

## KEYWORDS

Infrastructuring work; community health; pregnant women; pregnancy care; digital health

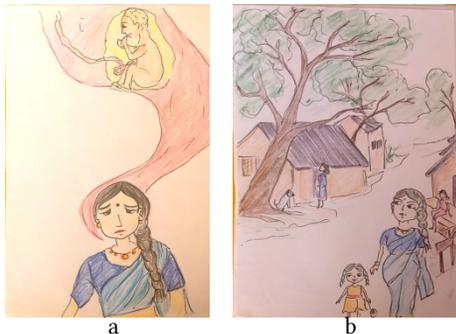


Figure 1: a) Kamala remembering her first pregnancy, and b) Kamala with her daughter as a result of a successful second pregnancy.

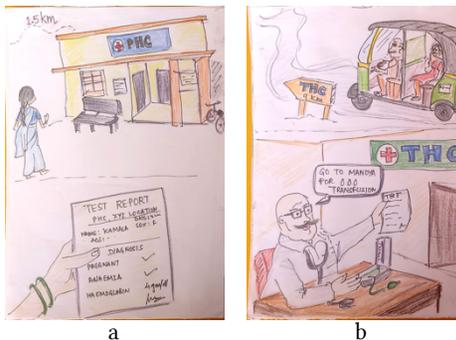


Figure 2: a-top) Kamala visited the PHC to perform some tests, a-bottom) The PHC confirmed that Kamala was anaemic, b-top) Kamala and her husband travelled with the ASHA worker to the THC in a tuk-tuk, b-bottom) the doctor at the THC suggested to get a blood transfusion

# Infrastructuring Work during Pregnancy Complications in South India

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## ABSTRACT

The fragmented nature of healthcare services challenge pregnancy care in South India. In this case description, we show the amount of work that pregnant women, their caregivers and frontline health workers do supporting and sustaining the existing care infrastructures with particular focus on pregnancy complications. Our findings highlight how multiple stakeholders navigate through physical and social boundaries across public and private healthcare services. Based on a particular scenario, we propose a design concept to create an interactive and collaborative diet chart to promote the change of food habits and support the community healthcare infrastructure.

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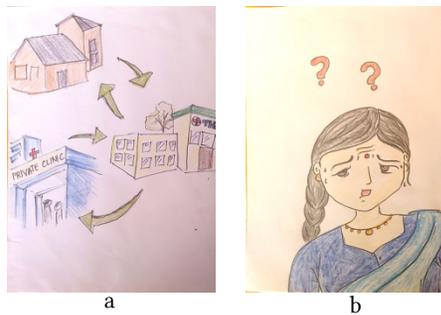
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**Figure 3:** a-top) Kamala Hb's level decreased to 7 (g/dL), a-bottom) Kamala with the diabetologist at the THC, b-top) Kamala and her husband consulted a private diabetologist, b-bottom) Kamala started an insulin treatment.



**Figure 4:** a) Kamala's interactions with the public and private healthcare services, b) Kamala worries about her health after all her efforts to keep control of her diseases

## INTRODUCTION

The fragmented and complex nature of healthcare care services as well as the socio-cultural inequalities, practices, and community perceptions challenge pregnancy care infrastructures in South India [1, 3, 7, 8]. These challenges are exacerbated by the low utilization of existing healthcare services [11] as well as the increase of non-communicable diseases [6]. Healthcare services are usually provided at three levels including primary health centres (PHC) and sub-centers (SC) at the first level providing basic medical assistant regarding maternal and child health, prevention and control of diseases, health education, and etc. [7]. The second level includes district hospitals (THC) and community health centres and the third level includes more specialized hospitals [7]. Besides the vast public health infrastructure and existing maternal health programmes (e.g., Janani Suraksha Yojna, etc.), many women still do not have access to pregnancy care services [5]. In particular, Karnataka state has seen a shortfall of the human infrastructure (e.g., junior health assistants, medical specialists) at the SC and district level and a decline in the utilization of public health services as people often prefer private services over public ones [7]. To alleviate the burden in healthcare services, a number of frontline health workers are becoming the first and often the only access to basic health services in rural areas [9, 10]. As a result, women and caregivers interact with heterogenous stakeholders in pregnancy care, however, due to its fragmented nature with many breakdowns, they often spend a lot of effort and money when seeking help [5]. Through a series of workshop with different community stakeholders [1], we started a project investigating the everyday challenges of pregnancy care in South India. In the following scenario, derived from our user studies, we highlight the everyday challenges and experiences of women and their caregivers when seeking help during pregnancy complications:

*Kamala is 7months pregnant and lives in a joint family. This is her third pregnancy and her first on was eight years ago that ended in a still birth at the eighth month (see Figure 1a). Her second pregnancy was successful and she has a 3 years old daughter (see Figure 1b). To confirm her third pregnancy, as she started vomiting and her period stopped, she walked to the nearest PHC about 1.5km away (see Figure 2a-top). The test at the PHC not only revealed her pregnancy but also confirmed that she was anemic with low hemoglobin (Hb) count (4g/dL) and she was asked to go to the THC for a follow-up (see Figure 2a-bottom). The frontline health worker, Sarita who is an accredited social health activist (ASHA) in the local area, took Kamala and her husband to the THC by an autorickshaw (tuk-tuk) which is located 9 km. away from her village (See Figure 2b-top). At the THC, the doctor suggested to go to the Mandya Hospital that is 40 Km away to get a blood transfusion (see Figure 2b-bottom). Kamala and her husband traveled to the Mandya Hospital by public transportation where she was administered two pints of blood over six days. After the blood transfusion, her Hb levels went up to 9 (g/dL), but dropped to 7 (g/dL) after a month (see Figure 3a-top). Kamala and her husband went back to the THC and her doctor told her to get a "blood tube" [a pint of red blood cells through IV transfusion] and this was performed at the THC. While her Hb increased, Kamala also became aware that her glucose levels have increased during her periodic test at the THC. Kamala was referred to the diabetologist at the THC who recommended to initially control her glucose level through diet and exercises (see Figure 3a-bottom). However, her glucose levels were not in control.*



**Figure 5: Gathering information about the current diet to support the creation of a collaborative diet plan**



**Figure 6: Visualizing the current diet and “ideal” diet after creating the collaborative diet chart**



**Figure 7: Adding notes, voice recordings and other meals to the diet chart**

Subsequent tests revealed that her glucose was continuously high and she consulted a private diabetologist in Channapatna, one km. away from the THC. The diabetologist put Kamala on an insulin treatment and recommended weekly blood tests at his clinic. Now on her 7<sup>th</sup> month of pregnancy, Kamala moves between the THC to meet her doctor, the private clinic to get blood tests and back to the THC with the results, and then back home after a hectic full-day trip in a tuk-tuk (see Figure 4a). In addition, Kamala also visits the private lab in Ramanagara to get ultrasound scans.

## DISCUSSION AND DESIGN OPPORTUNITY

The scenario revealed different challenges and the amount of “infrastructuring” work that Kamara, her husband and the ASHA worker performed while navigating, connecting, and adapting different public and private healthcare services to the woman’s needs. This immense amount of physical, social and emotional work almost on weekly basis left Kamala very worried and stressed (see Figure 4b). Although Kamala and her family perceived the transfusions to have caused diabetes, both of these conditions are driven by poor diet. Thus, we envision a socio-technical solution taking advantage of the tablets frontline workers use while performing household visits. The main concept idea is to support frontline health workers and pregnant women to collaboratively plan and create diet charts (see Figure 5 and 6) aiming to track women’s diets, and any additional information e.g., notes and voice recordings (see Figure 7), during household visits promoting habit formation and health education that can potentially lead to a change of food habits.

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