

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

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

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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 [70]. 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 [11, 37, 41, 55, 58, 59, 87, 95, 97]. Such work has focused on a variety of chronic conditions, including hypertension [95, 97], diabetes [37, 58, 59], irritable bowel syndrome [41], and migraines [87]. Research has documented the perceptions, beliefs and behaviors toward chronic disease management [57, 60, 95], including self-management practices of diabetes patients [59], sociotechnical complexities in introducing blood pressure measurement technologies among older adults [95], and motivations and barriers in managing multiple chronic conditions [23]. 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 [34, 43], however not much attention has been given to hypertension management. Hypertension is the main risk factor for

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50 cardiovascular diseases such as heart attacks and stroke, and are responsible for one-third of total
51 deaths in India [69].

52 Existing research on blood pressure management in the Global South comes mainly from the
53 health and medical fields, with lesser connections to technology. This health literature examines
54 patients' perceptions, beliefs, experiences, and expectations on the management of hypertension,
55 and barriers to access health services [47, 49, 53, 65, 80]. These studies reported low knowledge
56 around hypertension treatment, high patient load on doctors, prevalent use of alternative medicines,
57 long travel distance and long waiting time at healthcare facilities, and high cost and non-availability
58 of medicine, as major barriers. Based on the findings, studies recommend mainly non-technology
59 driven solutions, including improving patient-doctor relationships, increasing the availability
60 of high-quality low-cost local medical facilities with adequate supplies of medicine, conducting
61 awareness campaigns and mass screening programs, and considering patients' sociocultural and
62 economic backgrounds in providing healthcare services. Even within Global South, wide sociocul-
63 tural, economic, infrastructure, psychosocial, and technology differences exists, making it difficult
64 to generalize findings. In summary, the HCI literature lacks a focus on hypertension management
65 in the Global South, and the health literature on hypertension in Global South lacks an engagement
66 with technology and HCI.

67 To address this gap and building upon prior work, our work focuses on understanding blood
68 pressure management among low-income communities in India and provides recommendations
69 for designing technologies better suited to this context. Our research aims to answer: How low-
70 income individuals living in resource-constrained regions of semi-urban/rural India access and
71 utilize existing healthcare infrastructure and technology to manage their abnormal blood pressure?
72 How does their sociocultural and economic status shape their belief, perception, capability, and
73 adopted strategy (or lack thereof) for blood pressure management? To understand how patients
74 approach managing blood pressure in India, we conducted a qualitative study interviewing 21
75 people clinically diagnosed from low/high blood pressure. Although attributes like age, caste,
76 and religion significantly impacts an individuals' access to healthcare services, our study focuses
77 on low-income communities in India (people earning less than \$10 per capita per day [46]), a
78 demographic representing 97% (estimates vary) of the population [46]. We recruited participants
79 from the rural and semi-urban areas of Haryana, Uttarakhand and Uttar Pradesh in India.

80 Our findings contribute to the fields of HCI, CSCW, and healthcare research in the following ways.
81 First, our results revealed a rich and nuanced understanding of the BP ecosystem in which trust
82 and social relationships broker key aspects of blood pressure management and care. Trust in BP
83 readings was not only dependent on the type of device, but also on the person operating the device.
84 Second, in an environment in which few individuals can afford to own personal BP measurement
85 devices, we describe patterns of both opportunistic and deliberate sharing of devices, with implied
86 social norms around the boundaries of that sharing. Third, we observed an interesting interplay
87 in treating chronic disease as chronic or non-chronic, based on convenience. For instance, when
88 it comes to monitoring BP, participants treated it as a non-chronic condition and only measured
89 their BP during discomfort; however, treating it as a chronic condition, participants consumed
90 minimal salt and walked long distances irrespective of discomfort. Finally, economics played a
91 key role; though BP measurement was free of cost in most scenarios, the cost of a companion
92 accompanying the patient added to the transportation and lost wage cost. We conclude with design
93 recommendations to inform the future of chronic disease management in resource-constrained
94 settings, including reducing trust barriers by altering the visualization of BP readings, leveraging
95 the familiarity of legacy representations, introducing novel tools in familiar settings, and combating
96 interactive disinformation. This adds to a growing body of work in the HCI for Development
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community [44, 48, 74] 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 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 [24, 36, 40]. 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 [71]. There are several studies that have investigated BP management in low resource communities in the Global North (such as Hmong community in US [92], French-and Swahili-speaking African migrants living in UK [20]), as well as in the Global South (like India, Pakistan, Bangladesh, Sri Lanka, Indonesia, Kenya [47, 49, 53, 65, 66, 80]).

Awareness and treatment of hypertension has been found to be low in low- and medium-income countries [19, 49, 53]. 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 [80]. The asymptomatic nature of hypertension further exacerbates this issue [33]. 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 [53, 65, 80]. Underlying the significance of religious beliefs in Pakistan and Bangladesh, Legido-Quigley et al. [53] 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 [53, 65, 80]. Moreover, adherence to medication has been found to be poor among hypertensive patients in Bangalore, India [93], 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 [47, 49]. 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 [49]. 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. [47] 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.

148 However, relevant technology-related questions have not been answered—such as how patients in
149 low-resource settings get their BP measured, the challenges they encounter and how they cope
150 with them, how they log their BP readings, how they approach teleconsultation, and how trust and
151 relationships impact the use of technology in BP care—which is the focus of our work.

152 2.2 Understanding chronic disease management with a technology lens

153
154 Technology influences almost every aspect of chronic disease management—access to information,
155 connecting with doctors and peer groups, monitoring and logging, medication adherence, and
156 self-experimentation. Access to information is vital in managing health conditions, and searching
157 for health information online is fairly common. Pew Internet Research found 80% of Internet users
158 searched for health information online (on WebMD and popular search engines), and it is the third
159 most popular online activity [51]. There is even widespread adoption of online health support
160 groups and health video logs, wherein individuals suffering from chronic conditions share their
161 experiences and knowledge with others. Huh et al. [37] studied diabetes patient support groups,
162 and analyzed online diabetes communities on dLife.com. They found patients helping each other
163 in finding individualized strategies to best manage their diabetes, which led to people in the support
164 group developing a common understanding towards effective diabetes management. Liu et al. [55]
165 studied methods used by health video bloggers suffering from diabetes, HIV and cancer, to establish
166 deep connections and interactions with their viewers.

167 Apart from gaining information and connecting with peers, technology has been widely used to
168 connect with healthcare providers. Specifically, the COVID-19 pandemic has heightened the need
169 for teleconsultations, to ensure that continued care is provided for chronic disease management
170 through remote mechanisms [11]. Studies have investigated patients' perceptions, experiences, and
171 expectations around teleconsultations in India [11] and Canada [73] and commented on technology
172 adoption during this shift to teleconsultation.

173 In chronic disease management, doctors usually recommend regular monitoring of disease-
174 specific health vitals and adhering to medication, along with lifestyle changes. Recent research
175 has explored development of mobile health technologies to ease the burden of measuring health
176 vitals at critical points throughout the day, *e.g.*, smartphone-based blood pressure monitors [97]
177 and lung function measurement [50]. There is a body of research on designing and evaluating
178 applications for storing and visualizing values generated from such monitoring tools, to enhance
179 self-reporting and self-management [23, 83, 94]. The availability of such rich health data has not only
180 triggered sensemaking and data science research in predicting disease progression and suggesting
181 customized health solutions [7, 81], but has also enabled research on self-experimentation, wherein
182 people systematically experiment with different strategies for improving their own health [91].
183 Self-experimentation frameworks have been proposed, along with supporting smartphone apps, for
184 people suffering from chronic migraine [87] as well as for irritable bowel syndrome, where personal
185 food triggers can be identified [41]. Continued tracking of health-vitals is challenging for most
186 individuals, and researchers have explored ways to make it easier. For example, Martin-Hammond
187 et al. emphasised the need for a culturally-informed community-based education programme to
188 encourage tracking of personal health informatics for maintaining cardiac health among black
189 Americans. [61]. Another study conducted in Denmark explored the socio-technical challenges
190 faced by of older adults while using BP device to manage hypertension such as, getting into the right
191 posture to measure BP and understanding and interpreting the BP readings. The study suggested
192 tagging contextual information (such as intake of alcohol or caffeine before measurement) and
193 presenting visuals to make it simpler for the target population to interpret health data [31].

194 Thus, several studies have been conducted globally to investigate management of a variety of
195 chronic diseases. However, there is a limited understanding of perceptions, beliefs, infrastructure,
196

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 <Anonymous Institute>. 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 [28]. 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 [32], 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 [42]. Moreover, hypertension has been found to be more prevalent among economically disadvantaged individuals in India [28]. 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 [72] 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 [45]), 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 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.

246 Participants were made aware that they could choose not to answer any question or leave the
247 interview at any time. At the end of the interview, we collected relevant demographic information.

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

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3.3 Participants

256 Twenty-one participants (8 female, 13 male) with an average age of 46.9 ± 11.9 years participated
257 in the study (Table 1). Fifteen of them were hypertensive, while the rest were hypotensive; on
258 average, participants were living with abnormal BP for 4.6 ± 5.1 years. Eleven participants were
259 from Uttarakhand, eight from Haryana, and two from Uttar Pradesh. All eight participants of
260 Gurugram, Haryana (from P12 to P19) were recruited via Karma e-clinic, of whom three were
261 still visiting the e-clinic and five had visited in the past. The other 13 participants recruited from
262 Uttarakhand and Uttar Pradesh had never visited Karma e-clinics, and were recruited by the public
263 hospital in Dehradun, personal networks, or snowball sampling. Only three participants owned a
264 BP measuring device. Two participants had a Master's degree, one had a Bachelor's degree, five
265 completed secondary school, five completed middle school, and eight completed primary school
266 only. Participant occupations included that of tailor, cook, maid, gardener, field laborer, shopkeeper,
267 accountant, teacher, porter, and housewife. The average daily per capita income of participants was
268 $\$1.35 \pm 1.02$, with the highest daily per capita income reported as $\$3.25$. Seven participants owned a
269 feature phone without an Internet connection, 1 participant did not own a phone (and used the
270 phone of a family member to communicate with us), and the remaining 13 participants owned a
271 smartphone. Eleven participants remembered their last BP reading exactly, while eight participants
272 were unaware of the normal BP range that should be expected. Only five participants had used
273 teleconsultation, of which four were recruited from Karma e-clinic.

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3.4 Data Analysis

276 Transcripts were analyzed using an inductive and iterative methodology [84]. Three authors
277 contributed to the coding process and the codes were iterated until consensus was reached. During
278 analysis, we (1) discussed coding plans, (2) created a preliminary codebook, (3) examined the
279 codebook and improvised/revised codes, and (4) finalized categories and themes. The first level of
280 codes were very specific such as "first occurrence", "medical adherence", "device sharing", "digital
281 versus manual BP device", and "role of friends and acquaintances". After several iterations, the
282 codes were grouped into three high-level themes: "lifecycle of BP management", "trust in the BP
283 ecosystem", and "access to BP care".

284

285

3.5 Positionality

286 All authors have varying levels of experience in healthcare-related research, and have conducted
287 fieldwork with diverse marginalized groups in India. Five authors identify as female and two as male.
288 Three authors are of Indian origin, one author has been in India for more than a decade, and one
289 author has visited India to conduct a healthcare-related ethnographic study for a different research
290 project. While the Indian-origin authors are middle-to-high income individuals, they frequently
291 interact with people from the low-income communities in their daily lives. They also understand
292 and communicate well in Hindi, the language in which the participants were interviewed. All
293 authors have an intimate understanding of HCI4D literature and contexts. Three authors have

294

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)

ID	Age	Sex	Village	Education	Profession	BP	BP year	Owns BP device	Last reading (days)	Phone Type	Monthly household income (INR)	# People at home
P1	51	M	Motharwala	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	Kherimansingh	Secondary	Porter	H	22.5	Yes	60	F	24k	4
P4	43	M	Ranichauri	Secondary	Field Assistant	L	2	No	15	S	11k	5
P5	39	F	Ranichauri	Secondary	Labourer	L	4.5	No	>365	F	3k	6
P6	39	M	Ranichauri	Middle	Gardener	L	1.5	No	2	S	6.5k	4
P7	44	F	Ranichauri	Primary	Tailor	L	1	No	30	S	5k	7
P8	59	M	Ranichauri	Middle	Gardener	H	4.5	No	0	F	8k	10
P9	30	F	Ranichauri	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

more than ten years of research experience in understanding healthcare management practices in the Global South. 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 RESULTS

In the following sections, we first describe the basic context of living with abnormal BP before exploring the intricate factors that mediate trust in, and access to, the ecosystem of care.

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' [10]. 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 (P9), 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.”

344 At the same time, 14 participants reported ‘experiencing discomfort’ that they associated with a
 345 change in blood pressure, prompting them to visit a doctor. Participants with low blood pressure
 346 described sleepiness, giddiness, tiredness and lethargy as their symptoms, and participants with
 347 high blood pressure associated anxiety, irritation, shaky legs and pain in the chest with the disease.
 348 Participants linked these symptoms with BP fluctuations and claimed that they ‘could feel’ when
 349 their BP increases or decreases, though there is scientific evidence to the contrary [9]. A few
 350 participants even took medications and visited the hospital based on such intuitions.

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

355 *“I bought this (BP machine) for my father. He had a BP problem... Once I casually*
 356 *(checked my BP), I didn’t know I could have BP, but I took a measurement and it*
 357 *showed I had BP, and it kept on increasing. I thought it was getting too high... Around*
 358 *120 is okay, 135 seems okay too, but when it rose to 160, I realized I should see a doctor.”*
 359

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

363 **4.1.2 Treatment.** Our participants engaged in a variety of treatments, including lifestyle changes,
 364 home remedies, and medicine.

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

369 *“After waking up in the morning, I drink tea and I go for a walk. I walk for 2 to 4*
 370 *kms. Then I exercise and do some yoga at home... I have reduced salt intake in my*
 371 *food... There has been a considerable difference because of reducing salt intake. And*
 372 *they (doctors) have told me to take a little bit salad, so I’ve also started eating some*
 373 *salads in the morning.”*
 374

375 While several such behaviors were prescribed, the extent of adhering to such lifestyle changes by
 376 our participants was linked to their self-evaluated efficacy and feasibility to perform that action [88].
 377 For example, P13 laughed and explained that she is not able to find time to run or for any kind of
 378 physical activities, while P19 conveyed that she cannot limit her consumption of salt as she “*can’t*
 379 *eat chappatis (Indian flatbread) without salt.”* Though participants were often aware of the benefits
 380 of healthy lifestyle habits, they opted for the feasible options only.

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

390 *Medicine and adherence:* Participants acknowledged the significance of (allopathic) medicine and
 391 expressed that they had experienced its benefit in terms of relieving discomfort. All participants
 392

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.

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 [80].

Lastly, adherence to medication was complicated by varying levels of 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 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 with their own BP measuring device reported not measuring their blood pressure frequently, either due to the required effort, or lack of trust on their personal BP device. For instance, P3 said, *“I have a BP machine, but I don’t measure it every week, or every month, 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 more than my previous reading, sometimes it comes 2-5 readings less... in that case, which reading should I consider to be my correct reading?”* We explore this lack of trust on the device later in detail.

Only 2 participants (P1 and P2) 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).”

This is consistent with previous research identifying that patients stop tracking health information when they believe their health is stable [12].

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.”

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 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

442 it enabled additional doctor visits (for a limited time, as needed) without paying additional fees. It
 443 also provided documentation on any prescribed medications. Despite these benefits, most partici-
 444 pants admitted that they are not able to keep the consultation summary for very long, as it gets
 445 misplaced.

446 4.2 Trust in the care ecosystem

448 Participants exhibited nuanced and interconnected relationships of trust and mistrust with different
 449 aspects of the care ecosystem, spanning medicine, technology, and people. These underlying
 450 dynamics of confidence, doubt, and the uncertainty in between formed a foundation for how
 451 participants approached the management of chronic disease and how they interacted with emerging
 452 technologies and models of care. For this paper, we are using Gambetta's [26] definition of 'trust',
 453 defined as: A person or an object is considered trustworthy, if there is a high likelihood that '*the*
 454 *actions executed by them are beneficial or at least not detrimental to us, for us to consider engaging in*
 455 *some form of cooperation with them*'.

456 4.2.1 *Trust in medicine.* Even though healthcare professionals counseled participants to take
 457 medicines regularly, some participants had their doubts as to whether or not the prescribed al-
 458 lopathic medicines could cure the disease "*from its root cause.*" As abnormal blood pressure is
 459 a chronic condition, it cannot be cured but can only be managed with medication and lifestyle
 460 changes. However our participants, reported treating their hypo/hypertension as any other acute
 461 disease (similar to [80]). Participants explored a variety of alternative medicines, such as Ayurvedic,
 462 homeopathic, and Unani medicine, as discussed in prior work from Bangladesh, Pakistan, and Sri
 463 Lanka [53], in hopes of curing BP related problems from the root cause. We also found participants
 464 changing medicine on the advice of friends or family, and even discontinuing medicine just to see
 465 what would happen. P1 described his struggle:

467 *"A friend told me, take medicine from 'that doctor', he is very good. Take it from that*
 468 *hakim, he gives very good medicine too. See... a patient's wish is that he gets relief,*
 469 *whichever place he gets medicine from. It's about getting relief. Whoever suggests*
 470 *whatever place, we get (medicine) from there. I have been taking medicines for more*
 471 *than 20 years, but no medicine has worked well for me." – P1.*

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

475 Participants also exhibited fears of becoming habitual with allopathic BP medicine and the
 476 potential long-term side effects on their health. Similar findings have been reported previously
 477 in low-resource settings of Hmong Americans [92]. Though participants were aware that regular
 478 medicine intake was beneficial, still they doubted the medicine, claiming that it was addictive. P17
 479 shared an incident when she stopped taking medicine, but later continued because of discomfort:

480 *"Someone had said, don't take so many BP medicines regularly, you'll get habituated.*
 481 *After stopping (the medicine), I was not able to walk. Legs and hands felt so lifeless,*
 482 *like there was no strength in my legs and hands. Then I started it (medicine) again."*

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

488 4.2.2 *Trust in BP measurement.* Participants had a complex mental model to assess the accuracy
 489 and trustworthiness of BP devices. We found the trust in BP devices to depend on a variety of factors,
 490

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.”

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. 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 devices, as previously reported by Montague *et al.* [64]. 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.

While sentiments of mistrust were common with respect to BP measurement, we also found misplaced trust. For example, P19 shared how her son uses iCare¹, a smartphone 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. 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 [77]. However, the iCare app lacks independent evaluation and FDA approval, leaving little reason to trust it [77]. 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 participants (16/21) 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.

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

540 Participants were typically unaware of teleconsultation. Doctors familiar to them did not provide
 541 it, and due to the power imbalance between doctors and patients in low-resource settings, it was
 542 challenging for patients to approach doctors via the phone (as previously discussed in [12, 17]). On
 543 being explained what teleconsultation means and asking them about adopting it if such an option
 544 exists in future, we found our participants hesitating in exploring teleconsultation and preferring
 545 physically visiting a doctor, mainly because of the novelty factor: “*I have never talked to a doctor*
 546 *on phone, how will I do that?*” – P9. This hints our participants lacking trust in the potential of
 547 teleconsultation as a means of accessing care. Even participants who had used teleconsultation
 548 reported that they felt more comfortable with face-to-face interactions, as they could express
 549 themselves better. This is consistent with prior studies [2, 100] finding that body language is an
 550 important supplement to verbal communication during face-to-face consultations. P11, who had
 551 never used teleconsultation, anticipated that it would be hard to articulate a problem to the doctor
 552 during virtual consultation:

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

557 Prior work studying teleconsultation in an urban Indian context [11] identified teleconsultations
 558 to work best for follow-up doctor-patient interaction, especially for chronic conditions. Karma
 559 e-clinic mainly provides teleconsultation for hypertension and diabetic patients in a hybrid manner,
 560 wherein health vitals (like blood pressure and blood sugar level) was measured by a local medical
 561 staff before connecting the patient with a doctor over a video call. Without a trustworthy BP
 562 reading, it impacted their trust in teleconsultation, as they believed prescription could be based on
 563 a faulty reading.

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

570 This highlights the intricate trust relationship between doctors, patients and accurate BP readings.
 571

572 **4.2.4 Trust in care providers.** Participants interacted with doctors, nurses, quacks, and medical
 573 store owners to seek support for BP management, and acknowledged their crucial role in managing
 574 BP. In spite of the trust placed in doctors, participants did their own diligence on doctors' advice.
 575 For example, P17 states: “*Even if the doctor recommends a medicine... I always get it checked by my*
 576 *kids on the internet and only then take it.*” This was mainly because the clinics are usually full of
 577 patients, hence at times the doctors are not able to provide full attention to every patient.

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

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

585 This is consistent with prior work finding that patients can feel neglected and dissatisfied when
 586 doctors are busy writing prescriptions and are unable to make eye contact [18].
 587

588

589 While private hospitals were viewed by participants as having a higher quality of care, their
 590 high costs often made them inaccessible. For example, P8 states: *“If someone goes to a good (private)
 591 hospital, they will ask for an X-ray, ultrasound, BP, blood test. After measuring everything, they make
 592 a bill of 2500-3000 rupees, in a jiffy.”* To reduce expenses, one participant reported seeking generic
 593 alternatives to prescribed brand-name drugs, which could reduce medicine costs many-fold.

594 In light of the challenges interacting with licensed doctors in public and private facilities, partici-
 595 pants often turned to unlicensed providers, commonly known as quacks [22, 67], for assistance
 596 with BP and other health problems. Participants maintained good interpersonal relationships with
 597 quacks, as they typically lived in the same neighborhood. For example, P1, who described doctors
 598 in government hospitals as uncongenial, viewed quacks as more accessible care providers:

599 *“In villages, there are small doctors (called) quacks. These quacks have BP machines as
 600 well. So, I go to them. They measure BP quite accurately... Big doctors don’t even tell us,
 601 at least quacks explain everything to us.”*

602 Usually in hospitals, the medical staff not doctors measures their blood pressure, and we found our
 603 participants to place more trust on quacks for measuring BP accurately over nurses/medical staff.
 604 Despite their lesser qualifications, quacks remain a critical part of the participants’ trust ecosystem.
 605 In the words of P20, *“He is from our village itself, so we trust him”*.

606
 607 **4.2.5 Trust in social circles.** Participants’ social circles played a key role in determining their trust
 608 in, and relationship with, the health ecosystem. Participants described how their choice of doctor
 609 was influenced by the opinion of their social circle: *“I had asked people I know (acquaintances) and I
 610 had taken their reviews (of the doctor). I had asked people where to get treatment.”* – P18. This shows
 611 how trust in some actors of the BP ecosystem, such as the social network of the participant, can
 612 foster trust in other actors, such as the healthcare provider. In addition to seeking guidance on
 613 doctors, participants also asked their personal networks for recommendations on lifestyle changes,
 614 alternative medicine, and buying a BP measuring device. Strong trust relationships also enabled
 615 unconventional means of accessing needed resources, as relayed by P10, who lives in a remote
 616 location:

617 *“Actually, there are no facilities where I live... Medicines are available 150 to 200 kms
 618 away from here. We order medicines through the bus drivers. I give the slip to them,
 619 they buy the medicine for me. I just have to give the total cost of the medicine. There is
 620 no transportation cost.”*

621
 622 At the same time, placing such trust in social ties was not without its hazards. As described
 623 previously (Section 4.2.1), some participants switched or stopped BP medicine on the basis of social
 624 influence without even consulting a healthcare provider. Moreover, health related rumors were
 625 prevalent in participants’ social circles, negatively impacting their ability to make informed health
 626 decisions. As P13 conveyed in astonishment, *“I got to know yesterday that if BP is low, then one should
 627 not eat potatoes! Someone in my neighborhood told me, the boutique owner... He said, ‘Bhabhi, your BP
 628 remains low, you should not eat potatoes.’ I didn’t know this.”* P13 was uncertain of what to believe.
 629 Prior work has reported sharing of such health-related rumors particularly during COVID-19 [5].

630 4.3 Access to care

631
 632 Ensuring that everyone has access to high quality healthcare remains a profound challenge in
 633 India. Just as trust relationships shaped participants’ engagement with health services, so too did
 634 social relationships played a critical role in mediating access to those services in the first place.
 635 This section explores the multi-faceted influence of social relationships on participants’ access to
 636 shared devices, access-related costs, access by women, and access to family caregivers.

638 4.3.1 *Access to shared devices.* While financial constraint, trust and usability prevented nearly
 639 all participants (18/21) from owning a personal BP device, it did not prevent them from accessing
 640 devices in other ways. In particular six participants mentioned sharing digital BP devices owned
 641 by their acquaintances, including neighbors and employers. Sharing goods among neighbors is
 642 commonplace, and it results in reducing economic burden and maintaining strong relationships [15,
 643 89].

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

649 *"I don't bring their machine to my home. They measure it. Their child does it, he is*
 650 *26-years-old. They tell me the BP reading... I don't even know what is the range of*
 651 *normal, low or high BP." – P13.*

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

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

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

666 4.3.2 *Hidden costs in accessing devices.* Participants offered detailed narratives regarding the true
 667 costs involved in accessing BP measurements. Though the direct cost of each measurement was
 668 considered to be minimal (0-20 INR) in most healthcare facilities, a few participants expressed that
 669 it was still substantial when compounded over a lifetime. Moreover, even if the measurements them-
 670 selves were free of cost, there were additional unavoidable expenses, including (a) *transportation*
 671 *cost:* from their home to the healthcare facility and back, (b) *daily wage cost:* most participants were
 672 daily wage workers and visiting a healthcare unit meant missing their daily wage, (c) *miscellaneous*
 673 *expenses:* on food, shopping, etc., and, importantly, (d) *companion cost:* participants were usually
 674 accompanied by a family member to visit the healthcare unit, increasing costs in each of the three
 675 prior categories and also requiring effort from the companion.

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

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

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

686

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

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

693
694 4.3.3 *Women’s access to care.* Interviews showed that women’s access to care was affected by
695 social and cultural constructs, including predefined gendered roles and familial expectations from
696 women in Indian society [8]. The gendered segregation of duties renders women and children
697 to be dependent on men for their financial needs, including healthcare-related expenses. P19, a
698 housewife suffering from hypertension, admitted that her non-adherence to medication was driven
699 largely by the non-affordability of drugs, while P17 subscribed to the idea of putting her family
700 above herself and her health. The societal expectations of women to fulfill domestic responsibilities
701 and serve as primary caregivers also limits their ability to focus on their own health. This has been
702 reported previously by Razvi and Roth [82]. For instance, P9 has multiple household responsibilities
703 that interfere with her access to care: “I don’t have time to go to the hospital. I keep on working... I
704 have buffaloes. I have two small kids too.” Likewise, bemoaning the demise of her sister and family
705 struggles, P15 stated:

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

710 Women’s access to care was further impeded by their restricted mobility (as discussed in prior
711 literature [38]) and dependence on male family members to accompany them to the hospital. In the
712 case of P9, she used to visit the hospital regularly while she was pregnant, and was also getting
713 treated for hypotension. However, after her pregnancy, she stopped visiting the hospital: “The
714 distance to the hospital is an issue... I was pregnant around three years back... Since then, I haven’t
715 visited the hospital.” Though the distance between her house and the hospital did not change, there
716 was a behavioural difference in visiting the hospital for maternal versus BP-related health concerns.
717 Prior research has concluded that families in low and middle-income countries tend to spend fewer
718 resources on non-maternal health of women in comparison to their maternal health, in spite of the
719 seriousness and severity of the non-maternal health concern [29].

720
721 4.3.4 *Access to family caregivers.* Relationships with family members played a key role in bolstering
722 access to care, not only as advisors and companions but also as continual sources of help with BP
723 management. For instance, P4, who is hypotensive, shared “my wife adds more salt in pulses,” and
724 P9 mentioned that her family prepared home remedies for her and even provided physical support
725 when needed:

726 “Whenever I feel discomfort and not able to walk, my mother-in-law holds me and
727 helps me walk. Once, I was in the field, and my health deteriorated in the field itself. At
728 that time, my mother-in-law carried me home. She gave me lemon water and glucose
729 water.” – P9.

730 Family members also served as technology intermediaries. For example, P3, who owned a digital BP
731 device, shared that his daughter helps him to place the cuff before each measurement, P17’s children
732 help in finding more information online about the disease and medication prescribed by the doctor,
733 and P19 used the iCare smartphone app to measure blood pressure (although wrongfully) with ease.
734 Moreover, as mentioned previously, participants also reported that family members often served as
735

736 essential companions during hospital visits, providing guidance as well as needed emotional and
737 physical support.

738 5 DISCUSSION

739
740 Our study provides insight into people's lived experiences with blood pressure management in
741 low-resource areas of northern India, spanning semi-urban and rural settings. We found that
742 ownership of BP devices was rare among participants due to monetary constraints and low trust in
743 digital BP devices; however, sharing of BP devices was common. Even when BP measurement
744 was inexpensive or free at a healthcare facility, patients were deterred from measuring their BP
745 regularly due to their perception of BP as a non-chronic disease, the additional requirement and
746 cost of needing a companion to travel to the facility, and moral beliefs against over-use of free
747 services. Participants' social circles played a critical role in providing recommendations for doctors,
748 medicines, devices, and smartphone applications for BP management, as well as in mediating
749 patients' access to, and trust in, such resources. Although participants generally described their
750 family members as being supportive, sometimes the household responsibilities that participants
751 undertake, particularly among women participants, dissuaded them from accessing care. In the
752 remainder of this section, we reflect further on how trust and relationships impact BP management
753 in India, before considering potential implications for design.

754 5.1 The role of trust and relationships in BP management

755
756 *Trust in BP measurement devices.* Our findings uncovered a nuanced and unexpected relationship
757 between the accessibility and perceived trustworthiness of a BP device. While participants had
758 increasing access to digital devices for measuring BP at home (or at a neighbor's home), they
759 also voiced distrust in the accuracy of such devices. According to participants, one of the most
760 important characteristics of a trustworthy device was that consecutive readings were consistent.
761 While this may sound like a reasonable expectation at face value, in practice there were multiple
762 interconnected factors that impacted the consistency of readings obtained.

763 One source of inconsistency in BP measurements owes to natural biological fluctuations. As blood
764 pressure varies from heartbeat to heartbeat, variation in consecutive BP readings is expected [101].
765 Furthermore, when people measure BP at home, they usually don't pay attention to physical factors
766 such as their back posture, arm position, cuff size, leg-position, and maintaining silence during
767 measurement [21, 30, 68, 76], any of which can lead to an incorrect BP reading, irrespective of the
768 device's accuracy. Additional factors can explain discrepancies between measurements taken by
769 oneself at home, and those taken by a professional in a healthcare facility. For example, patients'
770 anxiety and conditioned response to hospital environments may cause a temporary increase in
771 blood pressure in a hospital setting, known as the "white collar effect" [39, 68].

772 If such variations are a routine aspect of BP measurement, then from where did patients come to
773 expect consistent readings? The answer, we posit, is not from the technology itself, but from the
774 people who typically mediate patients' access to, and understanding of, their BP measurements.
775 Firstly, a health professional is not likely to take repeated readings of a patient's BP (nor is a patient
776 likely to request consecutive readings, due to prevailing power dynamics). Even if a measurement
777 is repeated, it is likely to be communicated to the patient in a consistent way; for example, if the
778 best-in-class manual measurement (a mercury sphygmomanometer) gives consecutive readings
779 of 119/83 mmHg and 125/79 mmHg, the healthcare professional might summarize the reading
780 as around 120/80 (i.e., in the normal range of BP). But as devices become digital and move into
781 patients' hands, the opposite occurs. With a home-based digital device, a patient may conduct
782 multiple measurements owing to its 'ease of use' [35, 52]. The digital readout hides no information,
783 and the resulting variability leads patients to question the accuracy of the device.

785 To summarize, our findings suggest that human agents can augment the perceived consistency
 786 in BP readings and trust in BP devices. However, easy access to BP devices, by end-users with
 787 incomplete knowledge of the expected variability, can ultimately degrade the trust placed in those
 788 devices. In agreement with the Technology Acceptance Model [35, 52], the perceived ‘ease of
 789 use’ of a digital BP device may increase the intention to use the device, but only initially. In the
 790 long run, the ease of use may, ironically, lead to decreased trust and decreased utilization of BP
 791 devices—unless other steps are taken to correct it (something we consider in the next section).

792 *Sharing and intermediation.* Participants’ sharing of BP devices had several similarities, and some
 793 distinctions, to prior findings on intermediated usage of technology in low resource communities [85,
 794 86]. While device sharing occurs either due to users’ financial constraints, cultural norms, or both,
 795 mediation takes place when a tech-savvy user enables a digital experience for a less tech-savvy
 796 user.

797 In contrast to sharing of smartphones, which can have privacy implications [85], a digital BP
 798 device does not store any personal information, except for the last few BP readings (not linked
 799 to any specific user). This may result in fewer hesitations in sharing a BP device, at least with
 800 respect to privacy, compared to sharing a smartphone. In addition, we did not find any stigma
 801 associated with abnormal BP, and neighbors were often aware of each other’s BP condition, making
 802 it easier to share devices than it might be in other contexts. Still, the physical boundary between
 803 different homes does add a hurdle for those who share devices between households, as patients
 804 are wary of taking too many favors from neighbors. Similar to the case of smartphones, we found
 805 intermediated usage of BP devices, with device owners helping patients to place the cuff across their
 806 arm, or interpreting readings for them. Notable similarities between shared use of non-medical
 807 technologies and BP measuring devices include interpersonal trust between the beneficiary user
 808 and intermediate user, availability of the intermediate user, confidence of the intermediate user in
 809 using the device, and the feeling of taking someone’s favor by the beneficiary user [86].
 810

811 *Teleconsultation.* In high-income countries, teleconsultation has been described as easy-to-use,
 812 saving patients’ time and resources, especially for chronic disease management [25]. Even research
 813 conducted in resource-rich Indian communities [11] found increased use of teleconsultation during
 814 COVID-19, highlighting the efficacy of teleconsultation in providing remote care. In comparison,
 815 we found that teleconsultation was not widely used by our participants, mainly due to unawareness
 816 and lack of access. More than one-third of participants were not smartphone owners, making
 817 tasks like fixing online appointments and videoconferencing with healthcare providers infeasible.
 818 Less than 50% of Indians own a smartphone [1], and smartphone penetration is much lower in
 819 rural India [13]. Prior work [11] also reported doctors’ concerns about the video resolution and
 820 placement of patients’ videos during teleconsultation, both of which affect the quality of care.

821 With the rise in telehealth services in India, it is critical to compare its cost with the cost of
 822 accessing care through physical consultation. Teleconsultation eliminates the cost of transportation,
 823 the loss of daily wage, and the social cost of relying on an acquaintance to accompany them.
 824 However, it requires the patient (or one of their acquaintances) to be a smartphone user, be aware of
 825 the platforms offering such services, and help the patient during the teleconsultation. Although the
 826 high cost of teleconsultation services provided by private healthcare platforms could impede low-
 827 income communities from accessing care, the government of India initiative like eSanjeevaniOPD²
 828 provide telehealth services at a subsidized rate. Of the five participants who had an experience
 829 with teleconsultation, four were connected to Karma e-clinic, one of the organizations through
 830 which we recruited participants. Karma e-clinic proved to be successful in onboarding patients to
 831

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

834 a telemedicine platform. Patients were well-acquainted with Karma nurses, who belonged to the
835 same village as the patients and engendered trust to engage with the teleconsultation platform.
836 Other services in India, including Jiyyo Mitra e-clinic [3], follow a similar model. The pattern of
837 using local, trusted intermediaries as portals to care is also embraced more broadly in India, for
838 example, by leveraging community health workers or ASHAs.

839 5.2 Design implications

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

842 *Design personal BP devices to explain and interpret data, not just measure it.* Participants distrusted BP
843 measuring devices that showed different readings in consecutive measurements [64], even though
844 similar variations might have been hidden or tolerated when interpreted by human intermediaries.
845 To address this trust barrier, the device could move beyond merely reporting raw, numerical results,
846 and instead help patients to interpret results as well as the significance of any trends observed.
847 For instance, if the same patient measures BP multiple times within 10 minutes, then instead
848 of displaying the actual BP readings, the interface could display a message stating, “Your BP is
849 similar to the last time. Click to expand.” More generally, an ideal device should mimic a health
850 worker’s ability to contextualize the results and explain what they mean, including summarizing
851 and visualizing trends over time. We believe that such design modifications could help patients to
852 trust their personal devices and motivate them to monitor BP more regularly.

853 *Use legacy representations to boost device familiarity.* While trust in the competence of healthcare
854 professional determines the confidence that our participants have in the BP reading, their trust
855 also depended upon the type of BP device used for measurement. We found our participants
856 preferred manual BP devices over digital devices. While this preference is grounded primarily in
857 perceptions of accuracy and functionality, the stark differences in look and feel do little to reassure
858 users that they can expect familiar results as they move from a manual device to a digital one.
859 As a modest boost to familiarity and trust, we propose to embrace legacy representations and
860 make digital BP devices appear more similar to manual devices. We hypothesize that under the
861 supervision of a qualified healthcare professional and/or with sufficient self-training, people would
862 start trusting the readings from a digital BP device as well. This design principle should not be
863 limited to BP measuring hardware. For instance, researchers have been working on estimating
864 BP using smartphones without any external attachments [97]. The visual design of such apps
865 can also be similar to manual BP devices (with mercury manometers) to establish familiarity and
866 trust, following the design principle of *skeuomorphism* [6], wherein design cues are taken from
867 the physical world. Skeuomorphism allows users to rely on their prior knowledge about an object,
868 based on their real-world physical experience, thus enabling easier adoption. Skeuomorphism has
869 been successfully used in leading operating systems and applications (including calendars and
870 notetaking) to reduce their learning curve [90]. We believe using such an approach for medical
871 devices and apps will not only help in adoption, but also in establishing trust in the measurement
872 accuracy.

873 *Introduce novel tools in familiar settings.* We identified three reasons behind participants’ hesitancy
874 in teleconsultation in spite of owning a smartphone: (1) lack of familiarity with doctors providing
875 a teleconsultation service, (2) lack of trust in their personal digital BP device, and (3) lack of
876 familiarity and trust in their ability to express themselves properly on a video call. In other words,
877 transitioning to a remote consultation requires participants to adopt a radically different context of
878

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. 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 [65], Philippines [62], Bangladesh [53, 66], Pakistan [53] and Sri Lanka [53, 75] 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.

Combat interactive disinformation. Although only one of our participants was using a smartphone application called iCare to measure her BP, there has been ongoing discourse about the accuracy of iCare and similar apps such as IBP (Instant Blood Pressure) [63]. Significant literature has shown that IBP outputs inaccurate BP estimates based mainly on demographic data [77, 78] and has the lowest accuracy as per the British Hypertensive Society scoring system [79]. Though both these applications have been removed from the App Store [63, 79], researchers found users trusting such applications mainly because lower than expected BP readings promote user satisfaction [78]. As an interactive system is providing inaccurate information deliberately to deceive its user, we term it '*interactive disinformation*' [5, 96, 98]. An interactive disinformation system may or may not use the user input to generate its output. While online health-related misinformation has mostly focused on the cause, treatment, and/or prevention of diseases [16, 27], interactive disinformation is very personalized, resulting in minimal digital dissemination but very serious impact. Efforts have been made to minimize such health-related interactive disinformation. For example, there exists a pathway for getting approval as a medical application on Google Play and the Apple App Store.

932 However, regulation of smartphone health applications is challenging due to a lack of standardised
 933 quality maintenance practices, absence of formal evaluation and monitoring before deployment,
 934 and direct reach of applications to consumers, who have varying levels of health literacy [56]. Prior
 935 research proposes a multi-pronged approach to managing inaccurate health apps [14, 54, 99]. We
 936 propose an explicit ‘health permission model’ for such inaccurate applications that asks upon every
 937 use, “Do you give this application permission to make medical recommendations, which might not
 938 be accurate?” Moreover, stricter restrictions need to be employed by Google Play and Apple App
 939 Store with respect to health applications.

941 5.3 Limitations

942 We acknowledge several limitations of this work. First, as the authors were fluent only in English
 943 and Hindi, we recruited participants from the resource-constrained regions of north India, wherein
 944 a majority of people are fluent in Hindi. Given the rich socio-cultural, economical, and demographic
 945 diversity of India, our findings may not be generalizable to the rest of India. Thus, the findings of
 946 this study at best serve as preliminary research in the context of understanding blood pressure
 947 management among low-income communities in rural/semi-urban parts of north India. Second,
 948 the small sample size limited our analyses. A larger number of participants is required to identify
 949 broader trends. Finally, our study did not account for factors, such as caste or religion, that might
 950 affect or shape an individual’s perceptions of BP management in India. A deeper exploration of
 951 these is a topic for future work.

953 6 CONCLUSION

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

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