Bridging Disconnected Knowledges for Community Health

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We present a qualitative inquiry of the Mohalla (neighborhood) Clinics introduced by the government of Delhi (India) to improve access to healthcare among the “weakest sections of society”. We share our findings from fieldwork conducted in and around two Mohalla Clinics to understand the provision and uptake of healthcare services and healthy practices, uncovering factors that obstruct access and adoption. We thus draw on and extend research that examines challenges facing public health infrastructures in underserved contexts by taking a critical feminist approach. Using Haraway’s lens of situated knowledges, we highlight the disconnects present across the partial perspectives of the clinics’ stakeholders, including the healthcare providers, community health workers, and patient groups. We also analyze how these disconnects affect collaborations, negotiations, and contestations around healthcare. Finally, we provide takeaways from our research towards bridging disconnected knowledges by way of redesigning healthcare interventions, revisiting patient empowerment, and redefining the role of frontline health workers as key infomediaries.

CCS Concepts: • Human-centered computing → Empirical studies in HCI;

Additional Key Words and Phrases: Healthcare; situated; India; qualitative; HCI4D; ICTD

ACM Reference Format:

1 INTRODUCTION

A vast and growing body of Computer Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI) research is engaging with healthcare systems globally to target improved provision and uptake of healthcare (e.g., [28, 53, 91, 113]). Much of this work occurs within large-scale public health infrastructures that necessitate collaborations across variously motivated actors from disparate backgrounds, including doctors, patients, frontline health workers, and funding organizations (e.g., [2, 17, 55]). Combined with the fact that healthcare is laden with values, emotional labor, and differences in expertise (e.g., [40, 47, 105]), it is difficult to understand how public health infrastructures can be designed to meet the needs of diverse stakeholders. This is particularly true for underserved contexts, where differences in stakeholders’ perspectives may be further amplified due to the presence of greater inequities.

We study the complex ecologies of the Mohalla (neighborhood) Clinics in Delhi (India) as a relatively recent and highly relevant example of the types of infrastructures being implemented to improve access to healthcare in underserved contexts. Delhi’s state government introduced...
these clinics in 2015 [85], advertising them as a respite from otherwise long waiting times and expensive healthcare options to address basic health needs of the “weakest sections of society” [85, 109]. Comprising the lowest tier of a comprehensive three-tier healthcare system proposed by the government [80], Mohalla Clinics proposed to cover the last mile in healthcare delivery by offering free consultations to patients, medication, and over 200 medical tests. Government hospitals and poly-clinics make up the first and second tiers, respectively. At present, over 100 Mohalla Clinics have been set up to support the existing understaffed and overworked facilities. The Delhi government claims it will open a total of a thousand such clinics across the city [80].

To understand how this newly introduced public health infrastructure might accomplish its ambitious objectives, we began our research by asking who the (intended) stakeholders in the Mohalla Clinics infrastructure were and how the clinics engaged them. This led us to uncover the use and non-use of the clinics, as well as the diverse priorities and practices of stakeholders in the clinics’ ecologies. Seeking to understand the processes that effected patterns of use and non-use, we asked how the material and human elements (e.g., doctors, patients, medicines, advertising) of formal and informal healthcare infrastructures (e.g., clinic appointments, alternative medicine) interacted with each other, under the influence of intersecting societal and cultural norms. To construct a holistic understanding of the clinics’ functioning from these multiple parts and processes, we analyzed our data through Donna Haraway’s lens of situated knowledges, in which she argues for “politics and epistemologies of location, positioning, and situating, where partiality and not universality is the condition of being heard to make rational knowledge claims” [41]. Haraway’s call for situated claims and insistence on retaining complexity was apt for making sense of the Mohalla Clinics, without reducing or prioritizing away the varied needs of its diverse stakeholders.

We contribute to CSCW research a rich application of Haraway’s lenses [41, 42], to obtain deep insights regarding the design of and for a complex multi-stakeholder sociotechnical system. To healthcare research in CSCW and HCI, in particular, we demonstrate how Haraway’s perspective generates opportunities for technology design to bridge disconnects across stakeholder perspectives, and create room for collaborations. Additionally, we highlight how the target patient groups’ perspectives are not adequately understood, represented, or addressed in the current design of the clinics. Here we expand the scope of research on patient empowerment (e.g., [40, 67, 81, 89, 98]) to include complex, underserved environments. Finally, we show how the situated knowledges of frontline health workers (popularly known as ASHAs, short for Accredited Social Health Activists) place them in a unique position to bridge the perspectives of doctors and patient groups targeted by the clinics. Thus, to global health research in the field of Information and Communication Technologies and Development (ICTD), we provide a critical perspective on the ASHAs’ roles as infomediaries and not just intermediaries (as discussed in prior research [28, 91, 113]). Overall, we derive implications for design that might connect and leverage partial and situated (if disconnected) knowledges in meaningful ways, to benefit an actively growing research focus on constrained healthcare environments.

2 RELATED WORK

Our paper draws on and extends research that examines challenges facing public health infrastructures in underserved contexts by taking a critical feminist approach informed by Haraway [41, 42]. Our analysis also contributes to CSCW literature by deepening its understanding of collaborations, negotiations, and contestations around healthcare. We detail these contributions below.

The CSCW and HCI communities have long looked at improving access to and quality of healthcare through the use of technology in diverse settings (e.g., [52, 69, 76]). This work intersects with ICTD’s expanding focus on healthcare in underserved contexts (e.g., [28, 54, 77, 86, 107, 113]). Such contexts are often located in the Global South, and characterized by unorganized markets in...
health services and commodities, porous boundaries between public and private health care sectors, and lack of state regulatory capacity [5, 6]. Resource allocation is frequently a challenge, with low doctor-to-patient ratios and a lack of skilled healthcare professionals [27, 88]. In India, frontline health workers have been shown to be critical for covering the last mile in healthcare delivery to help patients get the care they need, interfacing between local communities and larger public health infrastructures [99]. Prior research on these frontline workers in ICTD has focused primarily on capacity building, information dissemination practices, and improving medical expertise (e.g., [28, 56, 74, 91]). We extend this literature by examining the workers’ situated knowledges; in particular, we highlight their unique ability to surface target patient groups’ partial knowledges, so that healthcare interventions might better connect with patients’ lived realities, which are increasingly receiving attention from HCI researchers as they unpack the impact of environment, culture, social dynamics, and gender on health (e.g., [54, 55, 77, 103]).

Information-sharing between stakeholders in healthcare settings has been extensively studied, and signals the importance of formal and informal communication in assessing quality of health and decision-making around terms of care [19, 100], such as through support groups [12, 63] and discussions between doctors and patients [67]. We extend this work by leveraging our data on the use and non-use of the Mohalla Clinics to reveal multiple disconnects, particularly between the healthcare providers and the target patient groups. We study these disconnects using Haraway’s work on situated knowledges, which prior research has drawn on to question the positionality of HCI researchers [34], highlight the importance of reflexivity in HCI research dissemination practices [18, 61], or preserve perspectives [21, 94]. Haraway highlights the epistemologies of location—asking us to question what we know (or do not know) about a system when we take a certain point of view [41]. She uses the metaphor of “vision” to highlight the embodied nature of knowledge and describes seeing as a physical act that is always situated in a complex and biased body, rejecting the notion of disembodied objectivity—“a gaze from nowhere” [41]. Investigating the factors that obstruct vision from every point of view allows us to make recommendations for technology design that can work with these obstructions to thereby resolve pending disconnects between knowledges.

Unpacking situated knowledges is particularly challenging when engaging in an ecosystem fraught with politics and contradictory opinions, such as the Mohalla Clinics. Haraway further stresses on the coexistence (and acceptance) of contradictory knowledges in A Cyborg Manifesto [42], where she offers the political myth of a cyborg—an amalgam of animal and human, machine and animal, and physical and non-physical. The cyborg represents a utopian vision where beings do not belong to some essential category, but are constructions of partial and contradictory standpoints. Although Haraway primarily uses this metaphor to refer to the self [14, 42], we borrow the cyborg myth to think about public health infrastructures, comprised of human and non-human, physical and non-physical elements (such as stakeholders, resources, infrastructures, rules and regulations). The cyborg thus represents a patchwork of perspectives in the ecology of the Mohalla Clinics, all of which are partial, frequently contradictory, and currently disconnected from each other. While the metaphor of vision helps focus on the perspectives of individual stakeholders, the cyborg myth allows us to investigate how these knowledges interact with each other and non-human elements. This leads us to consider how technology might lead to better collaboration between disconnected knowledges, and how technology itself might offer a form of situated knowledge.

Despite prior attention to greater involvement of multiple stakeholders in health interventions (e.g., [9, 35, 45, 56, 70]), an understanding of partial knowledges remains fairly nascent. There is an implicit assumption that there exists a scientific truth that healthcare providers, or those implementing the intervention, are privileged to know and share with (potential) patient groups. This undermines the knowledge that the target communities hold that can inform practice, such as
challenges they face in implementing medical advice and gaining access to healthcare facilities, preferences for different types of care, and cultural beliefs and practices. Additionally, interventions are often rolled out in collaboration with organizations (e.g. [28, 86, 113]), and might be highly partial to the agendas of these organizations. The lens of situated knowledges is thus essential to aligning the design of public health interventions with feminist and activist approaches rooted in civic participation and a serious consideration of the environment in which interventions are deployed [7, 22, 33, 60, 108].

CSCW research has studied tensions around collaborations amidst public health interventions, sans examination of situated knowledges. This work includes investigations into the role of digital technologies in negotiations and contestations around care (e.g., [20, 38, 47, 69, 90]). Such contestations often revolve around the roles that patients and caregivers play in healthcare. Research on the use of ICT by critically ill patients to retain ‘normalcy’ [64], balancing of caregiver roles with personal life and relationships [19], and self-management of disease [82] contribute to an understanding of individual stakeholders. Specific to patient empowerment, recent work on collective sense-making by patients on online health forums [65] and patient behavior during emergency visits [84] focuses on patients playing active roles towards their care. Research on the effect of internet health information on patient-physician interactions and underlying power dynamics [15], and on the role of patients and informal caregivers as care partners during hospital stays [69, 71], further indicate a move away from a limiting, top-down perspective where patients are passive recipients of care [71]. Our research expands the scope of patient empowerment to include the situated knowledges patients can offer their healthcare providers.

3 METHODOLOGY

We studied the Mohalla Clinics intervention in the Batla House and adjacent Zakir Nagar areas of Delhi, which consist of urban but predominantly low-to-middle income neighborhoods [95]. These areas are largely occupied by illegal migrant settlements lacking access to basic services. We took a critical ethnographic approach to examine social inequalities and the role of social structure, power, culture, and human agency [13]. In this paper, we use the clinics’ intervention as a probe to unpack the challenges and complexities that arise in accessing and providing healthcare. We aim to inform the design of interventions targeting similarly under-resourced contexts.

We conducted extensive (non-participant and participant) observations, recording data in the form of photographs and handwritten notes, and semi-structured interviews, in the form of audio recordings. We studied two Mohalla Clinics (700m apart), a government dispensary, and six nearby slums that the clinics were supposed to serve. Interviewing patients as well as slum residents allowed us to uncover factors leading to both use and non-use of the clinics. Our fieldwork lasted three months (May 2016 to July 2016), including one month in clinical settings and two months in the slums. We interviewed four ASHAs, three doctors (one at each clinic and one at the dispensary), four staff, one Auxiliary Nurse and Midwife (ANM), three Non-Governmental Organization (NGO) workers, 30 slum residents, and 30 patients (15 at each clinic).

Almost all patients we interviewed had visited the clinic at least once during the previous month; many described themselves as repeat visitors. Patients belonged to low-income groups (i.e. the target “weakest sections” [80]) and lower middle-income groups. Based on the Housing and Urban Development Corporation classification, target low-income groups include those with an annual household income under INR 2 lakhs (approx. USD 3.1K) and lower middle-income groups include those with incomes between INR 2 lakhs and 12 lakhs (approx. USD 3.1k to USD 18K) [23]. All interviewees at the slums and Yamuna Clinic belonged to the low-income group. At Nooh Clinic, two of 15 interviewees fell in the low-income group, and the remaining belonged to the lower middle-income category. Many interviewees were migrants from the states of Bihar,
Uttar Pradesh, and West Bengal. Participants were predominantly Muslim and 18-68 years old. We gained appropriate access to the six slums we studied while conducting participant observation with the ASHAs. The ASHAs introduced us to these communities and we recruited participants using snowball sampling [37], gaining referrals to other members in the community. In the clinics, we recruited patients while they were waiting during peak hours. Interviews in the clinics generally lasted 15 to 30 minutes, although some went over an hour. Interviews outside the clinics lasted 30 to 60 minutes. The questions we asked in our interviews focused on the interactions between different actors in the healthcare system, ranging from patients to workers to experts, also inquiring about their engagement with the system (or lack thereof), and the factors that influenced it.

Extensive observations inside clinical settings allowed us to observe patient-doctor interactions and the staff’s workflows. We also accompanied health workers on house visits to observe their work in the slums. These took a total of approximately 15 hours of observation at Nooh clinic, 20 hours at Yamuna Clinic, and 30 hours in the slums. Since most patients visiting the clinics were women, and the ASHAs generally talked to women during their house visits, most of our interviewees were women too. This bias in our sample means that our findings naturally lean towards concerns and challenges faced by women. Also, some migrant groups we encountered spoke in languages we did not know. For understanding the health practices of these groups, we relied on intermediated perspectives shared by the ASHAs, who belonged to the lower middle-income group. This fieldwork was rigorously reviewed and approved by the institutional review board at our university. This also entailed obtaining necessary written permissions from the Mohalla Clinics in Delhi.

All three authors collectively analyzed our data using the inductive process documented by Merriam [68]. We began with open coding, assigning codes to short phrases. Our first round of coding generated codes such as “discovered clinics by chance”, “lack of access to clean water leading to rashes”, and “lack of awareness about the clinics” that followed our data closely. The following rounds of coding resulted in higher level codes such as “locating the clinics”, “medical conditions faced by slum communities”, and “localized sharing of information”. To ensure quality, all the authors coded the data separately and the generated codes and themes were discussed together. During
Table 1. Participant demographics for the study.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age Group</th>
<th>Location</th>
<th>Role</th>
</tr>
</thead>
<tbody>
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<td>P1</td>
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<td>Noor Clinic</td>
<td>Patient</td>
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<td>P2</td>
<td>F</td>
<td>30-35</td>
<td>Noor Clinic</td>
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<td>P3</td>
<td>F</td>
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<td>Noor Clinic</td>
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<td>P4</td>
<td>M</td>
<td>40-45</td>
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<td>D6</td>
<td>M</td>
<td>55-60</td>
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<td>Doctor</td>
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<td>Staff</td>
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<td>Patient</td>
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<td>20-25</td>
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<td>F</td>
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this iterative coding process, we focused on findings around delivery and uptake of health services and healthy practices, and how they shaped and were shaped by the various stakeholders in the state healthcare system. It is this process of inductive analysis that surfaced themes around partial perspectives and brought us to engage with Haraway’s lens of situated knowledges [41]. We also note here that though we had multiple data sources during our field work—doctors, patients, NGO workers, ASHAs, and health staff—triangulation was not always an appropriate choice for checking...
data quality because of the contrary viewpoints that various groups sometimes held, even within the same group (such as across patients). Our analysis focuses on experiences and opinions that were echoed by multiple participants, also presenting contrary opinions.

All data was collected, transcribed, and translated by the first author who is fluent in the local dialect and has lived in the neighborhood for a year, at a five-minute walk from both clinics. This allowed for a grounded experience and extended interactions with participants, situated in the larger historical, sociocultural, and political context. All three authors are women of Indian origin and have conducted research across India, including in Delhi. We share a commitment to local and global development, and are sensitive to social constructs such as class and religion in our work. As we engage with Haraway’s notion of situated knowledges [41], we emphasize that the analysis we offer is situated, presented through the lens of our biases, conscious and unconscious. In keeping with Haraway’s recommendations and a feminist alignment with self-disclosure, we recognize these biases as we present our findings. Our own partial perspective renders “objectivity” impossible [41]; instead we strive towards a self-reflexive discussion of the various knowledges we encountered in the ecology of the Mohalla Clinics.

4 FINDINGS

Our findings detail the challenges in the delivery and uptake of the Mohalla Clinics, highlighting the intervention’s inattention to the partial and disconnected knowledges across its various human and non-human components [41, 42].

4.1 Locating the Mohalla Clinics

After asking around and checking with multiple small businesses, many of whom were unaware about the clinics or vaguely recalled a “dispensary”, we were able to locate two Mohalla Clinics in unremarkable buildings, with a single nondescript banner indicating their presence. The information-sharing potential of physical clinical spaces has been highlighted before [110], and our findings showed that other material infrastructure like banners, location, and housing structures also carry political implications for healthcare uptake, as we outline below.

Interviews with patients at the clinics revealed that many residents frequenting the clinics had been informed about their existence by a neighbor or family member and lived “right (t)here” (P4). Other patients had trouble locating the clinics and learned of them only by chance—P2, for example, lived near Yamuna clinic and told us, “I just happened to be passing by and saw a crowd. I asked someone what was happening and learned that a dispensary had opened.” We asked slum residents about the Mohalla Clinics during our house visits with the ASHAs, and learned that most residents were unaware of the clinics’ existence. P16, who lived across the road from Yamuna Clinic, said, “There is no dispensary near my place. Are you sure? I did not hear of this in my community, no one mentioned it to me.” Once participants learned about the clinic, however, they voiced willingness to visit. For instance, P1 told us that though she had discovered it by chance, she would “come again to show [her] children to the doctor.” The stark contrast in perspective of the clinics’ users and non-users may indicate that not only was information about the clinics hard to find, but was also isolated within communities, with many low-income communities unaware of their presence.

We tried to understand why information dissemination about the clinics was leading to isolation of knowledge within communities. The doctors told us that the government relied on word of mouth to spread information about the clinics to avoid overcrowding. This resulted in distribution of this knowledge based on the limits of residents’ social ties. Moreover, radio and newspaper advertisements did not indicate locations. Although there were sources providing the locations on the internet such as the state government’s Facebook page [1], these were not generally accessed across low-income groups given the cost of accessing the internet and their limited internet
savviness, as we found. Such dissemination could further lead to only higher socioeconomic groups encountering information about the clinics. Appropriate media for disseminating information among underserved populations [73] and across “digital divides” [4, 54] have long been discussed in ICTD, CSCW, and HCI. Our findings indicate the importance of also taking into account the potential of media outreach to amplify inequalities between various socioeconomic groups, even within the same neighborhood for the same intervention, which the Mohalla Clinics failed to do.

Given that all our participants either owned or had access to a mobile phone in their household, knowledge about the clinics could also have been disseminated via SMS messages. In fact, during interviews with slum residents we found that they often received SMS/MMS messages from many local health programs with information about healthy practices and government services. However, P16 shared, “we get so many such messages that we rarely see them.” Thus, the patients’ situated knowledge of healthcare information offered by mobile phones was a combination of information from sources that actually interfered with each other. Interviews indicated that residents, hence, relied on ASHAs—who were employed by the health department of the Delhi government (also responsible for instituting the clinics)—to receive information about health services. Though this resulted in some redundancy of information, it also served as an important reinforcement tool, as uncovered in prior work in clinical settings [11]. ASHAs were expected to visit each household in the area assigned to them by the government, and to conduct demographic surveys, provide information about healthy behaviors, and deliver maternal care. However, they shared that though they were responsible for disseminating information about government healthcare services such as monthly immunization drives, they were under no obligation to mention the clinics. This may have been a deliberate decision by the government or an oversight, but highlights the need for collaboration across interventions to prevent patients from feeling overwhelmed with information and to guide them to relevant health resources.

We see that as a consequence of the processes described above, knowledges were situated and isolated within groups. Even though the clinics were physically within reach, communities had not heard of them. The situated knowledges offered by mobile phones (SMS messages), media, and signboards were a translation of the knowledge meant to be delivered by government, but they could be received differently (or not at all) by target groups than intended. The presence of these tiny knowledge clusters amidst larger spaces of ‘not knowing’ evidently kept the Mohalla Clinics from reaching their target patient groups. While the information reaching a larger population might not be desirable from a logistical standpoint, reaching the target population was a stated goal that was not finally addressed. Here, we note that a longitudinal study might account for the impact of time on the distribution of information among different communities, which we did not examine. We also note our bias towards the perspectives of the underserved communities, further shaped by our limited access to the government’s perspective as we were unable to interview those implementing the Mohalla Clinics despite arduous efforts.

4.2 Uptake and Operation of the Mohalla Clinics

Nooh Clinic was located in a well-maintained apartment complex, and Yamuna Clinic was near the slums along the polluted Yamuna river [72]. The locations shaped who visited each clinic—naturally, most visitors lived close by. As a result, although the clinics were within a ten-minute walk from each other, the visiting populations were socioeconomically distinct.

Our observations and interviews at the Nooh Clinic showed that the clinic was teeming with patients, most of whom were women belonging to the lower middle-income bracket whose families earned a living as auto-rickshaw drivers, tailors, shopkeepers, and owners of small businesses. The clinic treated over 100 patients in the four hours it operated daily, with waiting times varying between ten minutes to an hour depending on the time of day (based on our observations and the
the crowds grew later in the day. The per-patient consultation time ranged from one to ten minutes depending on the medical condition, with consultations lasting around two minutes on average. Each patient’s demographic and medical information was recorded using a tablet provided by the government. However, a doctor (D6) shared, “This is a nuisance. It takes so much time to record the data and distracts me from my work. … The government also wants me to take pictures of patients but I don’t always do that, some Muslim women wear the burka and don’t like to have their picture taken.” A similar sentiment was echoed by the doctor (D13) at Yamuna Clinic (discussed in detail later) who stated, “The mobile application developers just want the data we are collecting. I have heard that there is money to be made by selling data.” Though the tablet represented an opportunity to capture and reflect the situated knowledge of both patients and doctors, the doctors were not convinced of its purpose or usefulness.

All participants reported being satisfied with the service provided at Nooh Clinic when asked about their experience. Though we clarified to our participants that we had no stake in the intervention, we acknowledge that the highly positive responses may be an indication of bias as a result of our position of power relative to the participants [26]. Our interviews indicated that before the opening of this clinic, some participants had frequented the government dispensary five minutes away and waited long hours for a consultation, while others visited private clinics in the area that charged INR 80-400 (approx. USD 1.2-6.1), not inclusive of medicines. The introduction of the Mohalla Clinics was seen as a relief by these individuals. Media articles also aligned with these findings—interviews conducted with patients at Nooh Clinic primarily reported positive experiences and ease in healthcare access with the setup of a free Mohalla Clinic in the area [3, 30].

We observed that patients visiting the clinic would sometimes encounter friends while waiting or discover common acquaintances during conversations with fellow patients. This was not unexpected since the patient population was fairly homogeneous in terms of socioeconomic status (lower middle-income) and most patients learned of the clinic from friends and family. Contrary to findings in previous research, which uncovered that patients experience clinical spaces to be harsh environments to access and exchange information [110], we observed that the physical space of the clinics was comfortable and conducive to sharing knowledge, perhaps due to ties between incoming patients, and limited space, facilities, and distractions. However, more could be done to facilitate collaboration and information-sharing using existing artifacts. We observed that the posters in the clinics received little attention despite providing information on topics considered high priority by the government, such as maternal health and tobacco cessation. In comparison, a randomly placed weighing scale was an object of curiosity and there were often people waiting to use it. Such artifacts indicate that design could better guide conversations and sense-making activities among patients [76] and reflect the situated knowledge and experience of the doctors by communicating health information they think is relevant for incoming patients.

On visiting the Yamuna Clinic, we formed a different impression of the healthcare provision activities of the clinics. The operation of this clinic was very similar to that of Nooh Clinic—the available facilities, waiting times, consultation time per patient, and hours of operation were comparable. Though two participants reported dissatisfaction with their experience (the services they expected—bandaging and scabies medicine—were not available), all others reported being satisfied. However, in contrast to the crowd visiting Nooh Clinic, most patients here were women belonging to low-income groups. Further, the doctor (D13) at the clinic noted: “After over 30 years of medical practice, I am seeing classic medical conditions here that I only read about in medical textbooks.” He was referring to cases of worm infestation, malnutrition, scabies, and eye infections that he treated every day. He also shared that he frequently encountered cases of abuse, poor sexual health, and pregnancies at a young age that he found himself (and Yamuna Clinic) ill-equipped to
deal with. These problems seemed unique to low-income patients and our interview with D13 further revealed the shortcomings of the health system in addressing the needs of this population:

"Most patients visiting this clinic have poor education and belong to low-income groups. They aren’t knowledgeable about healthy practices. Many women coming here were married young and have three to six children. … Also, many people do not keep medicines at home or use medicines left over [from prior consultations], to them keeping them is like a bad omen and they throw them out. Educated people keep medicines at home and know what to take and when, but these people do not have this awareness." (D13)

The doctor’s account of medication being thrown away indicates how providing the medical (situated) knowledge of doctors and free medication (and other material resources) is not enough. In the absence of a culture of taking medicine, medicine takes on a different meaning and may be considered to be inauspicious. Additionally, as seen above, the difference in physical locations, despite the short distance of 700 meters that separated them, evidently played a significant role in the delivery and adoption of healthcare services. HCI and CSCW research may benefit from paying more attention to where interventions are introduced in the larger healthcare infrastructure and surrounding ecology.

Despite certain concerns and limited support from the government for dealing with the needs of disadvantaged groups, doctors at both clinics appeared positive about the intervention. However, our interviews indicated that better understanding of the doctors’ perspectives could shape the design of the intervention to be more sustainable:

“I think the Mohalla Clinic is a very good initiative, it is giving a lot of relief to the patients. One issue with the initiative and its sustainability is that the doctors and staff are paid very poorly. At least if they stop paying, the doctors can work as long as they want.” (D13)

Our interviews indicated that the relationship between ASHAs and doctors was cordial and they had frequent encounters. ASHAs often consulted the doctors about medical conditions, shared family and personal concerns, and received free medication to treat medical problems in their family. The doctor at Nooh Clinic (D6) occasionally interfaced with the ANM in the area regarding medicines and supplements that she needed to distribute among residents. However, the doctor at Yamuna Clinic (D13) had a strained relationship with the ANM (A29). He shared his perspective on how though the Mohalla Clinics were supposed to coordinate and be staffed by the area’s ANM, she was rarely present to help. During our time there, he also had an argument with the ANM about immunizations taking place right outside the clinic and disrupting his work due to the resulting noise. Improved collaboration and sharing of situated knowledges about operation of the clinics and the responsibilities of each type of health worker could help align the goals of doctors, ASHAs, and ANMs to resolve the current disconnect.

4.3 Bottlenecks on the Healthcare-Seeking End

The clinics’ timings and waiting times were serious deterrents to seeking healthcare. The clinics operated only during the day and participants were unable to take a break from work to visit the doctor due to the financial loss involved. P10 shared why she visited private clinics, saying, “Throw money at them and the work gets done [quickly].” This is in contrast to the time she would have to spend waiting in a government clinic. More darkly, P1 shared the consequences of waiting for healthcare—an acquaintance who waited a month for her appointment at a government hospital “was already dead by the time her turn arrived...” However, the clinics too faced resource constraints which prevented them from providing extended hours. All the doctors and staff we interviewed had either accepted employment to supplement another source of income or to give back to society. Finding such doctors and staff willing to accept a low pay was likely difficult. Extending hours
was not desirable for the existing staff either as D13 pointed out: “The government should consider limiting the number of patients. This is a very stressful job, I see a lot of patients for four hours and I want to be able to give each patient my full attention.” The political hurdles the government faced in the implementation of the Mohalla Clinics, which have received significant coverage in the media [79], made addressing resource constraints even harder.

The Mohalla Clinics also take into account our participants’ reliance on folklore and alternative medicine. Target patient groups lived in slum communities, which were comprised of open dwellings that facilitated information-sharing in general. Participants relied heavily on the testimonies of their family and neighbors regarding the type of care to seek. Sometimes this involved turning to folklore knowledge and Complementary and Alternative Medicine (CAM) [24] instead of allopathic forms of therapy, a pattern also reported in recent research [43]. There was a prevalence of “chhota-mota” (small-time) doctors—practitioners who are unqualified or practice alternative medicine [36]. P17 told us that these doctors were the first resort for most people in her community: “See these three small clinics? These are where most people [in my community] go. They take INR 50 [approx. USD 0.8] and are chhota-mota doctors. If something is beyond their expertise, they tell us to go to a better doctor.” There were other community-specific, non-medical ‘solutions’ that participants turned to. For instance, P19 shared that when a family member was facing a mental illness, the family decided to visit a local priest and perform prayers despite P19’s recommendation to consult a psychotherapist. When P24 had a broken arm, her family suggested visiting a local wrestler to set the bones in place despite her preference for visiting a doctor for an X-ray. We see that there were several kinds of medical knowledges that existed in the ecosystem and competed for the patients’ attention. They varied in terms of monetary cost, treatment effectiveness, mental comfort, and community trust. Acknowledging the value that patients place in these knowledges is necessary to be able to design patient-friendly interventions. We note our bias, and indeed the bias of most research interventions, towards allopathic treatment, but also acknowledge our sympathy towards alternative therapy due to exposure to circumstantial evidence of their effectiveness while living in Indian households.

In the case of migrants, who made up a large percentage of the target patient groups, our interviews indicated that missing documents posed as common deterrents for seeking healthcare. Many migrant workers moved often and did not keep their children’s immunization cards and/or birth certificates when they traveled. This made it difficult for ASHAs/doctors to know when to administer vaccines. Some migrant participants also could not access healthcare at government dispensaries because the permanent address on their documents was of their native place, which did not fall under the area of coverage assigned to the dispensary. Such rules and regulations could disproportionately affect vulnerable communities. The process of obtaining new documents was perceived as expensive and cumbersome by the communities we interviewed. However, on interviewing a Nepalese immigrant (P20) who was knowledgeable about the process of obtaining documents due to his status as an international immigrant, we learned that there were numerous places to obtain these documents, and the process was not as expensive. The migrant participants we had interviewed were unfamiliar with these places because they only knew what the dispensaries had told them—to apply for documents at the dispensary. Tighter information-sharing between migrant communities could help them address mutual concerns. The Mohalla Clinics did not require these documents and could be accessed by these migrant populations. However, since the clinics were new and ill-understood, they were associated with the same requirements, especially given that many considered them to be government dispensaries.

Language barriers also hindered healthcare access for some migrant populations. Many of the working members of the community could converse in Hindi and those who were unemployed felt little need to learn the language, making their communication with ASHAs difficult. This
was particularly a challenge because ASHAs largely interacted with the non-working members of families (generally the women). As one ASHA (A25) shared:

“Those living here speak Bengali and most don’t know Hindi. When we come around to administer polio drops, they don’t understand what we’re saying and we just hold the child and administer the drops considering it to be necessary and our duty. They don’t vaccinate otherwise. We have managed to administer polio drops to all the kids here.” (A25)

We see that there were challenges to healthcare access on the target users’ end which indicated disconnects with the government’s situated knowledges. We found that ASHAs were instrumental in helping resolve some of these disconnected knowledges by bridging the gap between the intervention and local communities. For instance, if not for the initiative taken by the ASHAs in the case of the Bengali community, they may not have sought vaccination for their children. This reluctance to seek care could transfer to other care-seeking behaviors as well. However, the ASHAs’ efforts were not enough, as there were also resource constraints. The ASHAs shared that due to the large population they were assigned to and the frequent travels of migrant communities, they were unable to see everyone each month. To avoid such scenarios, ASHAs were advised by the ANMs to address communities in most critical need of healthcare first. As an ANM (A29) said:

“I always tell you to start from the slums. Administer the polio drops in the slums. The vaccinations in the slums. Those in the flats can afford to get the vaccinations done from private clinics. For them, we have no value.” (A29)

Patients sometimes held rather discriminatory views against the clinics. Our interviews conveyed mismatched expectations with respect to the clinics’ services. Some patients had assumed that government healthcare services were of poor quality before visiting the clinics because of their prior negative experiences at dispensaries (such as medical negligence of doctors), an assumption that could have deterred attendance for others. Some patients visiting the clinics found themselves in need of medicines and services that were unavailable (e.g. scabies medicine and bandaging). According to a staff member (P15), patients had unrealistic expectations: “At this clinic, we cannot have all tests and medicines. The dispensary will obviously have more facilities. But people want everything to be done here which is not possible. The clinic is there only to provide immediate relief.” Another staff member (P14) voiced, “People think that just because the clinic is free, you can give no respect to the doctor and that another place that is more expensive is better.” Even when the clinics offered decent quality care, patients attached little value to it because it was free in contrast to other options. These examples highlight the disconnects across the situated knowledges of the doctors, staff, and patients that affected healthcare-seeking behavior.

4.4 Restricted Mobilities for Women

There were also obstructions to healthcare access that stemmed from restrictive patriarchal norms, which we are particularly sensitive to as women of Indian origin with strong feminist mindsets. Our interviews with ASHAs and women in slum communities indicated that women were considered responsible for running the household and making decisions regarding the health of the household, particularly of the children and older family members (since men were typically out working for most of the day). However, key decisions relating to sexual and (sometimes) maternal health were still made by men. This led to ASHAs counseling women on how to approach their husbands on the topic of family planning, as we observed. For instance, one ASHA (A26) advised, “You already have five children, do you want more? No, right? It’s a time of high prices. Talk to your husband about this.” ASHAs also noted that while talking to men about sexual health was uncomfortable, it often resulted in quicker and definitive responses and action. For instance, when a participant (P24) was hesitant and evasive about using contraceptives, her husband happened to enter the home as this
conversation was taking place and immediately agreed to his wife using an intra-uterine device. However, although men were willing to have their wives use contraceptives and even offered to take them to government facilities to get an intra-uterine device inserted or undergo surgery for permanent sterilization, they were unwilling to undergo similar safer and quicker surgeries such as vasectomies themselves [62]. The men we interviewed evaded an explanation of why, but the ASHAs claimed it was because they believed that they would lose their “manliness” [104]. Recent research in Kenya has indicated the potential of involving male partners in SMS-based family planning interventions [87]. Our finding surfaces the role of power dynamics and indicates that such conversations could be extended to offline environments. The ASHAs’ situated knowledges regarding arguments for family planning proved helpful in navigating such interactions.

**Constraints on the mobility of women** in a patriarchal society also shaped their ability to seek care. Limited mobility resulted in some women being unfamiliar with and unable to independently navigate the area they lived in (particularly those from migrant families). They had difficulty following directions to immunization sites as given by the ASHAs. For instance, P22 asked the ASHAs to show her the way to a site that was close by, which surprised the ASHAs. In other cases, women were forbidden from seeking healthcare altogether. In an extreme case, a woman who had come to Yamuna Clinic shared:

“I came here because my two-year-old is very weak and has not yet started to walk. We are very poor and cannot afford to see a private doctor… My husband is involved with another woman. He beats me and doesn’t give me money to see a doctor. I came here despite my husband telling me not to. If my child dies, then what?” (P10)

Free Mohalla Clinics provided a means for those financially constrained to access healthcare but could not account for the deep-seated patriarchal reasons that curbed mobility and held women back from accessing healthcare in the first place. As one doctor noted:

“During my time here, I have seen women visit the clinic despite their families forbidding them to because they have suffered visible signs of abuse. In some poor families, women are not given money to see a doctor… This is the story of every household.” (D13)

The doctor’s (D13) experiences with such cases of abuse and displays of bruises led him to believe that “more than medical treatment, there is a need for empathy.” This resulted in him changing the function of the clinic to adapt to patients’ well-being beyond physical health. Thanks chiefly to his initiative, the clinics provided a safe and comfortable environment for women to share their accounts. Doctors’ reliance on patient history and electronic and paper health records to make medical decisions has been well-studied [8]. However, we see that situated knowledge of doctors on patient needs beyond medical problems can help further shape interventions.

ASHAs too found their mobility restricted, which could affect their healthcare provision activities. We found that many women were motivated to become ASHAs after seeing the increased mobility and autonomy it afforded, such as A27 who said, “I am more independent and I feel that I am contributing to society.” However, despite the increased mobility, ASHAs found that traditional gender roles in their households and communities did restrict their movement. For instance, their timings were determined based on when their children and husbands returned from school and work and when their in-laws were not at home. Additionally, ASHAs reported being harassed and receiving unwelcoming responses from certain communities they visited. Despite their restrictions, ASHAs were able to make their routines work by, for example, working in pairs to lend support to each other, as A25 shared: “Some residents close the door and give us strange responses… together we can support each other and feel more confident.” Such comments also highlight the need to legitimize ASHAs’ roles as healthcare providers. ASHAs stated that the challenges they faced were unknown or of little priority to the government, pointing to gaps in the governments’ knowledges.

the ASHAs and the doctor at Yamuna Clinic (D13), we learned that some of these struggles were known to the staff at Yamuna Clinic and they were sympathetic, indicating (some) flow of situated knowledge from the ASHAs to the doctors and staff.

Prior research has reported the prevalence of patriarchal norms that constrain women’s behavior and mobility, and their ability to engage with interventions introduced for them [48, 54, 102, 111]. We add to this work by uncovering the impact of these restrictions on access to and provision of healthcare. Specifically, restricted mobilities shape access, and therefore constrict the breadth of knowledges that are accessible to the women in these slum communities as well as the ASHAs. We also highlight, however, the impact of information-sharing between ASHAs and women, ASHAs/women and male partners, women and doctors, and ASHAs and doctors on health behavior (taking up family planning) and healthcare provision (providing a safe space to discuss abuse at the clinic). In particular, ASHAs have an insider perspective as they are able to gain access into the women’s homes and lives, and could be leveraged as key influencers.

4.5 The Situated Nature of Health

Almost all slum residents we interviewed shared that challenging infrastructural conditions (lack of access to clean water or toilets), unhealthy surroundings (dust and smoke or polluted water around the slum), and overcrowded living conditions made it hard to avoid health complications. Also, unhealthy practices left unchecked by local authorities worsened already dire conditions.

Poor infrastructure, such as the lack of access to clean drinking water that we frequently encountered, could impact health. Many communities obtained water from the Yamuna river after filtering but P17 told us, “The water is so polluted that filtering is ineffective after five minutes and we receive yellow water.” According to the doctor (D13), this “yellow water” was responsible for the severe rashes many of his patients had. One slum community that lived on the roadside stated that their water source was a few streets away and the process of obtaining water was physically dangerous. P18 added, “You can see that we are parched; because of our situation with water everyone here is dehydrated.” When we asked P18 why the local dwellers had not installed a tank, she answered, “No one wants to take the responsibility. They don’t want others to take advantage (of the tank) when they have put in the effort to install it, even though it is not that expensive.” However, community support could result in concerted efforts to improve infrastructure when there was a consensus—when a community asked for a toilet and clean filtered water in the absence of support by the government, they pooled funds to make it happen (as shared by P17). Better infrastructure could impact health but community knowledge about its benefits was not enough to inspire action. It carried the burden of responsibility and implementing it required community unity. Prior civic engagement work has brought together stakeholders to provide shelter and basic social services, and could inspire similar efforts for healthcare infrastructure [60].

Often, participants’ medical conditions were linked to the environment they lived in. In the community on the roadside, many suffered from eye conditions due to the dust and toxins in the fumes released by passing vehicles. Pollution is an extreme concern in Delhi in general [93]. Additionally, the close quarters and overcrowding in slums, along with poor sanitation and water quality, assisted spread of diseases. The doctor (D13) shared: “Due to the living conditions in the slums, total eradication of infectious diseases such as scabies is practically impossible. Eradication requires community-wide efforts such as not mixing laundry and avoiding skin contact.” Cases of poor health practices also came to the fore:

“My neighbor sleeps on the floor with her one-year-old child with nothing but a bed-sheet... she told me it was because her child was urinating on the bed and it was difficult to clean up. Crazy woman, if she does that, diseases are obviously going to spread.” (P11)
Poor sanitation was also listed by ASHAs as a cause for concern. One ASHA (A25) said, “Many slum communities do not have a toilet due to financial constraints.” Even when communities did have access to a toilet, ASHAs found that it often went unused because of the long-prevailing habit of defecating in the open. More critically, community members were unwilling to take responsibility for cleaning and maintaining the toilet. Many of the migrant communities we visited had moved from remote rural areas and were more likely accustomed to older practices around sanitation. In addition to shortage of toilets, water stagnation was a common concern:

“The [neighboring] slum is surrounded by dirty water but people there just wade through it. They have sores all over their feet. They should get that filled with sand, but these are very poor people, who will bother to do that when their homes cost 300 rupees?” (P21)

We also found that the community played a key role in shaping health practices. Communities often traded remedies and shared health practices among themselves. For instance, P12, a diabetes patient, mentioned that she had heard from a neighbor that a certain plant could regulate her blood sugar levels. We also found that in addition to sharing these CAM remedies [24], residents would counsel each other in following a doctor’s instructions [43]. This collaborative information-sharing is similar to prior work on sense-making in online health communities [65]. The strong sense of community and reliance on neighbors could also result in healthy behaviors due to fear of being otherwise ostracized, such as in the case of P1’s husband:

“My husband drinks too much. I told him not to, but he wouldn’t listen. He started to feel ill so we visited a doctor and found that he had liver damage… He talked to many community members who convinced him to listen to the doctor and give up drinking.” (P1)

Above, we saw several instances that highlight the situated and place-based nature of health and disease. These findings were corroborated across community members, ASHAs, and doctors, and we would not have encountered them without conducting fieldwork with the ASHAs, indicating their regular engagement with the situated factors affecting health.

4.6 Provision of Situated Care

The situated nature of health resulted in situated healthcare provision by the ASHAs, doctors, and staff. To provide care, they drew on the knowledge they had developed about the health practices and concerns of target communities over time.

The ASHAs’ experiences with communities aligned with the evidence of community-wide behaviors. ASHAs shared that, generally, entire communities either cooperated or did not cooperate with them. When we accompanied ASHAs in their house visits, they pointed out slums where entire communities refused to immunize or deliver at hospitals. Over time, they developed situated knowledge about community health needs and behaviors that resulted in community-specific provision of healthcare by the ASHAs. To begin with, ASHAs could not rely on communicating with non-cooperative communities via mobile phones because their calls would often be cut. They had to visit these communities in person, often multiple times—a physically daunting task. To address community-wide issues, ASHAs would attempt to convince community members to adopt healthy practices by giving examples of their neighbors cooperating with them such as A26’s comment, “Sheeba [name changed] is using contraceptives, she just met me the other day to get pills. You should do the same.” We note here that privacy norms appeared to be loosely defined in this context, and sharing such information with neighbors and friends seemed to be common practice.

ASHAs also made a concerted effort to fill gaps (disconnects) in their situated knowledges about the communities they served and looked for logical arguments that addressed the sociocultural, religious, or environmental context. For instance, with taboo topics such as maternal health—certain groups believed that they would lose the child if they talked about their pregnancy, while others
cited religious reasons. In response, the ASHAs would explain how not discussing the pregnancy would be more harmful to the child. To overcome language barriers in certain migrant communities, ASHAs also used the internet to translate questions they wanted to ask, or established a relationship with someone in the community who could translate for them. For practices that were generations old, such as defecating in the open or not immunizing children, ASHAs would resort to berating the person and threatening them with legal consequences such as fines. ASHAs did not have the authority to carry out these threats, however, and they were either disregarded or questioned by the communities.

Similar processes took place at the clinics. When the staff and doctor at the Yamuna Clinic consulted with patients, they began by identifying the patients’ residence, such as “the community without access to clean water and suffering from rashes”. They were familiar with many of the patients coming to the clinic, many of whom were repeat visitors, and knew where they lived. They were thus able to determine when persons from the same vicinity faced similar symptoms, which facilitated identifying the underlying medical condition. We found these knowledges developed independently of the ASHAs’ knowledges, and there was little collaboration on this front.

Religion also played a role in healthcare provision. The region that we studied was predominantly Muslim. All the patients, slum communities, ASHAs, and clinic staff we studied were Muslim and were from the area. The doctor at Nooh Clinic (D6) was Muslim, the doctor at Nooh Clinic (D13) was a Sikh, and the ANM (A29) was Hindu; none of them were from this region. We (the authors) come from diverse religious backgrounds and beliefs. Our data revealed that ASHAs drew on the same culture and religion as local communities to break down strong barriers around sexual and maternal health. For instance, when P23 was unwilling to use contraceptives stating that “children are sent by God”, A25 retorted, “I follow the same God and I have read the scriptures. God only gives what you accept.” The ASHAs shared that to address such comments, they used the internet to learn and look for effective religious arguments to advocate for healthy practices. Religious institutions also supported healthcare provision by leveraging their function as community centers [92]. Mosques in the region announced when public health interventions such as immunizations were to be conducted, thus lending their support. When D13 declared his frustration about the incidents of abuse, an elderly male patient (P49) suggested that he could organize meetings at the mosque to educate men on this topic. Though religion was cited by some communities as a reason to reject healthy behaviors, it thus also provided solutions for “insiders” providing healthcare, such as ASHAs and religious institutions.

While the ASHAs navigated religious concerns comfortably, both doctors stated that they found it difficult to broach topics on sexual and maternal health (such as breastfeeding) with Muslim (especially female) patients. Our interviews with the doctors indicated that religion (Islam), culture, limited education, early marriage, and paternalistic attitudes were conflated and used interchangeably by doctors to explain the incidence of poor health and healthy behaviors. For example, D13 shared, “Before this job, I thought that Muslim women had many children because they care so much. Now, I feel the opposite because if they did, they would not have so many children with such little to give them.” Such attitudes reflect the need for nuanced intersectional perspectives on the local communities that the clinics served, which the ASHAs may be well positioned to provide.

Thus, the situated nature of health resulted in the provision of situated care by healthcare providers, especially ASHAs. There were several potential disconnects that had been addressed by the ASHAs’ situated knowledge of the communities they served. No doubt there were still others pending. Not only do we see above what the doctors (and the clinic staff) knew and did not know, what the ASHAs knew and did not know, and what the patient groups knew and did not know, we also see how these knowledges overlap and are constructed over time. In particular, we note that
the ASHAs play a crucial role in advancing these knowledges—be it for themselves, the patient groups, or the doctors and clinic staff.

5 DISCUSSION

We now engage with Haraway to discuss how we might rely on partial knowledges in public health infrastructures for improving access to healthcare [41, 42]. We also reflect on patient empowerment and how it involves empowering both patients and providers to engage with new and possibly disconnected partial knowledges. Finally, we discuss how and why global health interventions might privilege the knowledges of frontline health workers in collaborations between patients and providers, instead of merely leveraging them as carriers of information.

5.1 Redesigning Healthcare Interventions

Haraway’s perspective on situated knowledges highlights that privileging an “objective” or “universal” truth hinders examination of the multiple disparate, rational views that are essential to the construction of knowledge [41]. The Mohalla Clinics were able to extend the healthcare-providing capacity of the government but there was little sensitivity towards partial knowledges. Due to the doctors’ initiative, they were able to offer a certain level of sympathy or engagement to patients, but assumptions around the patients’ lifestyles and resource constraints constrained this ability. There was a limited appreciation for patients’ lived realities (such as the kinds of diseases affecting their communities, religious beliefs, challenges faced by migrants), or even the practices and assumptions of doctors (such as relying on immunization cards to administer appropriate vaccines or finding record-keeping on the tablets to be a nuisance). Because some knowledges were overlooked by the implementation, there was also little recognition of how these partial knowledges actually interacted, or the disconnectedness of each stakeholders’ knowledge. For example, patients’ knowledges rooted in religious systems made them resistant to directives such as using contraceptives. Though some ASHAs could leverage their knowledge to make religious arguments for using contraceptives, some doctors’ misunderstanding or unfamiliarity with patients’ religion and lifestyle resulted in them writing off such patients as unwilling to care for their children, for instance. There were disconnects in other dimensions as well, such as mismatched expectations around the clinics’ purpose or free healthcare, which broke down collaborations around care.

Seeking to resolve such disconnects, Haraway’s cyborg metaphor illuminates a pathway for the design of technology to bind disconnected partial knowledges. Haraway suggests that contradictory knowledges can coexist without having to eclipse one another, as is happening currently in the Mohalla Clinics system. She points to the materiality of the way the cyborg is constructed and embodies contradictions as evidence that it is possible to “see from both perspectives at once” [42]. We see how material elements affect disconnected knowledges in a few cases. For example, the presence of medicines in the home first embodied the benefits of medicine (a view shared by doctors and patients), but with recovery, shifted to embody bad omens (as seen by patients, not doctors). Another example is health-related SMS, which could actually communicate new knowledge to patients, but broke down communication because the frequency of texts did not match recipients’ phone use. Finally, physical location could change interaction of knowledges, such as when community members thought it could be easier to introduce new perspectives against abuse to men by facilitating conversations at the local mosque. It has been established that design can lead to inequity in use [115], and through these cases, we identify an underlying cause—the transfer of important knowledges through material elements is subject to misinterpretation, transformation, or oversight if material does not properly engage with existing aspects of disconnected partial knowledges. The design of the material and human infrastructures in healthcare interventions, then, could engage with different aspects of partial knowledges to more intentionally connect them.
ICTD and public health literature have both advocated for more community-centered approaches to design [9, 35, 45, 56, 70], such as community-led educational video production and participatory health research. However, when partial knowledges of target communities are assessed in conjunction with the “scientific truth” (or medical expertise) held by those implementing the intervention, local, situated knowledge seems to lose out. As we show, this makes healthcare interventions less effective for the very people they intend to serve. We might also see this privileging play out with the agendas of partner organizations that many interventions (e.g., [28, 86, 113]) work with. This concern may impact collaborative contexts outside public health that include many stakeholders with different types of expertise, such as teacher-student-parent interactions or education initiatives in domains such as agriculture [35], financial literacy [66], and more. We stress the need to not only acknowledge the biases of researchers and partners in their understanding of interventions, but also impart greater sensitivity to partial knowledges of all stakeholders in the design process [41].

5.2 Revisiting Patient Empowerment

CSCW and HCI work has begun to look at patient perspectives in the Global North (e.g., [10, 46, 58, 59, 64, 69, 71, 84]), as well as power dynamics in clinical [16] and non-clinical [107] provider-patient relationships. We enrich this expanding body of work by offering a perspective from both settings in acutely under-resourced urban contexts in the Global South. In particular, we highlight how what patients and doctors know and do not know creates a power dynamic in which patients are disempowered from negotiating their healthcare and doctors are discouraged by the system they work in to meet patients halfway.

Prior work on patient empowerment in CSCW has largely focused on supporting patient and caregiver practices that provide a sense of balance, normalcy, or agency [19, 38, 64] in managing health but that are still aligned with “rational” behavior like seeking hospital care. Residents in our fieldsites, however, frequently sought out other options such as CAM [24], religious support, and advice from community members already familiar with patients’ realities. These options may have provided inadequate medical care from doctors’ perspectives but might have afforded richer social and mental wellbeing to patients [43]. This was only compounded by the fact that doctors were frequently unprepared to address patients’ concerns—prior work has noted this can be due to patients’ information-sharing preferences [47], but we find that another reason is limited avenues for engaging with patients’ realities other than clinical data. Patient empowerment takes on a different definition when forms of care other than “scientific” information may succeed in empowering, defining empowerment as the patients’ right to choose the kind of care they wish to receive. However, there is still value in equipping patients and providers with information from each others’ partial knowledges such that negotiation of care can be less fraught with differences in expertise and more grounded in patients’ realities. We discuss how the design of technology and human infrastructure can play a role in appropriately and intentionally engaging both patients’ and doctors’ partial knowledges. We note that these points are based on our own constructed knowledge of what information should be shared and what the barriers to sharing are.

5.2.1 Connecting Disconnected Partial Knowledges. Patient empowerment in HCI and CSCW has often been about promoting patients’ active participation in their health [71], facilitated through systems like personal health informatics [78], online health platforms [57], and telemedicine [17, 101]. There are few such mechanisms in underserved contexts, but communication that is better adapted to social processes that might otherwise unintentionally transform collaboration are key. Voice-based telemedicine [51, 106] could better bind the partial knowledges of patients and doctors by working with overlaps of each knowledge and eventually yielding new connections between knowledges. For example, voice adaptations might not be entirely aligned with what healthcare
providers need access to from patients, but could simultaneously lower the overhead and resources required from patients and providers for clinic visits [17]. Combined with an understanding of patients’ access to technology [54], this could enable women with limited mobility to participate from their homes and make it easier to converse on taboo topics [105]. At the same time, such collaborative technologies have fixed hours and cannot generate conversations between patients, making communication of new knowledges limited to the point of interaction between patients and providers. Patient participation could be propagated further through offline information networks by leveraging existing information-sharing among residents, like the offline internet in Cuba [32] and dissemination of health videos via mobile phones and projectors [56, 74, 91, 114]. ASHAs already informally facilitate more dynamic sharing such as collecting and sharing health advice from residents and behavior changes in the community. This could be systematized, with ASHAs serving as moderators to ensure that networks propagate the knowledge they were intended to.

5.2.2 Addressing Barriers to Engaging with Partial Knowledges. Many interventions have targeted informedness about healthy behaviors and health services in Global South [74, 91, 113] and North contexts [44, 117], but past work has conveyed the inadequacy of even user-centered information dissemination initiatives [71]. We found that even when individuals or families did have information, other factors came in the way of receiving it. This points to the importance of designing technology to not just bind disconnected knowledges but also be sensitive to the barriers that prevent partial knowledges from engaging with each other at all. Our findings indicated that government SMS and MMS messages about health initiatives were ignored, and news and radio were heavily aligned with class boundaries, leading to a reliance on ASHAs for information. To better situate communication mechanisms in patients’ knowledge, SMS and MMS messages sent to community members could be personalized with text and voice notes provided by ASHAs to foment trust and legitimacy as demonstrated in previous interventions for maternal and sexual health [86, 97]. It is similarly important to recognize that patient groups seldom involve flat structures [56, 77, 107], and targeting positions of power situated in patient communities, such as religious leaders or head of households, and their physical gathering places may help motivate others to emulate healthy behaviors. Building on such opportunities to receive information, tracking learning over time may provide a better idea of what information is retained by communities and needs reiteration by ASHAs.

Doctors similarly face barriers to engaging with patients as well; designing technology to bridge the informal and formal networks is about equipping patients with information and changing formal systems to systematically receive that knowledge of patient needs. There was evidence that some doctors took the initiative to go beyond mere prescription of medicine, say, through lending a sympathetic ear to female patients who experienced abuse. This and similar practices could be systematized via material elements so that knowledge of patients’ contexts could be built into providers’ partial knowledges. Within the clinics, existing technology like the tablets currently only function as a record of the information that can feed doctors’ existing incomplete knowledges (possibly contributing to their perception of the tablet as not useful). However, they could be leveraged to maintain a database of information about patients’ beliefs and expectations to support a new understanding of patients’ perspectives and orient doctors in providing relevant care. Further, (anonymized) personas of patients could, over time, provide insight into and enable doctors to address underlying reasons for recurring medical conditions.

5.3 Redefining the Role of ASHAs

Our findings indicated that the ASHAs are key actors bridging the clinics with their patients [17]. Interacting with both the patients’ and doctors’ partial perspectives, they are uniquely positioned to help resolve disconnected knowledges from a more ecological perspective compared to prior work in Global North contexts where most information-sharing can happen within single settings.
Many ICT interventions have been developed to support ASHAs in their role as key intermediaries [56, 74, 116]. We examine how the situated knowledges of ASHAs could be leveraged in more meaningful ways. Thus, we align with previous efforts to empower ASHAs, legitimize their perspectives, and support increased agency to view them as infomediaries in addition [56, 74, 91].

There has been much research on phone-based data collection by frontline health workers [25, 29, 75, 83]. Coupled with training for recognizing patients’ perspectives, such systems could be extended to also facilitate the collection of hyperlocal, situated health data. For example, shared living conditions or beliefs that perpetuate health problems could be recorded on participatory mapping platforms [39, 112]. Recording of such qualitative data would privilege the knowledges of the ASHAs as moderators and translators between partial knowledges, instead of just conveyors of the knowledge that government policies deem useful.

Additionally, leveraging the notably personal and cordial interactions between ASHAs and doctors could help them address the situational challenges in their interactions with patients. ASHAs often informally asked doctors what they should do in different scenarios they might encounter with patients. Existing clinical decision support tools that are used to identify and treat specific diseases [31] could be adapted to provide more such contextualized advice, such as advising communities to stop mixing laundry and avoid skin contact with those infected with scabies until the condition is eradicated from the whole community. Such place-based medical advice could also be more readily offered in clinical settings as well. Currently, doctors draw on their limited interactions with a few repeat visitors to provide situated health advice. Instead, sensitizing doctors to the patients’ contexts (and even the ASHAs’ and ANMs’ own contexts) could be carried out by relatively much more experienced ASHAs during their interactions with doctors, ensuring a regimen of drawing connections between disconnected knowledges.

Current performance feedback tools for frontline workers focus on providing quantitative information such as the number of home visits conducted [28, 29]. We found that ASHAs extend care towards each other and their patients that cannot be captured quantitatively. Technology can be used to support, leverage, and extend these behaviors, as Karusala et al. recommend [49]. For instance, ASHAs accessed the internet to find arguments compatible with patients’ beliefs for installing toilets or for women approaching their husbands about sensitive issues. Social media and messaging of different mediums could be used to share these strategies with other ASHAs, building on peer learning systems [116]. Technology could also in turn provide care by addressing ASHAs’ personal safety concerns and helping them coordinate field visits with other ASHAs.

During our study, we learned that ASHAs adapted their approach to introducing new knowledge based on the cooperation levels of the community, switching between the affordances of technological and human infrastructure as required (such as making in-person visits if residents ignored phone calls). Researchers and policy makers could better leverage this understanding of community cooperation to gauge the potential efficacy of hyperlocal interventions and more easily identify appropriate community structures, such as intermediaries [50], to facilitate health behavior change [96]. We also note that technology as an artifact holds power in these settings [115]. Its use could be leveraged to bring legitimacy to the ASHAs’ roles from communities’ and doctors’ perspectives and so that ASHAs themselves feel a sense of pride and self-efficacy, as explored in [56, 74, 91].

6 CONCLUSION

We conducted a field study of Mohalla Clinics in Delhi (India), drawing on Haraway’s work to highlight the importance of considering disparate, partial perspectives in the ecologies of such clinics [41, 42]. We emphasized that inadequate attention given to patients’ and health workers’ perspectives, and the low preparedness of the doctors at the clinics, resulted in the clinics being unable to address the needs of target patient groups. We concluded by contributing to ongoing,
important conversations in the fields of ICTD, CSCW, and HCI towards redesigning healthcare interventions, revisiting patient empowerment, and redefining the role of ASHAs as infomediaries. Our paper demonstrates how Haraway’s critical feminist perspective [41, 42] might inform future Mohalla Clinics and similar large-scale, complex health care interventions.

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