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Infrastructural Artefacts in Community Health: A Case Study of Pregnancy Care Infrastructures in South India

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Abstract. The work of frontline health workers providing access to pregnancy care services to women in South India is highly distributed and often overlooked in the design of healthcare infrastructures. Unlike clinical and nonclinical personnel who engage in different care practices within and across hospital departments with clearly established work roles, the work of frontline workers is performed across different geographical areas beyond the boundaries of the hospital and with loosely defined roles and resources making the coordination of work more complex. Based on a case study investigating the work of frontline health workers, we report a number of material infrastructural arrangements (the Thayi Card, physical and digital registers, and mobile phones) that played a major role supporting community health practices. We conclude by discussing the opportunities that these artefacts offer for the design of healthcare infrastructures.

Introduction

In healthcare, infrastructures relate to all physical, relational, spatial and structural entities (human and nonhuman), their functional capacities and the arrangements and configurations of these elements that support and sustain healthcare practices at all levels (from community and home care to national and regional services) including facilities (e.g., health centres, operating rooms, laboratory), equipment, staff, information systems, management, financing, and etc. (Smith and Bryant 1988). Taking a socio-technical perspective, Star (1999) draws attention to the social and material arrangements of people, routines, artefacts, conventions and the

visible and invisible work needed to sustain infrastructures. While Orlikowski (2007) highlights the relational role of materiality and how material artefacts should be treated as "relational products" in practice, Star and Ruhleder (1996) refers to infrastructure as a highly relational concept describing "something that emerges for people in practice, connected to activities and structures" rather than "sinking into the background". Aligned to this perspectives, Shove (2017) highlights how material artefacts can have an "infrastructural" relation to the practices they enable and how they shape each other over time. Thus, artefacts should not be understood only by their intrinsic material aspects but within the infrastructure in practice.

Previous HCI and CSCW research in healthcare have looked at the information and human infrastructure in place to support healthcare work practices in a complex and distributed environment such as hospitals (González et al. 2005; Bossen and Markussen 2010; Fitzpatrick and Ellingsen 2013; Bossen et al. 2014; Tang et al. 2015; Stisen et al. 2016; Stisen and Verdezoto 2017). While healthcare information infrastructures have been introduced as a way to mitigate the increasing demand of healthcare delivery aiming to reduce errors, support coordination and enhance the overall efficiency and quality of care of healthcare services through the use of Information and Communication Technologies (ICT) (Haux 2006; Pollock and Williams 2010; Piras and Zanutto 2016), the human infrastructure relates to the social system supporting the work done across healthcare settings including clinical and non-clinical personnel, patients, caregivers, etc. (Tang et al. 2015; Stisen and Verdezoto 2017; Gui and Chen 2019). However, healthcare infrastructures reach far beyond the boundaries of the hospital and accounts for the home (Aarhus et al. 2009; Chen et al. 2012; Nunes et al. 2015), municipality care settings (Bossen and Grönvall 2015), and community health settings (Pinelle and Gutwin 2003; Pinelle and Gutwin 2006). While there has been recent attention to investigate the social and material arrangements of care infrastructures at home (Danholt and Langstrup 2012; Langstrup 2013; Weiner and Will 2018), there is limited research investigating the role of these socio-material arrangements in community health infrastructures especially in developing countries (Fitzpatrick and Ellingsen 2013).

In developing countries, public health infrastructures are supported by multiple entities and organizations including a particular group of close-tocommunity health care service providers, often termed as 'frontline health workers' (Ismail et al. 2018). Frontline health workers are part of the human infrastructure that supports community health, including community health workers. volunteers, health extension workers and community social service providers, etc. (Collyer 2006; Mireku et al. 2014). Frontline health workers deliver counseling and health education programmes, support early identification and registration of new pregnancies and neonatal outcomes as well as making referrals (Mireku et al. 2014; Sharma et al. 2014). Although frontline health workers are being accepted and appreciated by healthcare professionals and the community (Mireku et al. 2014) and have shown potential to improve the uptake and access of healthcare services (Adam et al. 2014; Lunsford et al. 2015), their work is often unheard (Oliver et al. 2015) and overlooked within the overall healthcare infrastructures.

In India, frontline health workers are considered "intermediaries"

(Ramachandran et al. 2010; DeRenzi et al. 2017) and "infomediaries" (Ismail et al. 2018) of a wide range of community-based healthcare services. However, existing norms, community power structures, socio-cultural practices, lack of monetary incentives, limited knowledge, lack of resources and the fragmented and distributed nature of care services challenge the work of frontline health workers (Saprii et al. 2015; Ismail et al. 2018; Bagalkot et al. 2018). Although a number of IT support for community health exists (Ramachandran et al. 2010; DeRenzi et al. 2017; Vashistha et al. 2017), these have mostly focused in providing training and feedback on work performance (e.g., number of visits) for one group of frontline workers overlooking the collaborative work of different groups of frontline health workers. Based on a project investigating the challenges of pregnancy care practices (Bagalkot et al. 2018), we investigate the distributed and complex work of heterogeneous groups of frontline health workers in South India. The analysis presented in this paper focuses only on the existing material arrangements in community health that emerged from our diverse studies including six focus groups with 23 frontline health workers and a visit to the district hospital and 27 household interviews as secondary data. We identified material arrangements that have an infrastructural relation to community health practices.

Case Study: Pregnancy Care in South India

In India, public health care services are divided into three levels (Bagchi 2008). The primary level includes the primary health centres (PHC) that offer curative and preventive services, and the sub-centres (SC) as the first contact point for the community offering services for maternal health and disease control. At the second level, we find district hospitals and community health centres and at the third level medical colleges, specialized hospitals, etc. (Bagchi 2008). The first and second levels are complemented by ambulance services and community health (CH) services provided by frontline health workers (different from the community health centres), a web-based mother and child tracking system (MCTS), different government-supported schemes and incentives aiming to reduce maternal and infant mortality (Rate 2017), and private health services (Baru and Nundy 2008).

Session	Activities	Participant
S1	Focus group with AWs and JHAs at the PHC Getting an overview of roles and responsibilities as well as primary health facilities, services and infrastructural arrangements they interact with.	JH1-JH5 AW1- AW4
S2	Focus groups with Health Navigators Getting insights about the community experiences and perceptions of different roles of frontline health workers, their counselling activities and additional challenges they face.	HN1-HN6
83	Focus groups with Health Navigators Brainstorming potential interventions to tackle the challenges uncovered by the interviews with pregnant women	HN1-HN6

 Table I. Focus Groups and Visit to the District Hospital

S4	Focus group with ASHAs at the Taluka District Hospital Getting insights into the everyday practices of ASHAs workers, recruitment criteria, responsibilities, motivation, and infrastructural arrangements they interact with.	A1-A4
S5	Focus groups at the Urban Anganwadi Centre Getting insights into the everyday practices of AWs, recruitment criteria, responsibilities, motivation, and infrastructural arrangements with particular focus on artifacts they interact with.	JH6 AW5
S6	Focus groups at the Rural Anganwadi Centre Getting insights into the everyday practices of AWWs, recruitment criteria, responsibilities, motivation, and infrastructural arrangements with particular focus on artifacts they interact with.	AW6 A5 HN6
S7	Visit to the Taluka Hospital and Additional Interviews Confirmation of insights and continuous exploration of practices, roles and perceptions at the THC.	A1 A2

In this paper, we report our engagement with different frontline health workers in rural and semi-urban areas of Karnataka state, South India. Through the help of our local collaborator, MAYA Health¹, we conducted six focus groups with 23 frontline health workers: five Accredited Social Health Activists (ASHAs), six Health Navigators (HNs), six Junior Health Assistants (JHAs), and six Anganwadi workers (AWs), and 27 interviews with community households. The primary data comes from the focus groups in which frontline health workers were invited to discuss about their everyday work practices, roles and challenges in relation to the healthcare services they provide. Table I provides a summary of the focus groups sessions and the visit to the Taluk district hospital. The secondary data comes from the household interviews that mapped the pregnancy journey showing the challenges and interactions between diverse entities of the healthcare infrastructures. The initial analysis was guided by an open coded approach by the first four authors. The material artefacts and arrangements were identified as the main concept from the initial analysis and thereof represent the main concept for further exploration. The study received three institutional ethical approvals from the ethical review boards at the University of Leicester, Loughborough University and the Srishti Institute of Art, Design and Technology.

Infrastructural Artefacts in Community Health

The Thayi Card: Multiplicity of Uses within the Healthcare Infrastructure

The Thayi Card, according to Ministry of Health and Family Welfare Government of Karnataka, is a 'comprehensive mother and child registration booklet', and is used as a unique identification document enabling fair disbursal of public health services under the various schemes, including health counselling, tracking of

¹ MAYA Health: <u>http://mayahealth.net/</u>

vaccination during and post pregnancy, institutional birth, distribution of supplements and nutritious food, and health insurance². It was introduced as part of the Mother and Child Tracking System (MCTS) outlined in the National Rural Health Missions (NHRM) 2005-2012 (Rate 2017). It now continues to be used as a key document to track mothers and infants under the Reproductive and Child Health (RCH) policy initiative (Rate 2017). Apart from the initial intended use, we found multiple usages of the Thayi Card simultaneously figuring as a material element in several practices and how the infrastructural relation to them changes in practice.

Unique identification and tracking of pregnant women in rural areas

In our studies, we found that AWs or ASHA workers or both (based on who is active in a particular locality) conduct periodic surveys of households in their designated areas, and collect a set of basic information for various purposes. One of these is the survey termed as 'line-listing' of pregnant women with the purpose of registering them on the MCTS system and disburse the Thayi Card. An ASH worker mentioned, "We do our own line-listing of pregnant women in our locality, and take the women to PHC to register them (on the MCTS) and get them the Thayi card." (S7A2). At the PHC, information about the pregnant woman is entered manually by a data operator into the MCTS system, which generates a unique numeric identifier for each pregnant woman. This numeric identifier is then printed on the Thayi Card, which is then handed over to the woman and her family. In the areas where ASHA workers are not present, the Anganwadi center becomes the site of registration as the designated JHA visits the Anganwadi center periodically for administering vaccines, counselling, and registering new pregnant women on the MCTS and issue the Thayi card and give it to the women. The unique identifier of the Thayi card is designed to enable access to the digital data from the MCTS system by both the frontline workers and the care- providers at the PHC & THC.

A portable "health record" during and post pregnancy in rural areas

The Thayi Card acted as a form of portable 'health record' of the pregnant women in the rural areas, where all the health information of the pregnant women is either recorded or attached to it. This includes all the information about height, weight, last date of menstruation, due date, etc., and all prescriptions by the doctors at the PHC and blood test reports gets attached (stapled) on the inside of the card. This is done so that the data is available for follow-up at the THC and across other tertiary settings. Although in the urban area an 'Out Patient Department' (OPD) book is used to enter and maintain prescriptions, an ASHA worker mentioned, "*that's* [OPD book] *not available here* [at the rural PHC], *it's only in the urban THC. Here everything is entered directly into the Thayi Card. For medicines and tests they* [doctors] *write in slips and pin it to the card*" (S6A6). Thus, documentation practices are done differently between urban and rural areas. During our interview study, we found that most pregnant women moved to their mother's homes during the third trimester (eighth or ninth month). Here it is important to note that the institutional delivery of care did not get affected, due to the way the frontline health

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Thayi Card: https://www.karnataka.gov.in/hfw/nhm/pages/mh_schemes_thayicard.aspx

workers worked with the portable and unique properties of the Thayi Card and the underlying MCTS system to enable a more or less 'seamless' tracking of pregnant women across the geographical shift.

Thayi Card as a gateway for follow-up and verification

Frontline health workers also used the Thavi Card to verify multiple entries across data-registers (see next section). In particular, the AWs in the rural areas of our study mentioned that they write down the basic data about pregnant women, namely, the last menstruation period, vaccination dates, due date, etc. from the Thayi Card to verify the information recorded during the surveys conducted in their communities and update their data. For example, an AW in the rural area mentioned, "we refer to the Thayi Card and look up the last menstruation period and expected date of delivery and write down correct data [in the Pregnant Women & New Mothers' Register]. First the sister [JHA] would have already entered the date on the card. That data we enter into our registers" (S6AW6). Information logged in the MCTS system through the Thavi Card is also supposed to be used as a means to follow up with women, to provide timely reminders about specific care services they need to access. One of the pregnant women (R1PW3) we interviewed mentioned, "One day before my visit to the PHC, my husband got a call from the PHC reminding of the visit." However, several pregnant women we interviewed did not get either messages or calls reminding them about their upcoming visits either because they had lost their mobile phone (e.g. R4PW3) or changed the phone number registered in the MCTS system. In these cases, frontline health workers often took the initiative to follow-up on women and remind them of their periodic visits.

Acting as a health literacy artefact

The Thayi Card is also intended to be used as an Information, Education and Communication (IEC) material to enhance health literacy of the pregnant women, as it contains infographics explaining the various aspects of home-based pregnancy and infant care that the women and potentially other family members involved need to perform (see figure 1). This includes procedures about maintaining hygiene and cleanliness, suggestions about good nutrition, timely vaccinations, information about nominal height and weight of both the mother and the infant, symptoms to track in case of emergency, etc.

Both the urban and rural frontline health workers mentioned that they use the card infographics to counsel women and their families about pregnancy care at home, particularly about immunization. For instance, a rural ASHA worker mentioned, *"whenever I go for house visits I tell them to read it* [information on the Thayi card]. *I read it to them if they cannot read. We tell them to ask us anything if they cannot understand."* (S6A5). Although we found literacy issues understanding the Thayi card, we also found a multiplicity of uses beyond health education, figuring as material elements with additional roles and meanings in several practices.



Figure 1: a) Illustrations of the Thayi Card regarding potential problems during pregnancy and health services available; b) Information of check-ups, injections, weight and additional details

Thayi Card as a "Ticket" for free care and monetary incentives

In our study, frontline health workers highlighted that the infographic and suggestions are not enough to engage pregnant women as intended by the design of the Thayi card. They discussed how the Thayi Card only represents a 'ticket' to get financial incentives (money varies from 600 to 1400 INR) as part of one of the world's largest conditional cash transfer scheme, Janani Suraksha Yojana, that promotes institutional deliveries (Lim et al. 2010). For example, an ASHA worker mentioned during the interview, "*They* [Pregnant women and their families] *use it only for money.*" (S7A2). The Thayi card acts as a 'ticket' to financial incentives in a direct way, as it has a voucher attached to it when issued, which the pregnant women can claim most of the payment after the institutional birth. A junior health assistant mentioned, "*if the Thayi Card is lost, they will not have the voucher and will not be able to get money back. But they can access other free services due to the unique number* [registered on the MCTS] on it" (S1JH5).

Maintaining Multiple Physical and Digital Data-registers

The household surveys carried out by the frontline health workers usually record details such as pregnant woman's name, age, husband's name, bank account number (for direct transfer of financial benefits), stage of pregnancy, and phone number of the pregnant woman (or her husband's) for sending follow-up information. This information is recorded by the ASHA worker and is also maintained by the AW worker in a physical book / register termed as 'Record of Services offered for Pregnant Women & Nursing Mothers' (see figure 2). In addition, AW workers also verify the distribution of nutrition and track vaccinations that take place at the Anganwadi centre and the ASHA workers keeps the record to keep track of the financial incentives during the postnatal period.



Figure 2. Physical records of pregnant women and nursing mothers at the Anganwadi center

Information collected through these surveys are entered onto the MCTS portal. However only the JHAs and ASHA workers operated the digital portals, and AW workers maintain records in physical form. The portal that came across in the focus groups (S1 and S2) was MCTS portal. However, a JHA informed us that, "MCTS has been cancelled now but there's a new portal called RCH5" (S5JH6). According to a JHA some differences exist: "in MCTS there were 12-14 things to enter but now in RCH there are around 32 things to enter" (S5JH6). She also discourage data entry in the portal for AWs, "If data entry comes for everybody it will seem too heavy. For that we can't even sit anytime and enter. Even if we sit with it for 10 mins the head will feel heavy. I feel if data entry doesn't come for AW is best".

Mobile phones as Infrastructural Artefacts

Mobile phones were present in all our discussions with frontline health workers. The usage patterns varied depending on the role, responsibilities and digital literacy of frontline health workers, as well as perceived benefits versus costs. While some frontline health workers (e.g., S6A5, S5AW5) used feature phones, others (e.g., S5JH6, S4A1, S4A2, S4A3) used smartphones. The majority of the JHAs and urban ASHA workers have smartphones. Mobile phones were mostly used for calling and they served to share care information and coordinate household visits, hospital visits and camps/meetings, etc. We found that calling acted as a key communication channel to coordinate tasks and for quick resolution of issues in practice between women and frontline health workers. Calling was also used for counselling of women and their household members according to need and based on the familiarity with the patient, emergency of the situations and literacy. For example, an AW expressed "for the people who don't know how to read or the ones who don't have time to read, I have given counselling over the phone and asked them to look for things on the mobile. I tell them there is a lot of information about healthcare on the phone itself so look it up" (S6AW6). However, it can also have unintended consequences as described by a JHA (S1JH1) who has both a feature phone, used during community visits only for calls, and a smartphone used at home and for personal use. After couple of incidents of being disturbed late at night by pregnant women and their families who video-called her on WhatsApp, the JHA now only shares her feature phone number, as she considers this less intrusive.

Discussion and Conclusion

Our study shows a number of material arrangements that shape and are shaped by the community health infrastructures in South India. The social, cultural and political properties of the Thayi Card expressed through its multiple uses highlight the visible and invisible arrangements of care infrastructures (Langstrup 2013; Weiner and Will 2018) for community health that are inextricably related (Orlikowski 2007). When used as a portable record of the pregnancy journey including the contact points and use of public and private healthcare services, it also acted as a boundary object (Leigh Star 2010; Bossen et al. 2014) and coordination mechanism (Schmidt and Simonee 1996) (Schmidt and Simonee 1996) facilitating the exchange of information between different social worlds. When used to support health literacy, similar to the digital portals/registers, these artefacts can be seen as devices (Shove 2017) that are directly engaged with, and actively manipulated by women and/or frontline health workers during counseling or documentation practices respectively. The Thayi Card, similar to the physical registers, also have an infrastructural relation with documentation and verification practices that enable access and provision of healthcare services. Mobile phones emerged as an important infrastructural artefact that helped frontline health workers to actively call each other to share information, coordinate activities, and regain awareness while dealing with internally infrastructural misalignments and even nonalignment between frontline health workers practices. Mobile phones also acted as a medium to provide counselling to the pregnant women and families with some unintended consequences for the frontline health workers when receiving video calls.

Rather than focusing on the biopolitics of global health (Prince 2012; Storeng and Mishra 2014; Kenny 2015), our study shows the importance of understanding the multiple roles and usages of artefacts and the internal dynamics and local context of community health in practice before the design and introduction of digitally enabled infrastructures in developing countries (Schräpel 2010). Our future work seeks to further understand the invisible, infrastructural (Gui and Chen 2019) and emotional (Park 2017) work that frontline health workers do configuring, connecting, communicating, adapting and sustaining infrastructural arrangements within and across different healthcare settings to make them work for them and their communities. We are interested in further investigating the intended and unintended outcomes of infrastructural arrangements and misalignments and how these can be re-imagined, enhanced, or mediated through ICT to make them more visible (Calkins and Rottenburg 2017) to support a mutual reconfiguration (Tang et al. 2015) and negotiation of the multiple human and nonhuman entities in community health infrastructures. Our findings are most likely far from complete and we encourage HCI and CSCW researchers to continue investigating the socio-cultural practices and material arrangements that conform and influence pregnancy care infrastructures as well as the many intersecting infrastructures (Bjørn and Boulus-Rødje 2018) that can influence community health in developing countries.

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