

# ***"Is it even giving the correct reading or not?": How Trust and Relationships Mediate Blood Pressure Management in India***

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While chronic disease afflicts a large Indian population, the technologies used to manage chronic diseases have largely been informed by studies conducted in other sociocultural contexts. To address this gap, we conducted qualitative interviews with 21 patients clinically diagnosed with abnormal blood pressure (BP) living in low-resourced communities of Haryana, Uttarakhand and Uttar Pradesh in India. We found that patients' trust in the BP ecosystem and social ties plays a significant role in shaping their perceptions of technology and chronic care. Trust in one actor of the ecosystem fosters trust in another, e.g., trust in BP reading depended on the type of device and the person measuring the BP. We also observed nuanced sharing and intermediation of BP devices. Based on our findings, we recommend designs to boost patients' trust, familiarity, and access to technologies used in BP management and improve their experience of care in low-resource settings in India.

CCS Concepts: • **Human-centered computing** → **HCI design and evaluation methods**; **User studies**.

Additional Key Words and Phrases: blood pressure, hypertension, qualitative study, low-resource community, healthcare

## **1 INTRODUCTION**

Chronic noncommunicable diseases are the leading cause of death and disability in the world, and the burden is highest in the Global South. Of premature deaths from chronic diseases, 86% occur in low- and middle-income countries [74]. In India, two in three people suffer from a chronic disease [4].

A rich body of research in the HCI community has focused on understanding chronic disease management and proposing solutions to monitor, self-experiment, track, and treat chronic conditions [12, 40, 45, 59, 62, 63, 93, 100, 102]. Such work has focused on a variety of chronic conditions, including hypertension [100, 102], diabetes [40, 62, 63], irritable bowel syndrome [45], and migraines [93]. Research has documented the perceptions, beliefs and behaviors toward chronic disease management [61, 64, 100], including self-management practices of diabetes patients [63], sociotechnical complexities in introducing blood pressure measurement technologies among older adults [100], and motivations and barriers in managing multiple chronic conditions [26]. These studies provide an important outlook on chronic disease management within the Global North. However, with the rapid rise of chronic diseases globally and increasing penetration of technology in the Global South, it is imperative to study current practices, and design potential solutions, that are situated within that context. Within the HCI literature, a few studies examine chronic disease management (particularly diabetes) in the Global South context [37, 47], however not much attention has been given to hypertension management. Hypertension is the main risk factor for

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cardiovascular diseases such as heart attacks and stroke, and are responsible for one-third of total deaths in India [73].

Existing research on blood pressure management in the Global South comes mainly from the health and medical fields, with lesser connections to technology. This health literature examines patients' perceptions, beliefs, experiences, and expectations on the management of hypertension, and barriers to access health services [51, 53, 57, 69, 86]. These studies reported low knowledge around hypertension treatment, high patient load on doctors, prevalent use of alternative medicines, long travel distance and long waiting time at healthcare facilities, and high cost and non-availability of medicine, as major barriers. Based on the findings, studies recommend mainly non-technology driven solutions, including improving patient-doctor relationships, increasing the availability of high-quality low-cost local medical facilities with adequate supplies of medicine, conducting awareness campaigns and mass screening programs, and considering patients' sociocultural and economic backgrounds in providing healthcare services. Even within Global South, wide sociocultural, economic, infrastructure, psychosocial, and technology differences exists, making it difficult to generalize findings. In summary, the HCI literature lacks a focus on hypertension management in the Global South, and the health literature on hypertension in Global South lacks an engagement with technology and HCI.

To address this gap and building upon prior work, our work focuses on understanding blood pressure management among low-income communities in India and provides recommendations for designing technologies better suited to this context. Our research aims to answer: How low-income individuals living in resource-constrained regions of semi-urban/rural India access and utilize existing healthcare infrastructure and technology to manage their abnormal blood pressure? How does their sociocultural and economic status shape their belief, perception, capability, and adopted strategy (or lack thereof) for blood pressure management? To understand how patients approach managing blood pressure in India, we conducted a qualitative study interviewing 21 people clinically diagnosed from low/high blood pressure. Although attributes like age, caste, and religion significantly impacts an individuals' access to healthcare services, our study focuses on low-income communities in India (people earning less than \$10 per capita per day [50]), a demographic representing 97% (estimates vary) of the population [50]. We chose to focus on the axis of income class as it greatly determines the access to healthcare in India. We recruited participants from the rural and semi-urban areas of Haryana, Uttarakhand and Uttar Pradesh in India.

Our findings contribute to the fields of HCI, CSCW, and healthcare research in the following ways. First, our findings revealed a rich and nuanced understanding of the BP ecosystem in which trust and social relationships broker key aspects of blood pressure management and care. Trust in BP readings was not only dependent on the type of device, but also on the person operating the device. Second, in an environment in which few individuals can afford to own personal BP measurement devices, we describe patterns of both opportunistic and deliberate sharing of devices, with implied social norms around the boundaries of that sharing. Third, we observed an interesting interplay in treating chronic disease as chronic or non-chronic, based on convenience. For instance, when it comes to monitoring BP, participants treated it as a non-chronic condition and only measured their BP during discomfort; however, treating it as a chronic condition, participants consumed minimal salt and walked long distances irrespective of discomfort. Finally, economics played a key role; though BP measurement was free of cost in most scenarios, the cost of a companion accompanying the patient added to the transportation and lost wage cost. We conclude with design recommendations to inform the future of chronic disease management in resource-constrained settings, including reducing trust barriers by altering the visualization of BP readings, leveraging the familiarity of legacy representations, introducing novel tools in familiar settings, and combating interactive misinformation. This adds to a growing body of work in the HCI community [48, 52, 78, 79] that

emphasizes the significance of understanding health beliefs shaped by the local sociocultural context to guide the design and development of digital health technologies.

## 2 RELATED WORK

Our work is mainly informed by two areas of relevant research: studying chronic disease management using a technology lens and chronic disease management related studies in Global South. As each chronic disease has a rich literature, we only focus on blood pressure management here. Below we discuss prior works in these areas, with a note that our research extends prior literature and examines blood pressure management practices and beliefs in the low-income communities of India in order to develop technology-driven healthcare solutions suitable for that population.

### 2.1 Hypertension management related studies in the Global South

Prior work in the public health domain aims to understand the prevalence, awareness, treatment, and management of hypertension worldwide. Many of these studies are situated in resource-rich settings of the Global North, *e.g.*, in USA, Canada, Australia and Europe [27, 39, 44]. However, it has been pointed out that the strategies employed to manage blood pressure in resource-rich settings are different from low-income communities due to differences in sociocultural acceptability, infrastructure availability, and economic affordability of healthcare solutions [75]. There are several studies that have investigated BP management in low resource communities in the Global North (such as Hmong community in US [98], French-and Swahili-speaking African migrants living in UK [22]), as well as in the Global South (like India, Pakistan, Bangladesh, Sri Lanka, Indonesia, Kenya [51, 53, 57, 69, 70, 86]).

Awareness and treatment of hypertension has been found to be low in low- and medium-income countries [21, 53, 57]. For instance, people residing in the rural Yogyakarta province of Indonesia were found not to believe in the concept of ‘chronic disease’, as they think that they are either sick or not, falsifying the possibility of a lifetime disease [86]. The asymptomatic nature of hypertension further exacerbates this issue [36]. Moreover, studies found that hypertension patients in the Global South (including studies in Bangladesh, Indonesia, Kenya, Pakistan and Sri Lanka) were ambivalent towards consuming allopathic medicine and preferred traditional/alternative medicine [57, 69, 86]. Underlying the significance of religious beliefs in Pakistan and Bangladesh, Legido-Quigley et al. [57] noted that participants were unclear about how to manage hypertension during Ramadan fasts, as they received no formal advice from healthcare providers. At the infrastructural level, long waiting at the hospital, shortage of medicines, inadequate and unreliable medical equipment, lack of healthcare providers, and on the economic front, cost of medicine and transportation to healthcare facility, loss of (daily wage) income, are added burdens that further hinder people with low resources from accessing care [57, 69, 86]. Moreover, adherence to medication has been found to be poor among hypertensive patients in Bangalore, India [99], mainly due to barriers in beliefs, access, and recall (remembering prescribed doses).

Previous qualitative studies conducted in India have described patients’ understanding of the condition and its causes [51, 53]. For instance, a study conducted with low resourced migrants in Delhi observed that patients were not aware if they are hypertensive or not, and mainly followed behavioral changes to control hypertension like a healthy diet and less stressed life [53]. Patients expressed the need for awareness campaigns to educate masses about the symptoms and risks of hypertension. Likewise, in urban areas of Chennai, a city in southern India, Kroeger et al. [51] found participants’ unwillingness to talk to neighbors and friends about their BP, which might be a reason for lack of awareness.

These studies present an important account of patients’ understanding of the disease, their reasons for (non-)adherence with treatment, infrastructure and economic barriers, and potential

solutions (including policy and infrastructural changes) with relevant sociocultural context in mind. However, relevant technology-related questions have not been answered—such as how patients in low-resource settings get their BP measured, the challenges they encounter and how they cope with them, how they log their BP readings, how they approach teleconsultation, and how trust and relationships impact the use of technology in BP care—which is the focus of our work.

## 2.2 Understanding chronic disease management with a technology lens

Work in the HCI community has shown that technology influences almost every aspect of chronic disease management—access to information, connecting with doctors and peer groups, monitoring and logging, medication adherence, and self-experimentation. Access to information is vital in managing health conditions, and searching for health information online is fairly common. Pew Internet Research found 80% of Internet users searched for health information online (on WebMD and popular search engines), and it is the third most popular online activity [55]. There is even widespread adoption of online health support groups and health video logs, wherein individuals suffering from chronic conditions share their experiences and knowledge with others. Huh et al. [40] studied diabetes patient support groups, and analyzed online diabetes communities on dLife.com. They found patients helping each another in finding individualized strategies to best manage their diabetes, which led to people in the support group developing a common understanding towards effective diabetes management. Liu et al. [59] studied methods used by health video bloggers suffering from diabetes, HIV and cancer, to establish deep connections and interactions with their viewers.

Apart from gaining information and connecting with peers, technology has been widely used to connect with healthcare providers. Specifically, the COVID-19 pandemic has heightened the need for teleconsultations, to ensure that continued care is provided for chronic disease management through remote mechanisms [12]. Studies have investigated patients' perceptions, experiences, and expectations around teleconsultations in India [12] and Canada [77] and commented on technology adoption during this shift to teleconsultation.

In chronic disease management, doctors usually recommend regular monitoring of disease-specific health vitals and adhering to medication, along with lifestyle changes. Recent research has explored development of mobile health technologies to ease the burden of measuring health vitals at critical points throughout the day, *e.g.*, smartphone-based blood pressure monitors [102] and lung function measurement [54]. There is a body of research on designing and evaluating applications for storing and visualizing values generated from such monitoring tools, to enhance self-reporting and self-management [26, 89]. The availability of such rich health data has not only triggered sensemaking and data science research in predicting disease progression and suggesting customized health solutions [87], but has also enabled research on self-experimentation, wherein people systematically experiment with different strategies for improving their own health [25, 45]. Self-experimentation frameworks have been proposed, along with supporting smartphone apps, for people suffering from chronic migraine [93] as well as for irritable bowel syndrome, where personal food triggers can be identified [45]. Continued tracking of health-vitals is challenging for most individuals, and researchers have explored ways to make it easier. For example, Martin-Hammond et al. emphasised the need for a culturally-informed community-based education programme to encourage tracking of personal health informatics for maintaining cardiac health among black Americans. [65]. Another study conducted in Denmark explored the socio-technical challenges faced by of older adults while using BP device to manage hypertension such as, getting into the right posture to measure BP and understanding and interpreting the BP readings. The study suggested tagging contextual information (such as intake of alcohol or caffeine before measurement) and presenting visuals to make it simpler for the target population to interpret health data [34].

Thus, several studies have been conducted globally to investigate management of a variety of chronic diseases. However, there is a limited understanding of perceptions, beliefs, infrastructure, and chronic disease management strategies in the low-income communities of India, particularly for hypertension management. Our work is centered around addressing this gap and proposing technological solutions within that context.

### 3 METHODOLOGY

To holistically understand the ecosystem of chronic disease management within the low-income setting in an Indian context, we opted for a qualitative research methodology and employed semi-structured, open-ended interviews as our research tool. The study was approved by the Institutional Review Board at Microsoft Research India. In this section, we present the interview methodology, participants' demographics, and our data collection and analyses techniques.

#### 3.1 Research Context

For our study, we recruited participants from the semi-urban and rural areas of three North Indian states, namely Haryana (Daula, Baluda and Kherla villages in Gurugram district), Uttarakhand (Motharwala, Indrapur and Kherimansigh villages in Dehradun district, Ranichauri village in Tehri Garhwal district, and Bharsar village in Pauri Garhwal district), and Uttar Pradesh (Bhoora and Danda villages in Moradabad district).

All these three states have a majority Hindi-speaking population. The prevalence of hypertension is relatively high in these states ranging between 9–15% of their total population [31]. Additionally, hypertension epidemiological studies found that over the last two decades, the prevalence of hypertension has stabilized in urban India, however it has risen significantly in rural locations [35], resulting in an urban–rural convergence of hypertension prevalence in India. In spite of that, access to healthcare facilities is still challenging in rural India [46]. Moreover, hypertension has been found to be more prevalent among economically disadvantaged individuals in India [31]. Therefore, we situate our study in the low-income context of India to understand blood pressure management related strategies in resource-constrained environments.

#### 3.2 Procedure

Interviews were conducted from Aug–Sept 2021. We used criterion sampling [76] and the following inclusion criteria for participants: (a) 18+ year old, (b) hypotensive or hypertensive for 1+ year, (c) belonging to a low-resource community (with income less than \$10 per capita per day [49]), and (d) comfortable in either English or Hindi. To recruit participants, we reached out to several healthcare facilities in the rural and semi-urban regions of the three states through our personal and professional networks. Recruitment was done via a public hospital in the Dehradun district, a private e-clinic in the Gurugram district, and authors' personal networks in other regions. To build trust, participants recruited through the hospital and e-clinic were contacted first by doctors and medical staff that were familiar with them, before sharing their contact details with researchers.

The e-clinic through which some participants were recruited was operated by Karma Healthcare, an organization that runs e-clinics in rural and semi-urban areas of India. The clinics provide access to a local medical staff, who prepare a preliminary report inclusive of vitals measurement (including temperature, blood pressure, and sugar level), and remote consultation with a doctor. As Karma had access to patients with abnormal blood pressure from the low-income rural community, the researchers contacted Karma (whose founder/CEO was a prior collaborator) to help with recruitment.

The interview questionnaire had a set of semi-structured questions, exploring themes such as the first occurrence of abnormal BP, treatment regimen and medication adherence, measurement and documentation of BP readings, availability of healthcare technology and infrastructure, the role of family, community, and doctors, and other factors influencing chronic disease management. Participants were made aware that they could choose not to answer any question or leave the interview at any time. At the end of the interview, we collected relevant demographic information.

Interviews were conducted remotely by the first author, in Hindi, over audio-only telephone calls. Calls were preferred to in-person meetings due to COVID-19 restrictions at the time. Calls were recorded with the consent of participants. Soon after each interview, the first author listened to the interview recording, translated it into English, and produced a verbatim transcription. Interviews had a duration of 45-60 minutes. Participants were compensated with Amazon gift vouchers or phone recharge worth 200 INR.

### 3.3 Participants

Twenty-one participants (8 female, 13 male) with an average age of  $46.9 \pm 11.9$  years participated in the study (Table 1). Fifteen of them were hypertensive, while the rest were hypotensive; on average, participants were living with abnormal BP for  $4.6 \pm 5.1$  years. Eleven participants were from Uttarakhand, eight from Haryana, and two from Uttar Pradesh. All eight participants of Gurugram, Haryana (from P12 to P19) were recruited via Karma e-clinic, of whom three were still visiting the e-clinic and five had visited in the past. The other 13 participants recruited from Uttarakhand and Uttar Pradesh had never visited Karma e-clinics, and were recruited by the public hospital in Dehradun, personal networks, or snowball sampling. While each participant had access to public and/or private health facilities, the travel time and cost of care varied. Only three participants owned a BP measuring device. Two participants had a Master's degree, one had a Bachelor's degree, five completed secondary school, five completed middle school, and eight completed primary school only. Participant occupations included that of tailor, cook, maid, gardener, field laborer, shopkeeper, accountant, teacher, porter, and housewife. The average daily per capita income of participants was  $\$1.35 \pm 1.02$ , with the highest daily per capita income reported as  $\$3.25$ . Seven participants owned a feature phone without an Internet connection, 1 participant did not own a phone (and used the phone of a family member to communicate with us), and the remaining 13 participants owned a smartphone. Eleven participants remembered their last BP reading exactly, while eight participants were unaware of the normal BP range that should be expected. Only five participants had used teleconsultation, of which four were recruited from Karma e-clinic.

### 3.4 Data Analysis

Transcripts were analyzed using an inductive and iterative methodology [90]. Three authors contributed to the coding process and the codes were iterated until a consensus was reached. During analysis, we (1) discussed coding plans, (2) created a preliminary codebook, (3) examined the codebook and improvised/revised codes, and (4) finalized categories and themes. The first level of codes was very specific such as "first occurrence", "medical adherence", "device sharing", "digital versus manual BP device", and "role of friends and acquaintances". After several iterations, the codes were grouped into three high-level themes: "lifecycle of BP management", "trust in the BP ecosystem", and "access to BP care". After writing the findings section, the authors collaboratively discussed the implications of the findings in several iterations, including ideation of potential design interventions that could address some of the challenges surfaced by the study. While such ideation was envisioned as part of the research design, the ideas themselves (which are presented as part of the discussion section) were not conceptualized in advance of the study.



Table 1. Demographic details of participants (Note: for ‘BP’, ‘H’ stands for high BP (hypertension) and ‘L’ stands for low BP (hypotension); for ‘Phone Type’, ‘F’ stands for feature phone and ‘S’ stands for smartphone; 1 USD  $\approx$  75 INR); for Village, ‘Mother\*’ stands for ‘Motherwala’, ‘Rani\*’ stands for ‘Ranichauri’, ‘Kheri\*’ stands for ‘Kherimansingh’.

ID	Age	Sex	Village	Education	Profession	BP	BP year	Owns BP device	Last reading (days)	Phone Type	Monthly income (INR)	# People at home
P1	51	M	Mother*	Secondary	Tailor	H	20	No	2	F	3k	6
P2	54	M	Indrapur	Masters	Teacher	H	1	Yes	1	S	30k	4
P3	64	M	Kheri*	Secondary	Porter	H	22.5	Yes	60	F	24k	4
P4	43	M	Rani*	Secondary	Field Assistant	L	2	No	15	S	11k	5
P5	39	F	Rani*	Secondary	Labourer	L	4.5	No	>365	F	3k	6
P6	39	M	Rani*	Middle	Gardener	L	1.5	No	2	S	6.5k	4
P7	44	F	Rani*	Primary	Tailor	L	1	No	30	S	5k	7
P8	59	M	Rani*	Middle	Gardener	H	4.5	No	0	F	8k	10
P9	30	F	Rani*	Secondary	Maid	L	3	No	>365	S	5k	5
P10	59	M	Bharsar	Secondary	Shopkeeper	H	9	No	12	S	7k	6
P11	40	M	Bharsar	Masters	Accountant	H	1.25	Yes	0	S	15k	3
P12	71	M	Daula	Secondary	Retired	H	5	No	0	S	33k	11
P13	29	F	Baluda	Secondary	Tailor	L	11	No	30	S	4.2k	6
P14	40	M	Daula	Bachelors	Business	H	2	No	4	S	50k	8
P15	42	F	Daula	Middle	Housewife	H	5	No	15	F	–	7
P16	40	M	Daula	Secondary	Shopkeeper	H	3	No	270	S	19k	4
P17	45	F	Daula	Secondary	Tailor	H	1	No	30	S	25k	4
P18	45	F	Daula	Secondary	Counselor	H	9.5	No	30	S	31k	5
P19	65	F	Kherla	Secondary	Housewife	H	1.5	No	7	–	35k	10
P20	56	M	Bhoora	Middle	Cook	H	2	No	180	F	2.5k	2
P21	30	M	Danda	Middle	Cook	H	1	No	30	F	10k	5

### 3.5 Positionality

Five authors identify as female and two as male. Four authors are based in India (three are of Indian origin and one is a long-term resident), and three authors are based in the USA. All India-based authors and one USA-based author have conducted fieldwork with diverse marginalized groups in India. While the Indian-origin authors are middle-to-high-income individuals, they frequently interact with people from low-income communities in their daily lives. These firsthand interactions contributed to their understanding of the complexities faced by low-income communities. They also understand and communicate well in Hindi, the language in which the participants were interviewed. All India-based authors have an understanding of HCI4D literature and contexts. Three of the India-based authors have more than ten years of research experience in understanding healthcare management practices in the Global South. All the USA-based authors were interested in understanding India’s role in the global health landscape and opportunities for a multinational technology company to address them. The authors acknowledge the potential influence their institutional affiliations may have had in shaping a study that adopts a technology determinism lens. However, the authors purposefully refrain from such an approach and instead focus on holistically understanding the unique requirements of the target demographic. This encompassed their specific needs, current practices of blood pressure management, adoption patterns of diverse digital healthcare technologies, and the existing social infrastructure within their communities.

All authors view HCI research from an emancipatory action research mindset, aiming to conduct formative research to examine the opportunities, challenges, and tensions in using digital technologies for disease management among people in low-resource environments.

## 4 FINDINGS

In the following sections, we first describe the basic context of living with abnormal BP before relaying participants' accounts of the intricate factors that mediate trust in, and access to, the ecosystem of care. We defer detailed interpretation of the findings to the discussion section, which connects the observed phenomena to potential underlying causes as well as potential interventions.

### 4.1 Experiences of living with abnormal BP

**4.1.1 Symptoms and diagnosis.** Abnormal BP is often asymptomatic, earning it a reputation of a 'silent killer' [11]. Indeed, one-third of our participants were diagnosed 'accidentally', that is, without asking a doctor to examine them for symptoms related to BP. Instead, they were visiting a doctor for a different reason, such as a regular pregnancy checkup in case of P9 (F, 30 years, Low BP), or accompanying someone else to the hospital, as conveyed by P6:

*"My wife was ill, she had a mild fever, so I accompanied her... While I sat at the doctor's clinic... I started developing a sharp sudden sensation in my legs and began feeling very anxious. My entire face was covered in sweat. I started feeling dizzy. The doctor said you might have BP, you should sit down for some time. I sat there, he checked my BP, and gave me some medicine."* – P6 (M, 39 years, Low BP)

At the same time, 14 participants reported 'experiencing discomfort' that they associated with a change in blood pressure, prompting them to visit a doctor. Participants with low blood pressure described sleepiness, giddiness, tiredness and lethargy as their symptoms, and participants with high blood pressure associated anxiety, irritation, shaky legs and pain in the chest with the disease. Participants linked these symptoms with BP fluctuations and claimed that they 'could feel' when their BP increases or decreases, though there is scientific evidence to the contrary [10]. A few participants even took medications and visited the hospital based on such intuitions.

All participants, except one, were diagnosed with hyper/hypotension at a healthcare facility, in part because most participants did not have access to a BP measuring device. P2 performed a self-diagnosis prior to seeking a clinical diagnosis, as he already has a BP measuring device at home which his father used:

*"I bought this (BP machine) for my father. He had a BP problem... Once I casually (checked my BP), I didn't know I could have BP, but I took a measurement and it showed I had BP, and it kept on increasing. I thought it was getting too high... Around 120 is okay, 135 seems okay too, but when it rose to 160, I realized I should see a doctor."* – P2 (M, 54 years, High BP)

This timely healthcare-seeking behavior was enabled by several factors, including easy access to BP measurement, awareness about the normal range of blood pressure, proximity to the hospital, and experience in providing care to a hypertensive family member.

**4.1.2 Treatment.** Our participants engaged in a variety of treatments, including lifestyle changes, home remedies, and medicine.

*Lifestyle changes:* Participants spoke about their increased physical activity and changed dietary habits to maintain a normal blood pressure. Steps advised by participants' doctors included brisk walks, light exercise, yoga, decrease/increase intake of salt, reduce consumption of oil and fats, and promotion of teetotalism and vegetarian food. As P12 recounted:



*“After waking up in the morning, I drink tea and I go for a walk. I walk for 2 to 4 kms. Then I exercise and do some yoga at home... I have reduced salt intake in my food... There has been a considerable difference because of reducing salt intake. And they (doctors) have told me to take a little bit salad, so I’ve also started eating some salads in the morning.”* – P12 (M, 71 years, High BP)

While several such behaviors were prescribed, the extent of adhering to such lifestyle changes by our participants was linked to their self-evaluated efficacy and feasibility to perform that action [94]. For example, P13 (F, 29 years, Low BP) laughed and explained that she is not able to find time to run or for any kind of physical activities, while P19 (F, 65 years, High BP) conveyed that she cannot limit her consumption of salt as she *“can’t eat chappatis (Indian flatbread) without salt.”* Though participants were often aware of the benefits of healthy lifestyle habits, they opted for the feasible options only.

*Home remedies:* Participants also placed confidence in home remedies for managing their blood pressure, mainly because our participants perceived that they have no side effects and are economical. Out of the six hypotensive participants, five relied solely on home remedies, such as lemon water with sugar and salt, Indian tea/coffee with milk and sugar, and glucose water. These participants were not taking any medicines for hypotension. On the other hand, participants with hypertension relied on reducing salt intake. A participant P6 (M, 39 years, Low BP) also described consuming an indigenous plant, *chullu*, to get relief from BP-related headache. Home remedies are often passed down by generations or are local knowledge, thus making them a part of cultural and social wisdom.

*Medicine and adherence:* Participants acknowledged the significance of (allopathic) medicine and expressed that they had experienced its benefit in terms of relieving discomfort. All participants with hypertension had taken BP medicine once. However, participants voiced several challenges in adhering to medication.

First, participants admitted that they failed to adhere to medicine due to carelessness, workload, and forgetfulness. This highlights a gap between the intention and action of the participants. For instance,

*“I get busy at work... I keep thinking I should take medicine regularly. I am not able to keep that in mind. When I forget to take medicine, then in about 2 to 4 days, I face issues.”* – P1 (M, 51 years, High BP)

Second, participants displayed a propensity to stop taking medicine once the symptoms of abnormal BP subsided, thus treating a chronic disease like a non-chronic disease. Instead of taking medicine on a regular basis, a majority of our participants consumed medicine only when they experienced “discomfort”. Prior research in low-resource communities of Indonesia outlines similar behaviors and intuition-based medical adherence [86].

Lastly, adherence to medication was complicated by varying levels of access to and trust in the medicines themselves, which we discuss later.

**4.1.3 Monitoring and logging BP.** Regular measurement and logging of BP are crucial in managing hypertension and hypotension. It enables the patient to take the necessary steps to maintain BP in the normal range and avoid complications. While majority of our participants reported measuring BP at a healthcare facility only when they feel discomfort, four participants reported measuring BP when they were coincidentally in proximity to a BP measuring device, e.g., when visiting an acquaintance who owned a BP device. Similarly, P16’s (M, 40 years, High BP) grocery shop is located next to a Karma e-clinic, and he gets his BP measured bi-weekly at the e-clinic, or upon experiencing discomfort.

Interestingly, even participants who owned a BP measuring device reported measuring their BP infrequently, due to the required effort and/or lack of trust on the device. For instance, P3 (M, 64 years, High BP) stated, “*I have a BP machine, but I don’t measure it every day, or every week, because if I measure it I get more doubts... doubts about whether the reading is correct or not. Every time I measure my BP, it comes 2-5 readings different from my previous reading... In that case, which reading should I consider to be my correct reading?*” We explore this lack of trust on the BP measurement device later in detail.

Only 2 participants said that they had ever maintained a log of their BP readings, but now both had discontinued that practice. P2 explained:

*“Earlier I used to keep a diary. Now what I do is, as soon as I take a measurement, I take a picture with my mobile phone... Earlier my BP was fluctuating a lot between high and low, now it’s constant... So now there’s no use of it (record-keeping).”* – P2 (M, 54 years, High BP)

This is consistent with previous research identifying that patients reduce/stop tracking their health parameters when they believe their health is stable [13]. Furthermore, P11, who owns a BP measuring device, reported that he does not write his BP readings; instead, he has developed a mental model that helps him track his BP readings. He described:

*“I have decided on a range for myself, like 130 and 90. And now I stay in that range, so I don’t have to write down the measurement... On days when my BP goes above 130, then I am mindful that it has gone above 130. On those days I do some workout.”* – P11 (M, 40 years, High BP)

While such workarounds might be effective in the short-term, they prevent the user (and their doctors) to monitor and analyse BP fluctuations over a prolonged period of time.

In lieu of detailed logging by participants, the written summary of the last doctor’s consultation acted as a makeshift BP record, and was deliberately kept by 7 participants. P4 (M, 43 years, Low BP) even questioned the significance of logging BP separately, stating “*the measurement is already written in the slip (consultation summary).*” Three participants also sought to keep the consultation summary because it enabled additional doctor visits (for a limited time, as needed) without paying additional fees. It also provided documentation on any prescribed medications. Despite these benefits, most participants admitted that they are not able to keep the consultation summary for very long, as it gets misplaced.

## 4.2 Trust in the care ecosystem

Participants exhibited nuanced and interconnected relationships of trust and mistrust with different aspects of the care ecosystem, spanning medicine, technology, and people. These underlying dynamics of confidence, doubt, and the uncertainty in between formed a foundation for how participants approached the management of chronic disease and how they interacted with emerging technologies and models of care. For this paper, we are using Gambetta’s [29] definition of ‘trust’, defined as: A person or an object is considered trustworthy, if there is a high likelihood that *‘the actions executed by them are beneficial or at least not detrimental to us, for us to consider engaging in some form of cooperation with them’*. Our findings indicate that trust in one actor of the ecosystem (such as healthcare professional) fosters trust in another (e.g., BP device, medicine, lifestyle changes, BP device). On the other hand, mistrust is often due to unfamiliar technology, low health literacy, personal biases shaped by past experiences, and infrastructural challenges in the healthcare ecosystem.

4.2.1 *Trust in medicine.* Even though healthcare professionals counseled participants to take medicines regularly, some participants had their doubts as to whether or not the prescribed allopathic medicines could cure the disease “*from its root cause.*” As abnormal blood pressure is a chronic condition, it cannot be cured but can only be managed with medication and lifestyle changes. However our participants, reported treating their hypo/hypertension as any other acute disease (similar to [86]). Participants explored a variety of alternative medicines, such as Ayurvedic, homeopathic, and Unani medicine, as discussed in prior work from Bangladesh, Pakistan, and Sri Lanka [57], in hopes of curing BP related problems from the root cause. We also found participants changing medicine on the advice of friends or family, and even discontinuing medicine just to see what would happen. P1 described his struggle:

*“A friend told me, take medicine from ‘that doctor’, he is very good. Take it from that hakim, he gives very good medicine too. See... a patient’s wish is that he gets relief, whichever place he gets medicine from. It’s about getting relief. Whoever suggests whatever place, we get (medicine) from there. I have been taking medicines for more than 20 years, but no medicine has worked well for me.”* – P1 (M, 51 years, High BP)

Interestingly, even after consuming BP medicine for 20 years, P1 wasn’t able to understand the chronic nature of the disease. Contrary to his beliefs, all those medicine did work by keeping his blood pressure under control over the years.

Participants also exhibited fears of becoming habitual with allopathic BP medicine and the potential long-term side effects on their health. Similar findings have been reported previously in low-resource settings of Hmong Americans [98]. Though participants were aware that regular medicine intake was beneficial, still they doubted the medicine, claiming that it was addictive. P17 shared an incident when she stopped taking medicine, but later continued because of discomfort:

*“Someone had said, don’t take so many BP medicines regularly, you’ll get habituated. After stopping (the medicine), I was not able to walk. Legs and hands felt so lifeless, like there was no strength in my legs and hands. Then I started it (medicine) again.”* – P17 (F, 45 years, High BP)

Finally, we found participants stopped consuming medicine due to financial constraints as well. As our participants were from low-income communities, they were concerned about regular spending on medicine and doctor’s consultation to treat a life-long disease, and hence they stopped their medication as soon as they perceived that they ‘recovered’.

4.2.2 *Trust in BP measurement.* Participants had a complex mental model to assess the accuracy and trustworthiness of BP devices. We found the trust in BP devices to depend on a variety of factors, including the device type, context of the device usage, consistency between consecutive readings, and person using the device. For instance, P11 expressed his hesitations about measurements that he took himself, at home:

*“The machine that I am using, for that I wonder, whether it’s giving actual and accurate reading or if I am in the dark? Should I go to the hospital in Dehradun to check how much the difference is (between my digital BP device and hospital’s BP device)? Is it even giving the correct reading or not? This I can’t trust... Nowadays technology is also getting quite high-fi, so I don’t know.”* – P11 (M, 40 years, High BP)

One amongst several factors contributing to participants’ (mis)trust in BP device is whether they were manual or digital. Participants were particularly critical of digital devices and trusted manual devices over them. Two participants mentioned that their doctors recommended manual devices, as they were more accurate: *“One time, I went to the hospital, pregnant ladies were getting checked there. The gynecologist there, even she said that the manual one (BP machine) is usually better.”* – P18 (F, 45

years, High BP). Two other participants experienced discrepancies in consecutive readings from digital BP devices and stated that once their batteries deplete, their accuracy is not guaranteed. Participants' perceived trust in BP measurement was determined by the consistency in consecutive readings. Participants reported that in digital BP devices, there is "*large variation between consecutive measurements.*" The perceived accuracy of BP devices was also linked to the person performing the measurement. Manual BP measurements required training, usually undertaken by healthcare professionals. As participants trusted such providers, this trust translated to more trust in manual BP device. Similar findings have been reported previously by Montague *et al.* [67]. Digital devices, in contrast, needed no particular training, as the interface was straightforward and user-friendly.

Participants measured BP in a variety of settings, including government hospitals, private hospitals, clinics of unlicensed providers (called quacks), acquaintances' homes, and their own homes. The perceived accuracy varied across different environments. For example, users trusted private hospitals over public hospitals, in spite of the public hospital having a manual BP device:

*"In the government hospital... sometimes the BP machine gives inconsistent reading... there's not much satisfaction with the hospital. They never give a particular (fixed) reading. Sometimes, if they would give (a reading), then I would ask them to take another measurement, but then suddenly the reading would change. They had a pump one (BP machine) there."* – P11 (M, 40 years, High BP)

While sentiments of mistrust were common with respect to BP measurement, we also found misplaced trust. For example, P19 (F, 65 years, High BP) shared how her son uses iCare<sup>1</sup>, a smart-phone application, to measure BP by placing her finger over the phone's back camera. P19's son mentioned that iCare was recommended by his friend's wife, who is a doctor. Prior studies reported doctors recommending similar apps to their patients for BP measurement due to the afforded convenience [82]. While the iCare app is no longer available, it was once among the 25 most popular medical apps on the App Store, with over 1M downloads. and an average rating of 4.5. However, the iCare app lacks independent evaluation and FDA approval, leaving little reason to trust it [82]. Nonetheless, P19 trusted the iCare app and argued that its readings were similar to a manual BP device.

**4.2.3 Trust in teleconsultation.** With the exception of four participants who had used teleconsultation services provided by Karma Healthcare (through which we recruited), and one additional participant who had used teleconsultation via phone, the remainder of our 16 participants had never used teleconsultation. There were several barriers to the uptake of teleconsultation, from basics such as availability and awareness of services, to more nuanced factors rooted in trust and relationships.

Participants were typically unaware of teleconsultation. Doctors familiar to them did not provide it, and due to the power imbalance between doctors and patients in low-resource settings, it was challenging for patients to approach doctors via the phone (as previously discussed in [13, 18]). On being explained what teleconsultation means and asking them about adopting it in future, we found our participants hesitating in exploring teleconsultation and preferring physically visiting a doctor, mainly because of the novelty factor: "*I have never talked to a doctor on phone, how will I do that?*" – P9 (F, 30 years, Low BP). This hints that our participants lack trust in the potential of teleconsultation as a means of accessing care. Prior research revealed similar skepticism for teleconsultation services among patients from low-resource communities [19]. Even participants who had used teleconsultation reported that they felt more comfortable with face-to-face interactions, as they could express themselves better. This is consistent with prior

<sup>1</sup>iCare Health Monitor: <http://www.icarefit.com/>

studies [2, 104] finding that body language is an important supplement to verbal communication during face-to-face consultations. P11, who had never used teleconsultation, anticipated that it would be hard to articulate a problem to the doctor during virtual consultation:

*“If there is an emergency, then I can take (teleconsultation). But, if the doctor is available, then I think going to the doctor is better. The reason is that what if he is not able to understand? By sitting in front of the doctor, I will be able to make him understand better.”* – P11 (M, 40 years, High BP)

Participants’ lack of trust in their ability to communicate effectively with a doctor via teleconsultation, reflected as a lack of trust in the teleconsultation approach itself. Moreover, prior work studying teleconsultation in an urban Indian context [12] found it to work best for follow-ups, especially for chronic conditions. Consistent with that finding, Karma e-clinics provide teleconsultation for hypertension and diabetic patients, and in a hybrid manner, wherein health vitals (like blood pressure and blood sugar level) are measured by a local medical staff before connecting the patient with a doctor over a video call. In the case of our participants, varying trust in their personal BP devices impacted their trust in teleconsultation, as they believed prescription could be based on a faulty reading.

*“If I make a video call to the doctor, then I would tell my condition according to my BP machine. Now how can I be sure if my machine is telling right or wrong? The accuracy of the machine can’t be checked on WhatsApp. If my BP is normal but my machine says it is high, then obviously I would tell the doctor that my BP has increased this much, and the doctor would change the medicine according to the wrong reading.”* – P3 (M, 64 years, High BP)

**4.2.4 Trust in care providers.** Participants interacted with doctors, nurses, quacks, and medical store owners to seek support for BP management, and acknowledged their crucial role in managing BP. In spite of the trust placed in doctors, participants did their own diligence on doctors’ advice. For example, P17 (F, 45 years, High BP) states: *“Even if the doctor recommends a medicine... I always get it checked by my kids on the internet and only then take it.”* This was mainly because the clinics are usually full of patients, hence at times the doctors are not able to provide full attention to every patient.

Providers from different sectors elicited varying trust relationships with patients. Interactions with doctors in government hospitals were strained by several factors, including communication and body language:

*“The government hospital’s doctors don’t even look into our eyes while talking. They will just write the medicine... They think it is a crime to tell us the name of the medicine. They think they are doing some favour... We only go there because we are forced to go, we have to take medicines.”* – P1 (M, 51 years, High BP)

This is consistent with prior work finding that patients can feel neglected and dissatisfied when doctors are busy writing prescriptions and are unable to make eye contact [20].

While private hospitals were viewed by participants as having a higher quality of care, their high costs often made them inaccessible. For example, P8 states: *“If someone goes to a good (private) hospital, they will ask for an X-ray, ultrasound, BP, blood test. After measuring everything, they make a bill of 2500-3000 rupees, in a jiffy.”* – P8 (M, 59 years, High BP) P8 further shared that when local village doctors fail to treat a person, they have to travel to private hospitals located far away in the major cities of Uttarakhand. Expressing his helplessness: *“What options do we have? We have to save the person.”* To reduce expenses, one participant reported seeking generic alternatives to prescribed brand-name drugs, which could reduce medicine costs many-fold.

Patients' mistrust in personal BP management technologies, healthcare professionals' lack of attention to patients during physical consultations, and the high cost of accessing quality care all contribute to a tense dynamic in BP management. In light of the challenges interacting with licensed doctors in public and private facilities, participants often turned to unlicensed providers, commonly known as quacks [24, 71], for assistance with BP and other health problems. Prior studies have also documented similar interactions between patients and informal healthcare infrastructures like "parar-daktar" (doctor of the neighborhood) in Bangladesh [97]. Participants maintained good interpersonal relationships with quacks, as they typically lived in the same neighborhood. For example, P1, who described doctors in government hospitals as uncongenial, viewed quacks as more accessible care providers:

*"In villages, there are small doctors (called) quacks. These quacks have BP machines as well. So, I go to them. They measure BP quite accurately... Big doctors don't even tell us, at least quacks explain everything to us."* – P1 (M, 51 years, High BP)

Usually in hospitals, the medical staff not doctors measures their blood pressure, and we found our participants to place more trust on quacks for measuring BP accurately over nurses/medical staff. Despite their lesser qualifications, quacks remain a critical part of the participants' trust ecosystem. In the words of P20, *"He is from our village itself, so we trust him"*. Overall, we sensed a need for better individualized care and medical expertise at an affordable cost.

**4.2.5 Trust in social circles.** Participants' social circles played a key role in determining their trust in, and relationship with, the health ecosystem. Participants described how their choice of doctor was influenced by the opinion of their social circle: *"I had asked people I know (acquaintances) and I had taken their reviews (of the doctor). I had asked people where to get treatment."* – P18 (F, 45 years, High BP) This shows how trust in some actors of the BP ecosystem, such as the social network of the participant, can foster trust in other actors, such as the healthcare provider. In addition to seeking guidance on doctors, participants also asked their personal networks for recommendations on lifestyle changes, alternative medicine, and buying a BP measuring device. Strong trust relationships also enabled unconventional means of accessing needed resources, as relayed by P10, who lives in a remote location:

*"Actually, there are no facilities where I live... Medicines are available 150 to 200 kms away from here. We order medicines through the bus drivers. I give the slip to them, they buy the medicine for me. I just have to give the total cost of the medicine. There is no transportation cost."* – P10 (M, 59 years, High BP)

At the same time, placing trust in social ties was not without its hazards. As described previously (Section 4.2.1), some participants switched or stopped BP medicine on the basis of social influence without even consulting a healthcare provider. Moreover, health related rumors were prevalent in participants' social circles, negatively impacting their ability to make informed health decisions. As P13 (F, 29 years, Low BP) conveyed in astonishment, *"I got to know yesterday that if BP is low, then one should not eat potatoes! Someone in my neighborhood told me, the boutique owner... He said, 'Bhabhi, your BP remains low, you should not eat potatoes.' I didn't know this."* P13 was uncertain of what to believe. Prior work has reported sharing of such health-related rumors particularly during COVID-19 [7].

### 4.3 Access to care

Ensuring that everyone has access to high quality healthcare remains a profound challenge in India. Just as trust relationships shaped participants' engagement with health services, so too did social relationships played a critical role in mediating access to those services in the first place.



This section explores the multi-faceted influence of social relationships on participants' access to shared devices, access-related costs, access by women, and access to family caregivers.

**4.3.1 Access to shared devices.** While financial constraints and treating BP like a non-chronic disease prevented nearly all participants (18/21) from owning a personal BP device, it did not prevent them from accessing devices in other ways. In particular, six participants mentioned sharing digital BP devices owned by their acquaintances, including neighbors and employers. Sharing goods among neighbors is commonplace, and it results in reducing economic burden and maintaining strong relationships [16, 95].

Measuring BP on a shared device was a social experience. Participants usually went to the house of the device owner and took measurements there, instead of bringing the device back to their home. No money changed hands. In most cases, the device owner helped with the reading, including placing the cuff around the device borrower's arm and even interpreting the results for them. As pointed out by P13:

*"I don't bring their machine to my home. They measure it. Their child does it, he is 26-years-old. They tell me the BP reading... I don't even know what is the range of normal, low or high BP." – P13 (F, 29 years, Low BP)*

As flexible as this sharing may appear, boundaries still remain. Participants emphasized that they visited their neighbor's house *"only a few times a month"* to use a BP device, as both owners and borrowers looked down upon regular sharing practices. Borrowers viewed it as taking *"favors"* from device owners. P3, who used to regularly visit his neighbor for BP measurement, later changed his behavior:

*"I got to know that our neighbour has a BP machine. So I went to him... But lately, my habit has gotten worse. I feel bad... like without any reason, I am going to their house daily for measurement. It is not that people don't have work... So, now I have stopped going to their house (just to measure BP)." – P3 (M, 64 years, High BP)*

An owner of a BP machine, P11 shared a slightly different perspective, with neighbors using his BP device only when in need, and not on a regular basis, thus treating abnormal BP as an acute health condition: *"They don't have a particular time at which they come. Usually, when they get anxious or fall ill, they come to measure BP."*

**4.3.2 Hidden costs in accessing devices.** Participants offered detailed narratives regarding the true costs involved in accessing BP measurements. Though the direct cost of each measurement was considered to be minimal (0-20 INR) in most healthcare facilities, a few participants expressed that it was still substantial when compounded over a lifetime. Moreover, even if the measurements themselves were free of cost, there were additional unavoidable expenses, including (a) *transportation cost*: from their home to the healthcare facility and back, (b) *daily wage cost*: most participants were daily wage workers and visiting a healthcare unit meant missing their daily wage, (c) *miscellaneous expenses*: on food, shopping, etc., and, importantly, (d) *companion cost*: participants were usually accompanied by a family member to visit the healthcare unit, increasing costs in each of the three prior categories and also requiring effort from the companion.

Such 'hidden costs' in accessing BP measurement acted as a persistent barrier to access even if the measurements themselves were to be provided for free. As expressed by P8, two days' wages were exhausted for a *"free BP measurement"*:

*"I go by public transport (to the hospital). It takes almost 2 days' wages—the wage of the day on which I am not going to work, and another day's worth of wage is spent on transportation... Also, when one goes to the market, expenditure happens." – P8 (M, 59 years, High BP)*

Freely available services may also be left unused for other reasons, for instance, participants expressed moral obligation to not exploit free services unless necessary. P13 illustrated this belief with a lighthearted comment:

*“When I know that my BP is going down; my health is deteriorating, only then I will go and get it measured. (Just) because it is free, it doesn’t mean that we will go every day to get it checked. It is not a ‘prasad’ (free food given to devotees at a temple).”* – P13 (F, 29 years, Low BP)

Participants showed appreciation towards available health facilities, but despised free-riders and did not want to be associated with them. Finally, independent of the costs involved, regular measurement was also impeded by participants treating BP like a non-chronic disease.

**4.3.3 Women’s access to care.** Interviews showed that women’s access to care was affected by social and cultural constructs, including predefined gendered roles and familial expectations from women in Indian society [6, 9]. Consistent with prior studies conducted in India, we found that the gendered segregation of duties renders women and children to be financially dependent on men for their healthcare-related expenses [5].

P19, a housewife (F, 65 years, High BP), admitted that her non-adherence to medication was driven largely by the non-affordability of drugs, while P17 (F, 45 years, High BP) subscribed to the idea of putting her family above herself and her health. The societal expectations of women to fulfill domestic responsibilities and serve as primary caregivers also limits their ability to focus on their own health. This has been reported previously in the literature [88, 97]. For instance, P9 (F, 30 years, High BP) has multiple household responsibilities that interfere with her access to care: *“I don’t have time to go to the hospital. I keep on working... I have buffaloes. I have two small kids too.”* Likewise, bemoaning the demise of her sister and family struggles, P15 stated:

*“I want my BP to remain under control and be normal. But what to do? Should I not raise children? Five children. A few of my sister’s, a few of mine?... One of my sons, who is 21 years old, is handicapped. He is unable to walk... There are so many problems. What should I tell you?”* – P15 (F, 42 years, High BP)

Women’s access to care was further impeded by their restricted mobility (as discussed in prior literature related to women’s (intimate) health in the global south context [41, 68, 97]) and dependence on male family members to accompany them to the hospital. In the case of P9 (F, 30 years, High BP), she used to visit the hospital regularly while she was pregnant, and was also getting treated for hypotension. However, after her pregnancy, she stopped visiting the hospital: *“The distance to the hospital is an issue... I was pregnant around three years back... Since then, I haven’t visited the hospital.”* Though the distance between her house and the hospital did not change, there was a behavioural difference in visiting the hospital for maternal versus BP-related health concerns. Prior research has concluded that families in low and middle-income countries tend to spend fewer resources on non-maternal health of women in comparison to their maternal health, in spite of the seriousness and severity of the non-maternal health concern [32].

**4.3.4 Access to family caregivers.** Relationships with family members played a key role in bolstering access to care, not only as advisors and companions but also as continual sources of help with BP management. For instance, P4 (M, 43 years, Low BP) shared *“my wife adds more salt in pulses,”* and P9 mentioned that her family prepared home remedies for her and even provided physical support when needed:

*“Whenever I feel discomfort and not able to walk, my mother-in-law holds me and helps me walk. Once, I was in the field, and my health deteriorated in the field itself. At*

*that time, my mother-in-law carried me home. She gave me lemon water and glucose water.”* – P9 (F, 30 years, High BP)

Family members also served as technology intermediaries. For example, P3 (M, 64 years, High BP), who owned a digital BP device, shared that his daughter helps him to place the cuff before each measurement. P17's (F, 45 years, High BP) children help in finding more information online about the disease and medication prescribed by the doctor, and P19 (F, 65 years, High BP) used the iCare smartphone app to measure blood pressure (although wrongfully) with ease. Prior work has also documented family members playing roles as digital health intermediaries; for example, Bagalkot et al. [5] discuss the role of husbands in supporting their wives' use of digital healthcare tools during pregnancy. Moreover, as mentioned previously, participants also reported that family members often served as essential companions during hospital visits, providing guidance as well as needed emotional and physical support.

## 5 DISCUSSION

Our study provides insight into people's lived experiences with blood pressure management in low-resource areas of northern India, spanning semi-urban and rural settings. We found that ownership of BP devices was rare among participants due to monetary constraints; however, sharing of BP devices was common. Even when BP measurement was inexpensive or free at a healthcare facility, patients were deterred from measuring their BP regularly due to their perception of BP as a non-chronic disease, the additional requirement and cost of needing a companion to travel to the facility, and moral beliefs against over-use of free services. Participants' social circles played a critical role in providing recommendations for doctors, medicines, devices, and smartphone applications for BP management, as well as in mediating patients' access to, and trust in, such resources. Although participants generally described their family members as being supportive, sometimes the household responsibilities that participants undertake, particularly among women participants, dissuaded them from accessing care. Furthermore, we found the health behaviors exhibited by our participants to be intertwined with their context, making it hard to be separated. In the remainder of this section, we reflect further on how trust and relationships impact BP management in India, before considering potential implications for design.

### 5.1 The role of trust and relationships in BP management

*Trust in BP measurement devices.* Our findings uncovered a nuanced and unexpected relationship between the accessibility and perceived trustworthiness of a BP device. While participants had increasing access to digital devices for measuring BP at home (or at a neighbor's home), they also voiced distrust in the accuracy of such devices. According to participants, one of the most important characteristics of a trustworthy device was that consecutive readings were consistent. While this may sound like a reasonable expectation at face value, in practice there were multiple interconnected factors that impacted the consistency of readings obtained.

One source of inconsistency in BP measurements owes to natural biological fluctuations. As blood pressure varies from heartbeat to heartbeat, variation in consecutive BP readings is expected [105]. Furthermore, when people measure BP at home, they usually don't pay attention to physical factors such as their back posture, arm position, cuff size, leg-position, and maintaining silence during measurement [23, 33, 72, 81], any of which can lead to an incorrect BP reading, irrespective of the device's accuracy. Additional factors can explain discrepancies between measurements taken by oneself at home, and those taken by a professional in a healthcare facility. For example, patients' anxiety and conditioned response to hospital environments may cause a temporary increase in blood pressure in a hospital setting, known as the "white collar effect" [43, 72].

If such variations are a routine aspect of BP measurement, then from where did patients come to expect consistent readings? The answer, we posit, is not from the technology itself, but from the people who typically mediate patients' access to, and understanding of, their BP measurements. Firstly, a health professional is not likely to take repeated readings of a patient's BP (nor is a patient likely to request consecutive readings, due to prevailing power dynamics). Even if a measurement is repeated, it is likely to be communicated to the patient in a consistent way; for example, if the best-in-class manual measurement (a mercury sphygmomanometer) gives consecutive readings of 119/83 mmHg and 125/79 mmHg, the healthcare professional might summarize the reading as around 120/80 (i.e., in the normal range of BP). But as devices become digital and move into patients' hands, the opposite occurs. With a home-based digital device, a patient may conduct multiple measurements owing to its 'ease of use' [38, 56]. The digital readout hides no information, and the resulting variability leads patients to question the accuracy of the device.

To summarize, our findings suggest that human agents can augment the perceived consistency in BP readings and trust in BP devices. However, easy access to BP devices, by end-users with incomplete knowledge of the expected variability, can ultimately degrade the trust placed in those devices. In agreement with the Technology Acceptance Model [38, 56], the perceived 'ease of use' of a digital BP device may increase the intention to use the device, but only initially. It was observed that participants owning a BP device measured their blood pressure regularly when they purchased it. Regular BP monitoring was eventually discontinued as they began doubting the device's accuracy due to inconsistent consecutive readings. In the long run, the ease of use may, ironically, lead to decreased trust and decreased utilization of BP devices—unless other steps are taken to correct it (something we consider in the next section).

*Sharing and intermediation.* Participants' sharing of BP devices had several similarities, and some distinctions, to prior findings on intermediated usage of technology in low resource communities [91, 92]. While device sharing occurs either due to users' financial constraints, cultural norms, or both, mediation takes place when a tech-savvy user enables a digital experience for a less tech-savvy user.

In contrast to sharing of smartphones, which can have privacy implications [91], a digital BP device does not store any personal information, except for the last few BP readings (not linked to any specific user). This may result in fewer hesitations in sharing a BP device, at least with respect to privacy, compared to sharing a smartphone. In addition, we did not find any stigma associated with abnormal BP, and neighbors were often aware of each other's BP condition, making it easier to share devices than it might be in other contexts. Still, the physical boundary between different homes does add a hurdle for those who share devices between households, as patients are wary of taking too many favors from neighbors. Similar to the case of smartphones, we found intermediated usage of BP devices, with device owners helping patients to place the cuff across their arm, or interpreting readings for them. Notable similarities between shared use of non-medical technologies and BP measuring devices include interpersonal trust between the beneficiary user and intermediate user, availability of the intermediate user, confidence of the intermediate user in using the device, and the feeling of taking someone's favor by the beneficiary user [92].

*Teleconsultation.* In high-income countries, teleconsultation has been described as easy-to-use, saving patients' time and resources, especially for chronic disease management [28]. Even research conducted in resource-rich Indian communities [12] found increased use of teleconsultation during COVID-19, highlighting the efficacy of teleconsultation in providing remote care. In comparison, we found that teleconsultation was not widely used by our participants, mainly due to lack of awareness and access. More than one-third of participants were not smartphone owners, making tasks like fixing online appointments and videoconferencing with healthcare providers infeasible.

Less than 50% of Indians own a smartphone [1], and smartphone penetration is much lower in rural India [14]. Prior work [12] also reported doctors' concerns about the video resolution and placement of patients' videos during teleconsultation, both of which affect the quality of care.

With the rise in telehealth services in India, it is critical to compare its cost with the cost of accessing care through physical consultation. Teleconsultation eliminates the cost of transportation, the loss of daily wage, and the social cost of relying on an acquaintance to accompany the patient. However, it requires the patient (or one of their acquaintances) to be a smartphone user who is aware of the platforms offering such services; an acquaintance may also need to help the patient during the teleconsultation. Although the high cost of teleconsultation services provided by private healthcare platforms could impede low-income communities from accessing care, recent government of India initiatives like eSanjeevaniOPD<sup>2</sup> can be helpful as it provides telehealth services at a subsidized rate.

Of the five participants who had an experience with teleconsultation, four were connected to Karma e-clinic, one of the organizations through which we recruited participants. Karma e-clinic proved to be successful in onboarding patients to a telemedicine platform. Patients were well-acquainted with Karma nurses, who belonged to the same village as the patients and engendered trust to engage with the teleconsultation platform. Other services in India, including Jiyyo Mitra e-clinic [3], follow a similar model. The pattern of using local, trusted intermediaries as portals to care is also embraced more broadly in India, for example, by leveraging community health workers or ASHAs.

## 5.2 Design implications

Next, we discuss potential design recommendations that aim to improve BP management via better awareness and sensitivity to sociocultural factors in low-resource settings.

*Design personal BP devices to explain and interpret data, not just measure it.* Participants distrusted BP measuring devices that showed different readings in consecutive measurements [67], even though similar variations might have been hidden or tolerated when interpreted by human intermediaries. To address this trust barrier, the device could move beyond merely reporting raw, numerical results, and instead help patients to interpret results as well as the significance of any trends observed. For instance, if the same patient measures BP multiple times within 10 minutes, then instead of displaying the actual BP readings, the interface could display a message stating, “Your BP is similar to the last time. Click to expand.” More generally, an ideal device should mimic a health worker’s ability to contextualize the results and explain what they mean, including summarizing and visualizing trends over time. We believe that such design modifications could help patients to trust their personal devices and motivate them to monitor BP more regularly.

*Use legacy representations to boost device familiarity.* While trust in the competence of healthcare professional determines the confidence that our participants have in the BP reading, their trust also depends upon the type of BP device used for measurement. We found our participants preferred manual BP devices over digital devices. While this preference is grounded primarily in perceptions of accuracy and functionality, the stark differences in look and feel do little to reassure users that they can expect familiar results as they move from a manual device to a digital one. As a modest boost to familiarity and trust, we propose to embrace legacy representations and make digital BP devices appear more similar to manual devices. We hypothesize that under the supervision of a qualified healthcare professional and/or with sufficient self-training, people would start trusting the readings from a digital BP device as well. This design principle should not be limited to

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<sup>2</sup>National TeleConsultation Service: <https://esanjeevaniopd.in/About>

BP measuring hardware. For instance, researchers have been working on estimating BP using smartphones without any external attachments [102]. The visual design of such apps can also be similar to manual BP devices (with mercury manometers) to establish familiarity and trust, following the design principle of *skeuomorphism* [8], wherein design cues are taken from the physical world. Skeuomorphism allows users to rely on their prior knowledge about an object, based on their real-world physical experience, thus enabling easier adoption. Skeuomorphism has been successfully used in leading operating systems and applications (including calendars and notetaking) to reduce their learning curve [96]. We believe using such an approach for medical devices and apps will not only help in adoption, but also in establishing trust in the measurement accuracy.

*Introduce novel tools in familiar settings.* We identified three reasons behind participants' hesitancy in teleconsultation in spite of owning a smartphone: (1) lack of familiarity with doctors providing a teleconsultation service, (2) lack of trust in their personal digital BP device, and (3) lack of familiarity and trust in their ability to express themselves properly on a video call. In other words, transitioning to a remote consultation requires participants to adopt a radically different context of BP management, wherein the healthcare provider, the BP measuring device (i.e., the trusted manual BP device), and their way of communicating with the doctor all changed at once.

Instead of requiring patients to take a leap of faith to a setting where everything is unfamiliar, we recommend introducing each of the novel elements separately, in advance, from a familiar setting. Doing so may require adding redundancy to the existing system before the new system can be adopted. For example, to increase patients' trust in digital BP devices, doctors could use both a digital device and a manual device to measure BP during the first few consultations, transitioning patients to a digital-only device at a later time. Or to increase trust in a video consultation, doctors could install a mock consultation kiosk alongside their physical desk; visiting patients could simultaneously experience a video consultation and real-life consultation at the same time, thereby increasing their understanding and trust in the video technology for future remote consultations. If lesser-trained facilitators are involved in mediating remote consultations, they could be introduced to patients as part of a physical doctor visit. These facilitators could even visit the patient's house to measure blood pressure, acting as an intermediary between the doctor and the patient, thus enabling hybrid teleconsultation. Another way to enable teleconsultation could be by making the first visit for a new patient (or of a new condition for an existing patient) to be physical and follow-up visits virtually over teleconsultation. With sufficient design and preparation, by the time a consultation goes completely remote, the only thing that is new for the patient is the location; all other elements have been previously introduced, familiarized, and demonstrated to be worthy of the patient's trust.

*Reduce total cost of accessing care.* Prior work on understanding BP management practices in Kenya [69], Philippines [66], Bangladesh [57, 70], Pakistan [57] and Sri Lanka [57, 80] mentioned the cost of transportation and loss of daily wages as major barriers to accessing care. In addition to these, we found the cost of BP measurement to also include companionship cost, as the participant is usually accompanied to the healthcare facility by a family member. The daily wage and the conveyance charge of the companion needs to be accounted for as well, which further complicates the decision of visiting a doctor. Even if BP measurement is free of cost in a healthcare facility, the total cost of accessing that BP measurement can be high, due to the loss in daily wage, transportation cost, and companion cost. Moreover, this cost is compounded over a long duration, usually for a lifetime. These observations reinforce the need to establish an accurate and reliable BP measuring device at the local level, for example, in the custody of a trusted community health worker. At specific times of the day, trained community health workers with a BP device could be appointed



to the most frequently visited public places, such as bank offices, places of worship, markets, or schools, to check people's blood pressure and offer consultation with a doctor over phone, if needed, thus reducing the overall cost of accessing care. Involving community health workers in BP measurement will require learning from literature on designing technologies for them [42].

*Combat interactive misinformation.* Though only one study participant was using a smartphone application to measure her BP, concerns over the accuracy of this application (iCare) as well as a related application that was downloaded over 148,000 times (Instant Blood Pressure, or IBP) indicate a large scale problem that is worthy of discussion. Significant literature has shown that IBP outputs inaccurate BP estimates based mainly on demographic data [82, 83] and has low accuracy, leading to over four-fifths of individuals with hypertensive BP levels to be falsely reassured that their BP is in the nonhypertensive range [84], which is a reason for users trusting such applications [83].

The prevalence of engagement with such systems despite their limited accuracy is evocative of engagement with misinformation [7, 85, 101]. That said, an inaccurate health measurement application may not have all the usual connotations of “misinformation”, since the information it displays is different for each person and, moreover, requires an interaction with the user before any information can be displayed. We think that such applications are better described by a new term, *interactive misinformation*, which we define as inaccurate or misleading judgments that are derived (or claim to be derived) from information that a user inputs.

Interactive misinformation would include health measurement applications that use inaccurate sensing or calculation techniques to translate user signals to potentially misleading diagnostic information. It would also include a hypothetical application that ignores user inputs and generates static health information (e.g., outputting the mean population BP or small variations thereof). Using an interactive system such as a search engine or social network to discover (mis)information would not meet our definition of interactive misinformation, since users understand that the information found is not freshly generated as a function of their inputs. However, emerging generative AI platforms (such as ChatGPT) may be capable of interactive misinformation, as they generate statements in response to user inputs and part of those outputs may be misleading or incorrect. In the domain of health, interactive misinformation is distinct from general health misinformation, which often advances theories about the causes, treatments, and/or prevention of diseases [17, 30].

Efforts have been made to minimize health-related interactive misinformation. For example, there exists a pathway for getting approval as a medical application on Google Play and Apple App Store. However, regulation of smartphone health applications is challenging due to a lack of standardized quality maintenance practices, absence of formal evaluation and monitoring before deployment, and direct reach of applications to consumers with varying levels of health literacy [60]. Prior research proposes a multi-pronged approach to managing inaccurate health apps [15, 58, 103]. While solving the challenge of detecting and mitigating interactive health misinformation is well beyond the scope of this paper, we believe that stricter regulations and precautions in online app marketplaces could be an important part of the equation. For example, an explicit ‘health permission model’ for unverified health applications might ask, upon every use, “Do you give this application permission to make medical recommendations, which might not be accurate?”

### 5.3 Limitations

We acknowledge several limitations of this work. First, as the authors were fluent only in English and Hindi, we recruited participants from the resource-constrained regions of north India, wherein a majority of people are fluent in Hindi. Given the rich socio-cultural, economical, and demographic diversity of India, our findings may not be generalizable to the rest of India. Thus, the findings of

this study at best serve as preliminary research in the context of understanding blood pressure management among low-income communities in rural/semi-urban parts of north India. Second, the small sample size limited our analyses. A larger number of participants is required to identify broader trends. Finally, our study only focuses on the income class of the participants, but did not account for factors, such as caste or religion, that might affect or shape an individual's perceptions of BP management in India. A deeper exploration of these is a topic for future work.

## 6 CONCLUSION

Countries in the Global South, including India, bear an extraordinarily high burden of hypertensive and hypotensive patients. In this paper, we studied the BP management-related practices and ecosystem in low-resource communities of Haryana, Uttarakhand, and Uttar Pradesh in India. We offered insights into the patient's perspective of BP management, their experience in accessing care, and the trust they place in the BP ecosystem, ultimately influencing their healthcare-seeking behavior. The paper contributes to HCI literature by demonstrating that patients' social circles play a pivotal role in their BP management journey, providing recommendations about technology, necessary intermediation to access technology, and support needed for patients to trust and benefit from technology. Moreover, we provided context-specific accounts of the sociocultural beliefs and economic challenges faced by participants. Based on our findings, we proposed design recommendations to make health technologies and supporting human processes more attuned to the surrounding social context, an important step towards improving their accessibility, trustworthiness, and eventual impact on chronic disease management.

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