### 3.3 Data Collection Methods

Three members from Srishti carried out the 27 semi-structured household interviews accompanied by an HN of a particular selected area, who introduced the research team, joined the conversation as a recorder and a researcher. Each household interview session began with an introduction of the study and the informed consent and lasted for about 45 min to 1 hour. In total, 19 pregnant women and 8 nursing mothers were interviewed. Nursing mothers were asked to reflect on their previous pregnancy experiences. Interviews were aid by visual methods [12, 129] to construct and visualize participants' everyday embodied experiences [60] as they narrated them using sketching and mapping activities: A day in life and the pregnancy journey. Aligned with previous research [12, 29, 129], the visual activities helped overcome language barriers and the limitations of interviews while investigating everyday life practices in particular the societal structures and material elements that influence pregnancy care. While the interviews were conducted in Urdu (with women who belonged to Muslim religion and spoke Urdu) and Kannada (with women who belonged to Hindu religion and spoke Kannada), most of the sketching and mapping activities were conducted in Urdu/Kannada and recorded in English. As part of the main project, we also engaged with 18 frontline health works including Junior Health Assistants (JHA), Anganwadi workers (AW), Accredited Social Health Activist (ASHAs), and Health Navigators (HNs). In this

paper, we use data from the focus groups as secondary material to provide additional context to the insights from the household interviews and have been reported separately [212].

#### 3.3.1 Sketching a day in life

Sketching a day in life (DIL) is a tool we used for unpacking participant's activities throughout the day, inspired by the day reconstruction method [39]. During the sketching activity researchers asked pregnant women to recall their activities from the day before, while they sketched it on the paper sheets using different temporal, material and spatial dimensions and icons according to the narrative of participants replies including time, icons (e.g., home, hospital, coffee/tea, mobile phone), and basic wordings (see Figure 2). Sketching brought in linkages and familiarity to other data points such as food practices, medication routines, exercise routines, factors of mobility, immediate social network, use of technology, etc. which were mapped. This activity helped in building a rapport between the research team and participants. We also encouraged the participants to draw with us, but only three participants voluntarily contributed to these activities while the rest added verbal comments to the sketches in their local language, which we recorded in English. Similarly to our previous experiences introducing drawing activities in participatory research [167], women felt that they were "not good at drawing" and would rather sit and chat.



Figure 2: A "day in life" example from a participant from a semi-urban area (U1PW3)

#### 3.3.2 Mapping of the pregnancy journey

Mapping the pregnancy journey (see Figure 3) enabled pregnant women to think aloud about their experiences during their pregnancy journeys including the chronology of their pregnancy and/or previous pregnancies. The interaction through this mapping activity informed researchers about the navigation and mobility challenges to and across health care facilities when seeking and receiving care, the role of health workers, current health

conditions and concerns, government-based and private health services and existing health schemes and additional spatial and material elements that influence the pregnancy journey.

#### 3.3.3 Data Analysis

The recording and notes were translated and transcribed to English and combined with the generated materials (sketches) for thematic analysis [27]. Four researchers (three local and one international) initially checked the transcripts and generated materials multiple times to enable data immersion and conducted two separate rounds of analysis (2 researchers in each round) before merging. We iteratively reviewed and physically cut the transcripts and sorted them with the generated materials multiple times to support the identification of themes making constant comparison among the two teams. Initial examples of themes were "spatial and social dimensions of care services", and insights into "food practices vs. beliefs vs. lack of body awareness", "gender norms" and "households technology use". As soon as we identified embodied experiences interacting with care infrastructures as the main concept for further exploration, as it was prevalent in the narratives of the participants, we continue discussing, revisiting and grouping data into themes until no new themes emerged. We rearranged the overarching themes and place sub-themes under the major themes, and these were discussed with the frontline health workers participating in the project and local collaborators from MAYA. Although we also considered to discuss the themes with the same participants, this was considered ethically inappropriate by the multidisciplinary research team and local collaborators due to the sensitivity of the research context. The major themes were then adjusted after receiving feedback from the research team in 3 project workshops (2 in India and 1 in Leicester) and six pregnant women from a different phase of the research project that helped redefine the scope of the project. Four major themes are presented in the next section highlighting the embodied negotiations, practices and experiences during pregnancy including the infrastructural dimensions and socio-cultural practices that influence women's pregnancy experiences and how their embodied care practices are negotiated while interacting with the situated care infrastructures (e.g., people, norms, materiality, routines, spaces, etc.).



Figure 3: A pregnancy journey of a participant from a rural area (R4PW4).

#### 4 FINDINGS: EMBODIED NEGOTIATIONS, PRACTICES AND EXPERIENCES DURING PREGNANCY

The participants' accounts and experiences highlight the major negotiations women engage in with the care infrastructures throughout their pregnancy journeys. The participants shared multiple ways they negotiated with different assemblages of human non-human actors including people (e.g., mothers and mothers-in-law, husbands, friends, and frontline health workers), socio-cultural practices and norms, traditional beliefs as well as temporal (e.g., routines), material (e.g., physical and digital objects), and spatial (e.g., within and beyond the home and healthcare centers) arrangements that influenced their embodied experiences and practices during their pregnancy journeys. In the following subsections we describe the multiple embodied experiences of pregnant women while negotiating the infrastructural arrangements for knowing about, responding to and nurturing their changing bodies as well as traversing the spatial and socio-cultural dimensions of accessing healthcare facilities.

#### 4.1 (Dis) Embodied Knowing about and Responding to Changing Bodies

A large part of pregnancy experience for our participants was about knowing one's own body as well as of the growing fetus, and the changes that are happening with and within. The pregnancy experience for most of our participants began not during the phase of planning for a baby, but through embodied practices when the women realized that they have missed their menstrual periods, or in some cases when they have morning sickness. In other words, the women began their pregnancy journeys when their bodies showed signs of being pregnant. The ways that the pregnant women sought information, counsel, and recommendations about their changing bodies throughout the pregnancy journey, was shaped by a combination of their specific living arrangements (see Figure 4), relationship with their mothers and mothers-in-law, as well as the underlying gender norms of their household.



Figure 4: Social arrangements in the household

#### 4.1.1 Negotiating with the embodied knowledge of the mother and gendered bodily schemas

The mother of a pregnant woman (see Figure 4), and sometimes the mother-in-law came to figure centrally as part of human infrastructure in pregnancy care, particularly as a confidant and as a person who holds traditional and embodied knowledge of pregnancy supporting care practices using this knowledge at home. Indeed, almost all the participants confided they missed their periods to their mothers, even when they were living in a jointfamily arrangement with their husband and his parents. Women called their mothers over the phone to convey the message and seek recommendations or next steps, particularly if this was their first pregnancy. Also participants who lived with their husbands (in a nuclear family set-up away from both the parents and in-laws) in towns or cities called their mothers on the phone, and based on their suggestion visited the nearest clinic for check-up and confirmation. For example, one of our participants who lived with her husband in Bangalore city mentioned, "My menses stopped, and I called my mother. Then my husband took me to Raghav Clinic and the tests (blood and urine) confirmed that I was pregnant" (R4PW4). The quote further illustrates the gendered roles that the pregnant women (and their households) have to work with and how pregnancy is deeply embedded within gendered bodily schemas [137]. As revealed by our participants, post puberty, the women majorly interact with other women than men, even within the household. This cultural practice of social interaction not only makes the women confide in their mothers, but also, as we elaborate in subsequent section, renders the menthe husbands, brothers, fathers and fathers-in-law-as somebody who mostly act as a 'mobility aid' and gatekeeper of information and financial support.

The centrality of mothers in pregnancy care was further reinforced by our participants' desire to be at their parents' home during pregnancy as their workload reduces, and they are 'taken care of'. Our study shows that participants living in joint families get very little personal space as one participant mentioned, "*I return to my room* [on the second floor of the house] *only after dinner around 10 pm*" (U1PW1). Women had to do a range of household chores; and adjusted (or tone down) their expectations of care and negotiated with the ongoing routines of the joint-family household. For example, the mapping of the day-in-the-life showed how the meal timings are dependent on either men or children of the household: the breakfast is served in the morning often

when men in the house leave for work around 9-10 am (R4PW1), lunch is around 3pm in the afternoon when children return from school, and dinner when men return from work after 8pm (U1PW4). Women are mostly disembodied and disconnected from these household arrangements. At their parent's home, they do not have to perform all the adjusting and negotiation work, as most of these would be taken care of by the mother and sisters-in-law, if any. During our interview study, we found that most participants moved to their mother's homes during the third trimester (seventh, eighth or ninth month), and returned to 'their husband's home' after six months' post birth. This ongoing traditional practice further reinforces the role and the embodied knowledge that the mothers enact in their pregnant daughter's care at home.

As women married within religion, class, and caste groups, both the mothers and mothers-in-law shared mostly common knowledge about changing body and its needs during pregnancy. However, this knowledge is rooted in traditional understanding and does not always align with, and sometimes actively conflict with the medical understanding. One such understanding was that the fetus grows in the stomach. A participant (U2PW3) talked about having pain in the left side of her stomach as "my stomach has the baby" and it is making space while it is growing. In another instance R1PW2 shared that she conceived after a missed abortion, where she "got her stomach cleaned", referring to the signifies the dilation and curettage process. This way of understanding their bodies is possibly more relatable to the pregnant women as it is something that comes from the person whom they trust: their mothers, and gets incorporated and embedded in everyday practice and parlance as the pregnant women did not have access to any Sexual and Reproductive Health and Rights (SRHR) education during their lifetime and have to rely on the local knowledge that has evolved over time. However, sometimes such understanding can create situations where the pregnant women miss out on an ideal care (as prescribed by the medical professionals). For example, another participant (R4PW4) shared that her mother has advised her "to avoid fish because it has scales/thorns and it would scratch the baby in the stomach". These negotiations pose challenges for women about what is embodied or disembodied in women's pregnancy care practices due to the sociocultural context in which they live.

#### 4.1.2 Negotiating the socio-cultural norms, routines and digital practices

Most of our participants engaged with mobile phones to seek information about and respond to their changing bodies and foster their embodied learning experiences. Most of our participants had access to mobile phone either through their husbands (7 participants) or by owning a touchscreen enabled smartphone (11 participants). 9 participants neither owned nor had access to mobile phones. Women engaged with the mobile phones not in isolation, but as a part of a care infrastructure that they oftentimes put together by negotiating with their own low literacy levels, interface design affordances and limitations, cultural and gender norms, and people – husbands mostly, but also family and friends.

Participants (both those who owned smartphones and those who used their husband's phone) had to negotiate with an interface (and the underlying mental model) that was not designed for them. They mostly used apps as a gateway to information rather than the browser, revealing how for them the Internet appears as a set of Apps such as YouTube, Facebook, and WhatsApp. Participants used YouTube as both an interface to search content and watch it, using their voice, rather than text, to search content relevant for them. We observed that "changes in the body" of the baby (and not the pregnant woman) was a common keyword for search on their YouTube apps, showing their inter-embodiment relation with the baby [122] Participants also sought tips about embodied caring practices during pregnancy in relation to diet (U1PW5), and baby bathing videos, recipes, and

pregnancy exercises (U1PW1). Participants used social media apps such as Facebook and WhatsApp to share their embodied experiences during pregnancy such as images of babies, temple visits, travel, etc., and to consume content such as personal images and videos shared by their friends.

However, unlike the case of cultural or traditional forms of embodied knowing where pregnant women worked with the mother / mother-in-law, in the case of seeking information through digital technology they had to negotiate firstly the usually gendered domestic chores and routines, and secondly the husband, who took on a more prominent role when it came to technology access and control within the home.

Participants had to make time from their busy day to 'sit down with the phone'. When living at the in-laws' house the participants engaged with Smartphone apps in the late afternoons or in the night, once they finish the chores of cooking, cleaning, etc. While talking on phones was an activity that they could do even as they performed the daily chores, using the mobile phone for content consumption was considered as a dedicated activity. Watching TV interestingly was a social activity where the family sat together and watched the same content, mostly in the evenings. Except in the case of one participant, who mentioned, "*Nobody uses TV at our home, because we all have smartphones*" (U1PW4). This reveals an increasing trend of more smartphone ownership leading to more distributed content consumption within the households.

Meanwhile, the women who moved to their mother's home engaged with their smartphones whenever they could get access to it. In other words, they did not have to negotiate with the expectations of performing daily chores of the household, and their consumption of media and embodied learning was mostly shaped by if and when they have access to the phone. For example, a participant (R4PW4) who was living at her parents' home often uses the smartphone of her cousin's husband who lives nearby as he often left one of his smartphones at home, which the cousin brought to the participant's place, and they watched videos about baby care, henna art, food recipes, movies, etc.

Participants who did not have their own phones, had to request their husband to access their phones who gave them only when they were not using it, thereby limiting the access. The husbands also monitored the usage. For example, only two participants had their own Facebook accounts (R5PW1 & U4PW1), while all others shared the husband's account. The husband also acted as content moderator / verifier, as explained by R1PW2 who said "*in case of any doubt* [about the information in YouTube], *I ask my husband if it's true*". All these complex negotiations within the households both can empower but also constrain women embodied experiences, knowing and learning.

#### 4.2 Nurturing the Pregnant Body

Food is one of the central aspects of pregnancy care at home. Our study revealed how participants, even as they cooked the food in most households before shifting to their parent's home, as a way to nurture their pregnant body have to negotiate with traditional and communal knowledge about food during pregnancy, the gendered norms around food preparation and consumption, medical and care practitioners' advice and counsel or lack of it, and their own desires and changing taste for particular foods.

#### 4.2.1 Negotiating traditional food beliefs, medical advice, and own desires

Participants had to negotiate between food beliefs that usually follow generationally transferred family traditions, which have evolved and ossified over years, and the normative standards of medical advice. For example, a tradition we found was to splash the first milk of the mother on a wall and only then breastfeed the child. And

as medical knowledge points out in the scoping workshop, and something that a health worker mentioned during the study, that "the mother's first milk is considered to be rich in nutrients" [13].

Negotiating conflicts between beliefs and medical advice becomes even more important for pregnancies with complications. We found that women, for example with diabetes or hypo/hypertension managed to integrate their doctor's advice in their daily embodied caring practices related to food habits. Sometimes the traditional beliefs about food and the medical advice aligned. For example, both the doctors recommended pregnant women with anemia to consume pomegranates, anjeer (figs) and drumsticks, all of which are traditionally believed to 'increase blood (hemoglobin levels) in the body'. Sometimes integrating the medical advice is easy as in the case of R4PW1. The JHA had advised her to eat more salt in her food as she suffered from hypotension during pregnancy, and it was easy for R4PW1 who could add extra salt over food cooked for the entire household without much trouble. Other times, it was a challenge for women and their families to integrate medical advice about diet as part of their everyday food habits, as in the case of R4PW2. Her doctor had suggested R4PW2 to avoid rice and eat more of ragi (finger millet) and plain wheat bread as she is anemic as well as diabetic, R4PW2 lived with her husband and daughter in a joint family, which consisted of the parentsin-law and her husband's elder brother, his wife and their two children. R4PW2, who is 7 months pregnant has had a previous miscarriage, is anemic and diabetic. Every morning she cooks for the entire household with some help from the old mother-in-law and sister-in-law who is a tailor and a cook at the nearby Anganwadi center. Due to previous experiences and her ill-health the family has now shifted to considering the doctor's advice and eating more wheat rotis and ragi balls, than consuming white rice, which is more easily and cheaply available through the government's public distribution system and food rationing.

Moreover, we found that women did not get much relevant advice from the medical professionals about food and diet, making it easier for them to follow the advice suggested by their mother / mother-in-law or other elderly members of the household. However, women had to negotiate with their personal and changing taste preferences to accommodate the traditional food beliefs in their everyday diets. One of the traditionally rooted beliefs that we also encountered, across the religious and rural-semi-urban locations, was the notion of 'hot' and 'cold' food. Food was categorized into the potential effect they had on the pregnant body; some foods producing more heat in the body and others cooling the body. For example, foods such as coffee, papaya, chicken, fish, sesame seeds and drumsticks were 'hot' food, as they were believed to produce heat in the body, while fruits such as banana and sweet lemon were 'cold', as they were believed to reduce the body temperature.

An interesting pattern emerged while analyzing the pregnancy journeys that we mapped with the participants. The communities recommend hot or cold food groups according to when they believe it will suit the different stages of the maternity journey. For instance, hot foods were in general seen as harmful during the pregnancy, especially during the first trimester. And cold foods were avoided after birth, with a belief, expressed by one of our participants (U3PW1), *"till the baby is being breastfed, one should not eat cold food, as the child will have difficulties such as cold, nose block, fever, loose motions"*. While we did not find any conflict between such belief practices and medical advice given to the participants, they often had to negotiate this belief with their taste preferences, particularly when it came to consumption of tea or coffee. Although consuming tea or coffee (both brewed and boiled in milk and sugar) was considered to be harmful during the pregnancy period as they both are heat-producing foods, as our day-in-the-life-of mapping activity showed, almost all participants enjoyed their cup of coffee or tea twice to three times a day.

Such negotiations became easier in the case of U2PW2, who lived with her husband during the pregnancy phase, in a nuclear family setup away from both their parents and in-laws. While she had to manage the embodied care activities—of cooking and knowing and responding to their changing bodies—on her own with some help from her husband, she had more agency to navigate the food dilemmas. During the interview she emphasized on how she has started taking more care of herself since they started living away from the in-laws, as living in a shared space was difficult. "Nobody used to cook as per my choice", and now she "manages to eat better and visit the doctors all by herself" (U2PW2). Although negotiating conflicts was often hard for women, in some occasions these negotiations fostered their agency to act following their own desires.

#### 4.2.2 A case of subverting traditional norms to regain control over body.

In one instance, we came across the case of a new mother, Reema (U1PW2, name changed), who in a rather desperate measure, tried to utilize the belief about hot-cold foods as a way to push-back on the patriarchal norms dictating her becoming pregnant.

Reema lived with her mother and two younger sisters, along with her husband, who was 28 years old and worked as an attendant in a restaurant. During the interview, Reema mentioned she was 18 years old, and had two children; the older child was one year-three months old, and she was nursing the second child who was a month old. Reflecting on her pregnancy experiences. Reema did not want to be pregnant again after her first child, but when she missed her periods for two months in a row, her husband asked her to get a pregnancy test done. After three months, her mother suggested her to go to the doctor. She ignored both suggestions. In the fourth month, when her first child was only 6 months old, she did a home-test and it came back positive. Then she went to the Anganwadi center in her neighborhood to get registered on the MCTS system and get the Thayi Card. Finally, in the fifth month, she went to meet a doctor at a private clinic in Mandya (about 40 kilometers away) with her sister. Reema told us that she did not want to do a check-up as she wished the pregnancy to fail. Reema got pregnant against her wishes as, following the religious and cultural norms, her family does not believe in family planning measures, and medical abortion was a strict no. When she missed her periods twice in a row, Reema started to consume a lot of raw papayas, based on the traditional belief that as a 'hot' food it will induce an abortion or miscarriage. But when it did not happen even after four months, she had to force herself to visit the doctor, and finally gave birth. This is a particular case of disembodied knowing [220] as her wishes and desires were silenced due to the sociocultural norms and traditional gender roles especially around traditional taboo topics such as abortion.

Reema's case reveals how women, when pressed with not much control or say over their own bodies, sometimes resort to subverting the very norms and beliefs that come from the same traditional and cultural ground as those that create the situations where they are left without control and disembodied from her own desires. It is not as if Reema lacks an awareness of her body and its working, and hence could not leave a gap between her two children or did not go for medical advice in the first trimester of her pregnancy. In fact, she is deeply aware of her body as well as lack of support structure within her immediate surroundings in following up on what is best for her body and children. As a way to negotiate a pushback Reema had to resort to the local belief of consuming hot foods providing a space for resistance [127]. It is rather unfortunate that her strategy did not work, and she had to give birth. This case reveals how even with active interventions by primary healthcare workers to equip women with family planning rights, it is hard for some women to overcome the patriarchal norms that dictate their everyday life that try to control their own bodies. Reema's case brings about

how oftentimes individual resistance without structural support is not enough to overcome the restrictive sociocultural norms and practices embedded in the social context where pregnancy is experienced

#### 4.3 Negotiating Spatial Dimensions of Healthcare Facilities

Women who participated in the study accessed multiple healthcare facilities over the term of the pregnancy and birth; some public and others private. The participants had to physically move across the Primary Health Center (PHC), Taluk Health Center (THC, at the Channapatna town), private diagnostic centers, and the district hospital.

#### 4.3.1 Traversing multiple distances across distributed healthcare facilities.

Mostly the participants in semi-urban areas accessed private care facilities as opposed to women in rural areas who only accessed the public facilities due to the distances involved in traveling to the town. Rural participants accessed private facilities only if recommended by the doctors at the PHC/THC. However, during emergency situations women consulted other private facilities if their doctor was not available or the facility is closed at night. Two participants (U1PW3 & U1PW4) who had vaginal bleeding in the first trimester shifted to private clinics when the doctor at the THC was not available. What a doctor or a nurse recommends carried weight when it came to accessing a particular health facility. Sometimes the pregnant women changed their facilities based on the presence of a health worker or a doctor who has become known for their good care practices. For example, during her second pregnancy R4PW2 had to shift mid-way to a private nursing home as the lone doctor at the THC got transferred mid-way through her pregnancy. But now, she says, "there are three doctors at the hospital (THC). I trust them and I will go there for my delivery". Another participant R2PW1 trusts the THC to give her good care not only because her earlier pregnancies were successful at the THC, but also because a nurse working at the THC is her close friend. She mentioned how the nurse, who lived close by, was the one who got her registered for the Thayi card and keeps visiting to offer counsel and advice.

Participants usually visited the nearest PHC to confirm their pregnancy and to register on the MCTS system and get the Thayi card. For example, one woman mentioned that she had to get the Thayi card (by registering at the PHC) as "*wherever we go* [within the public health facilities] *they mandatorily ask for it*" (R1PW3). After the confirmation of pregnancy at the PHC, women were further referred to the Taluk Health Center (THC) in Channapatna for further tests and consultations, and for giving birth. While in theory the PHC is equipped to do vaginal deliveries, the doctors and the nursing staff at the PHC ask women to go to the THC as it has the facilities and staff to deal with emergencies and complications. The rural communities from our study were located within a range of 5 - 15 kilometers from Channapatna (see Figure 5), and the pregnant women visited the THC either on motorbikes or scooters driven by their husbands, or in an auto-rickshaw with mother, mother-in-law, or husbands.



Figure 5: Distances to the Channapatna THC from participants households

In principle the THC should have all the facilities required for pregnancy care and giving birth. Most of the participants had to visit private health facilities because the doctors and staff at the THC recommended they do so for a range of reasons and purposes. One of the recurring reasons was that the ultrasound scan device at the THC was not working, and hence the pregnant women were suggested to travel 15 kilometers to Ramanagara to get the scans done at a private clinic, paying out of their own pocket. As one participant (R4PW1) stated "the machine is broken here (at the THC) and the doctor sends everyone to SS Hospital in Ramanagara for the scans." Better scan result is another reason that the staff at THC gave when suggesting a private lab facility, as stated by one woman (R2PW1), "*they told me that Prerana* [a private diagnostic center in Channapatna] *will give you better results, so I went there*." Within the span of a month, women often have to visit both the public and the private care facilities. Participants had to make this extra journey on pillion-riding on the motorbikes with their husbands, take an auto-rickshaw or take the public buses, both of which posed risks and stress to their bodies while sitting in awkward positions for long duration on/in a moving vehicle. All the traveling clearly show how mobility practices are embodied and embedded into the spatial and temporal dimensions of care infrastructures while seeking and receiving health services.

#### 4.3.2 A case of traversing during 'high-risk pregnancy'

The THC also hosts a monthly meeting and counseling session for pregnant women who are identified as 'high risk pregnancy'. From one of the focus group discussions with the JHA nurses and Anganwadi workers we found that the factors considered to term a high-risk pregnancy are: being older than 35 years, high or low weight, diabetes, hyperthyroidism, prior pregnancies with c-section births, and low hemoglobin levels. The staff at the PHC makes the diagnosis and suggests the women to visit the THC on the 9th of every month. At the THC, women are shown movies about caring of their health and wellbeing and home, and additional tests are

performed based on their specific complication. However, women with high-risk pregnancies had more complicated journeys, and they had to perform additional physical, social and emotional embodied labor when seeking clinical help. A poignant case is the one from participant Seema (R4PW2, name changed) as follows:

Seema was 7 months pregnant during the interview, and this was her third pregnancy. While her first pregnancy was 8 years back, which ended in a stillbirth at eighth month, the second was successful and she has a 3-year-old daughter. When Seema began vomiting and stopped menstruating, she walked to the PHC (about 1.5 km away) and her pregnancy was confirmed. However, she was also severely anemic with hemoglobin (Hb) level at 4, and was referred to the THC for follow-up. The local ASHA worker took her and her husband to the THC about 9 km away in an auto- rickshaw (tuk-tuk), where the doctor suggested her to get a blood transfusion at the district hospital in Mandya, 40 Km. away. She went there by public transportation with her husband, where she was administered two pints of blood over six days. After the blood transfusion, her Hb levels rose to 9, but dropped back to 7 within a month. The doctor at THC suggested her to go for a 'blood tube' (a pint of red blood cells through IV transfusion), which was performed at the THC. After this procedure, though unconnected, her blood sugar levels rose during the periodic test at the THC. Then, Seema was asked to consult the diabetologist at the THC, who recommended initially to control her blood sugar through diet and exercises. However, subsequent tests revealed her high sugar levels, and she consulted a private diabetologist in Channapatna, about a kilometer away from the THC, who put her on insulin dose and recommended weekly blood tests at his clinic. Now in her 7th month of pregnancy she goes to the THC, after meeting with the doctor she goes to the private clinic to get her blood tests done, gets back to the THC with these reports, and comes back home; a hectic day long trip in an auto-rickshaw. In addition, Seema had to visit the private lab in Ramanagara for the ultrasound scans once every two months. This immense amount of physical, not to mention the emotional and social, work she performed almost on a weekly basis to travel across the distributed healthcare system has left Seema very worried and stressed. When asked if she has any questions for us post the interview, she asked, "please tell me what I can do to control my sugar? I am very worried."

#### 4.4 Negotiating When and Which Healthcare Facility to Access.

The decision-making process about when and which healthcare facility to access, involved work done by women, oftentimes without much say, to negotiate socio-cultural and gender norms, costs, as well as previous experiences and perceptions about good care, and preferences thereof.

#### 4.4.1 Negotiating norms to access critical care in time.

Participants had to negotiate cultural and traditional norms around stepping out of home while being pregnant that shaped when they accessed the healthcare facility and negotiating norms such as not stepping out after sunset, took on a detrimental role during emergencies. Most women shared that they went into delivery when they started feeling pain, some of whom waited to see if it lasted continuously. Interestingly few of our participants also stated that they will go to the hospital on the exact date of delivery given by the doctor. Their families held firm that that once you go to the hospital, you cannot just come back without the baby, as otherwise the neighbors may cast aspersions or ridicule (R5PW2). Beliefs arising from tradition also interfered with delivery, such as that "one should not give birth at night", regardless of the pain a woman might suffer through the night and go to the doctor only in the morning as experienced by a participant (U2PW2). Adhering to the same belief by her family as they lacked embodied knowledge then led to negative embodied experiences for

Seema (R4PW2) as she had a still-birth during her first pregnancy as they waited till the morning to visit the THC.

#### 4.4.2 Negotiating desires of better healthcare experiences

One of the central cultural norms that shaped women's access of healthcare facilities was the practice that the care and cost of pregnancy, birth and post-birth is borne by the woman's parents. To reduce costs the parents usually preferred government facilities, while the in-laws suggested private facilities due to the perceived notions of better care. Often, participants had no direct say in choosing the birthing hospital. For example, R2PW1 gave birth at the Channapatna Taluk Health Center (THC), as her mother decided it for her. R2PW1's elder sister also gave birth at the THC without any issues, and it is free as a publicly funded clinic, were the rationale underlying her mother's decision. However, there were quite a few instances when the participants did not want to utilize the public clinics for birthing. Women brought to this discussion a range of concerns and strategies such as, their own and their friends' previous experiences and the commonly prevalent notions and preferences in the community about the differing quality of care, and in some cases, their influences on the husband, to recover agency in the decision making.

Sharing and discussing prior embodied self-experiences, and / or that of sisters, and friends appears to be a dominant way that women wrought with the patriarchal structures of decision making at home. For example, a participant (R5PW2) recollected how a bad experience during the birth of her first child at the THC enabled her to decide to give her second birth at a popular private clinic and convinced her family of the decision. She mentioned, "during my first child they [THC] had not removed the sutures properly and I developed an infection. So, this time I am going to Balu Nursing Home [a private clinic]". Another participant (U1PW4) did not want to give birth at the public hospital as she had observed how during her visits to the THC, "They [doctors at THC] do not do proper 'checking'. They just give pills, do not check BP or anything. And above that there is always a long queue and it is very crowded." Sometimes women living in cities but staying with their parents for the birth and antenatal care shared with their parents how experiences of private clinics in the urban areas are more desirable. For example, R4PW3 mentioned how, "in city they [the healthcare professionals] gave a CD [a compact disk with the video of the ultrasound scan], here [at the THC] they did not even let me see the screen during the scan". However, she had to give birth at the THC for easy access of financial benefits offered by the government, which was a decision taken by her parents.

It was not that women only desired private care. Some participants also negotiated with their households for giving birth at the public hospitals, particularly district government hospital in Mandya, which had a reputation for preferring vaginal delivery over c-sections, unlike the private clinics and nursing homes. For example, consider the case of U2PW1. U2PW1 stayed with her husband and in-laws in Channapatna, but visited a private clinic in Mysore (where her parents live, about 80 Km away) once every month for check-ups. However, she did not want to give birth there, as she mentioned, "*My family* [parents] *visit a hospital in Mysore. But it is known for c-sections, and I want a normal delivery. So, I will go to Mandya* [government hospital]" The communities that the participants belonged consider c-section as being harmful for the pregnant woman and her child, and is expensive too. Because the desires of U2PW1 aligned with those of her family for a 'safer and cheaper' vaginal delivery it was easier for her to successfully negotiate with both the families about the choice of birthing facility.

Elsewhere, some women expressed their desires of birthing at a private clinic to their husband, who then took the decision, which meant that they had to prepare and arrange for the extra expenses for availing the services of a private clinic. For example, R3PW2, who has had a bad abortion experience previously at the THC, and hence prefers the private nursing home that she consulted regularly throughout the current pregnancy journey. Her husband too, because of all the troubles they went through with the previous experience is convinced about the better care provided at the private clinic. As she mentioned during the interview, "*I am going to deliver at Lakshmi Nursing home. My husband decided it*". This does mean extra costs and the government health insurance scheme (Arogya Karnataka Scheme<sup>4</sup>) will not cover all the costs, making the husband to arrange for these extra costs. This is an example of how deciding a place to birth should consider multiple aspects including previous experiences, gender norms, economic considerations as well as public health policies and insurance come together in a more or less aligned arrangement.

#### **5 DISCUSSION**

Our findings highlight key challenges influencing women's embodied experiences during pregnancy and they ways they gets affected and negotiated through different infrastructural arrangements including spatial and material elements of everyday settings, socio-cultural beliefs and relational practices within and beyond the home. Looking at pregnancy care practices through the lens of care infrastructures [43, 114, 216] helped us obtained deep insights regarding the complexity and sociocultural situatedness of pregnancy care and how this understanding could support the design of and for enhancing women's embodied experiences within the existing care infrastructures they interact to. Reflecting on these challenges and the unpacked infrastructural elements and previous HCI and CSCW research in healthcare, our study extends research understanding pregnancy care experiences [12, 143, 156, 157, 196], digital maternal health [15, 19, 109, 150, 205], the invisible work attached to pregnancy care practices [12, 84, 127], and care infrastructures in practice in the Global South [13, 31, 92, 143, 193]. Our work understanding the complexities of women's embodied experiences during pregnancy also aligns and adds to recent calls to further understand women's health and wellbeing [103, 110] going beyond looking at women's behaviours and medicalized views of pregnancy. Based on our findings, we propose design opportunities to design digital health technologies that can enhance and support women's embodied experiences of pregnancy care as a rich practice situated in diverse and yet within fragmented and distributed care infrastructures.

#### 5.1 The visibility and invisibility of body work during pregnancy

HCI and CSCW research has investigated the visibility and invisibility of work practices [131, 189] and there is a growing interest in examining the patient and caregivers "invisible" work especially in the context of chronic care management in the home and the hospital [67, 149, 191]. Yet patient's and caregiver's work often remain invisible to the healthcare infrastructure [104, 197, 208] as it takes place within and beyond clinical encounters [62, 164] moving into everyday life settings and routines [33, 84, 149]. In contrast, the visibility and temporality of pregnancy are very different from the "course of illness" and the everyday experiences and trajectories of care would have a very different connotation than the typical "illness trajectory" [191]. Yet there is limited understanding of the invisible work (physical, social, emotional) that women and caregivers do to reduce risk

<sup>&</sup>lt;sup>4</sup> <u>https://arogya.karnataka.gov.in/</u>

and enhance safety during pregnancy within and beyond the clinical encounters [84]. Especially the normative ideals of parenthood looking at parents as good, efficient, child-centered and responsible "risk managers" severely overlook the larger context (interactional, structural and cultural dimensions) and render "invisible" the embodied practices and heavy body work embedded in pregnancy, taking for granted the identity and moral work that women do to comply with the ideals of motherhood [63].

Our findings foregrounded the multiple ways in which women performed work through, with and on their bodies while negotiating the care infrastructures during pregnancy. We saw how women negotiated with their mothers and mothers-in-law, and the everyday routines of care-giving they had to perform and the medical advice to nourish their bodies according to their desires. The participants had to negotiate with socio-cultural, gendered norms while being bodily uncomfortable or in pain to decide where and when to access healthcare facilities, sometimes leading even to loss of pregnancy, as was in the case of Seema (R4PW2). They subverted traditional norms of food in attempts to regain control over bodily choices and pushed back on gendered norms to get access to better care at health facilities. They stressed their bodies while riding on a motorbike, autorickshaw or a bus so that they can get the best care for their bodies possible. We consider this as a form of 'bodywork' to highlight the work done by women in negotiation with the care infrastructures during pregnancy. Most of this work is invisible, even within their families, and to other women in the localities, till they experience it. This is also invisible to the designers of digital health interventions in the Global South, as we discuss in the related work section, where the focus has been mostly to given information and educate the women about their own bodies and nudge them towards better behaviors.

#### 5.2 Opportunities: Designing for Embodied Experiences with Pregnancy Care Infrastructures

Our findings offered us a rich space for speculating on if and how digital technologies could be a part of the pregnancy care infrastructures we encountered and studied, with a focus on what embodied experiences needed support from digital technologies. The ideas we present below have emerged from conversations with MAYA employees, field coordinators and HNs, as well as other frontline health workers and six women's households, through both planned participatory design sessions (details of which are out of scope of this paper and will be reported separately) and through informal conversations. Currently, we are in the process of developing the idea of a community network for community health knowledge through participatory design and action research.

# 5.2.1 Making body-work visible to support embodied negotiations through peer-to-peer local solidarity networks

As discussed above the pregnant women perform an immense amount of bodywork while negotiating with the human-non-human care infrastructures they are situated in. The body work of a pregnant woman, which is largely invisible to other young women across other localities, is a rich source of embodied knowledge that can benefit other women, particularly to learn strategies of negotiation, know-how, tips, and techniques of care, etc., all that are specific to the particular care infrastructures they share in common. Such sharing of embodied knowledge with each other, we imagine will foster a sense of solidarity, enhancing a sense of sisterhood and empowering each other with a collective arsenal to negotiate for better care experiences.

As subsequently discussed with the local collaborators from MAYA and the Health Navigators, we could design digital technologies that enable quick and easy content creation in the forms of oral and /or video

narratives<sup>5</sup> by the pregnant women to share their experiences with other women in the areas around to support peer-led healthcare [195]. The content creation and sharing platform could be anchored via a local, community owned WiFi Mesh<sup>6</sup> or other forms of Community Networks [158], as using broadband and / or mobile Internet is both expensive as well as takes the control of the content and platform away from the local communities and places it in the grasp of global powers.

Here we envision women as content creators and contributors on a safe, local network, formulating their own community moderation practices. This is in opposition to the current efforts at digital health for maternal wellbeing in Global South, where the focus is to educate and inform the women and their families with information that is coming in from central policymakers, such as the state. Furthermore, the frontline health workers who are mostly the information disseminators could take on a role of facilitators of local women, peer-to-peer solidarity networks. As our findings highlight many women had to negotiate with the male members of their families, often the husbands, to access Internet, which severely restricts their consumption of information, let alone the creation of it. Within a peer-to-peer solidarity network, the devices can be shared among each other, or offered by a frontline health worker such as the Health Navigator. This could also become a space for sharing and discussing strategies of overcoming patriarchal norms and other restrictions to their care, thereby moving away from feeling lonely, helpless, and desperate as Reema did when she consumed raw papaya in attempts to abort her unplanned pregnancy. Alternatively, the Anganwadi center could be the place where they meet and engage also with the creation and sharing of digital content, taking advantage of a community network at Anganwadi center [212], and turning it not only as a physical and social safe space, but also a digital one.

#### 5.2.2 Supporting Local Forms of Knowledge and Knowing

Moving a step broader from women's embodied experiences during pregnancy to the care infrastructures we see the possibilities for digital technologies a) to document and make available the rich embodied knowledge that the mothers and mothers-in-law hold, particularly about food and other practices of nourishment, and b) to support the families of pregnant women and the frontline health workers with the local know-how, how-to, and where-to of pregnancy care.

Local health knowledge repository. The rich embodied knowledge that the community holds, particularly by the older women in the households offered our participants care at home with a focus on food and nourishment, and also other forms of bodily care. While some of this knowledge was in conflict with the medical advice, most of it augmented the 'universal' nature of medical advice and rooted the care to specific local contexts in the form of food products that are affordable and yet nutritious, practices that are suitable to the everyday life contexts, etc. We could use digital technology to create a local repository of such commonly held knowledge of the locality, through recordings of oral histories and videos of food preparation tips etc. by the older women. Creating a set of tools to foster not only easy recording of this information, but participatory annotation, where the older women and the community health workers together discuss and annotate the information, would foster a repository that while addressing the conflicts between the embodied traditional knowledge and medical recommendations, fills the gaps between them and makes it available for other members of the community. This repository could be hosted on the community network we discussed in the sub-section above.

<sup>&</sup>lt;sup>5</sup> For example, <u>http://papad.pantoto.org/</u>, <u>https://www.inethi.org.za/</u>

<sup>&</sup>lt;sup>6</sup> https://open.janastu.org/projects/cowmesh

A Know-How Tool. Our findings highlight how women and members of their families had to engage with not only the medical and diet information, but information that was more temporal. The navigation across the entities of public and private care infrastructure was also socially and culturally situated, which again pose challenges on the pregnant women and their families while seeking the right information to make informed decisions both in a 'planned' manner, but also in ad-hoc, circumstantial ways. For example, to figure out which facility to visit and when, and what to do and where to go when you are visiting a THC or a district hospital, which private clinic to go for a scan, etc. involved dealing with and making decisions on ad-hoc, but very locally relevant information. A participatorily compiled and sourced tool that records such situated information and makes it available for the pregnant women and /or their family members will help ease the work done in decision making. Such tools could be made available with both the core actors, such as the PHC / Anganwadi center and the frontline health workers, and the 'peripheral' actors of the care-infrastructure, for example the auto-rickshaw driver, and the health navigators.

Broadly the opportunities for design we discuss here are informed by a feminist HCI [17] imagination that centers non-normative embodied experiences of pregnant women, and aims to support discursive and participatory engagement with the digital technologies that become a part of the care infrastructures. In this imagination, the pregnant women are not passive bodies that need to be educated, informed, or nudged towards healthy behaviors, but knowing and experiencing actors who create and share with each other in solidarity. Furthermore, the ideas we discuss embrace the situatedness of embodied experiences in the particular aspects of care infrastructures and aim to become over time a part of the infrastructure. Recent years have seen a body of work that takes on an embodied interaction perspective while designing for women's health in general [6, 28] but also pregnancy and maternal health [52, 215]. We hope the ideas we discuss in this paper to add on to this work, with a critical insight of going beyond the focus on a woman's body-in-isolation towards accounting for the bodily entanglements with the socio-cultural and gendered pregnancy care infrastructures.

#### 5.3 Reflections on Research Methods - Limitations

One of the main limitations of the study relates to the class and caste positionality of the research team belonging to an upper-middle socio-economic class and carrying caste privileges within the socio-cultural hierarchy that pervades India. To account for these positions, we engaged with different community stakeholders both, women and frontline health workers earlier in the framing of our research and shaping the study and analysis that was supported by our local collaborators MAYA Health. For example, we conducted our research through active participation of a team of six Health Navigators (HNs) from our field collaborators. Though they brought their deep understanding of the context and people from their communities, due to the nature of their health work, they did end up as *gatekeepers*. In earlier interviews the participants sought the approval of the HNs to answer certain questions, as well as to prompt certain questions. Over time however the HNs became more adept, and in fact they conducted interviews with women on their own and brought the data to the focus group discussion.

Furthermore, conducting these interviews in the household of the participants helped us to contextualize better, but it also made the process of research dependent on factors of the surroundings. More than one person (from the household or wider network) was always present during the interviews. The pregnant women in some cases were observed to be hesitant or silenced by people of authority at the home during her responses. This resulted in significant difficulties in conveying what the intended thought was. For example, a woman hesitated

to respond because of the presence of her mother-in-law next door and responded sometimes with hand movements. In this case, the visual methods of data collection were helpful to provoke interactions enabling women to participate actively even without answering with their own voices and using their body language.

In addition, there was a general perception among the participants that we belonged to a health agency, which initially hindered conversations. The high prevalence of health workers who did household visits, on the one hand helped not take the participants by surprise, on the other hand also became a limitation for developing a familiarity and rapport with the participants. The researchers (who were unmarried women) were asked questions of a personal nature, which though made the researchers uncomfortable initially, however, it served as a way to familiarize by being vulnerable and hence creating a safe space. However, the fact that the researcher was unmarried and were asking questions on pregnancy and contraception surprised participants and we in few cases noticed a certain hesitation and discomfort in the responses.

Our ongoing and future work includes a series of participatory design workshops with separate groups of pregnant women, their mothers and mother-in-laws, husbands and other men, and different health workers to gain a deeper engagement with the aforementioned themes and ideas for digital technology reported in this paper, including figuring out pathways to build and pilot test them.

# 6 CONCLUSION

This paper discussed the importance of understanding pregnancy care practices through the lens of care infrastructures to pay attention to the human and non-human assemblages that shape women's embodied experiences during pregnancy. Our findings from the qualitative study highlighted the multiple embodied experiences while negotiating the pregnancy care infrastructures in relation to knowing about, responding to and nurturing their changing bodies as well as traversing the spatial and socio-cultural dimensions of accessing healthcare facilities. Most digital health interventions in developing countries have focused on supporting information-seeking practices through messages, video-based health education, audio prompts and basic visualization. However, our study shows that we should have a deeper understanding of the dynamic changes in practices beyond the individual woman's behavior to account for all the different elements that are part of care infrastructures as well as how these shape the embodied experiences during pregnancy. We discussed two forms of design opportunities to further explore the potential of digital health technologies in developing countries aimed to support better pregnancy experiences. We position the paper to contribute to the emerging discourse centered around designing digital health for global south in specific, and digital health in general, driven by situated and collaborative design approaches.

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