

Sociocultural Dimensions of Tracking Health and Taking Care

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The field of personal health informatics has received increasing attention within the CSCW and HCI communities as health tracking becomes more affordable, accessible, and pervasive. Chronic disease management, in particular, presents tremendous potential for intervention given patients' ability to now actively participate in their care through tracking. The focus on 'personal' in health informatics, however, obfuscates the role of other cultural and ecological factors that might shape health tracking behaviors, and important information from alternative sources could be ignored by virtue of being subjective, complex, or simply hard to collect. To dig deeper into these negative spaces that may go untracked, uncover potential sources of important health information, and more completely understand current tracking practices, we embarked on an interview study with patients with cardiac diseases in Bangalore, India. In this paper, we present these patients' current health management approaches that are culturally situated, identifying both motivations and barriers to tracking, their attitudes towards online information, as well as cultural and ecological influences on their perceptions of cardiac care. We then discuss the interplay between our findings and current notions of, and approaches towards, patient empowerment and datafication of health.

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

Additional Key Words and Phrases: patient empowerment, healthcare, qualitative, datafication, HCI4D

ACM Reference Format:

Karthik S. Bhat and Neha Kumar. 2020. Sociocultural Dimensions of Tracking Health and Taking Care. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW2, Article 129 (October 2020), 24 pages. <https://doi.org/10.1145/3415200>

1 INTRODUCTION

The fields of Computer-Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI) research have actively been investigating the design and use of technology for patient-centered care. Identified by the Institute of Medicine as a goal for quality in healthcare [38], patient-centered care aims to support patients through increased patient engagement and information system use in care delivery [20]. Within CSCW and HCI, this research has focused heavily on personal health informatics (e.g., [14, 15, 44]), patient engagement (e.g., [33, 62, 77]), and novel interaction technology (e.g., [36, 65, 96]), among other topics. A key underlying motivation in these works is that gathering increasing amounts of diverse individual health data is likely to assist towards overall health and wellbeing, and improved provision of patient-centered care. Consequently, recent research and design have focused on health tracking such as self-reported meal tracking (e.g., [54]), physiological data collected from wearable devices (e.g., [36]), and other health indicators like blood reports [93] collectively shaping insights into a person's health and wellbeing.

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2573-0142/2020/10-ART129 \$15.00

<https://doi.org/10.1145/3415200>

This approach to health tracking has *negative spaces* in that certain data that pertains to health management are unaccounted for by virtue of being hard to collect, subjective, or complex. These negative spaces, we posit, are important to recognize and explore to inform better design of future health tracking technology and work towards the goal of collecting diverse health data. Some examples of these negative spaces include informal care networks that play a variety of different roles in an individual's care, thereby affording under-collected and complementary data. Further, cultural taboos and/or incorrect assumptions about technology could impact health tracking and care management. Additionally, most tracking technology today explores health tracking as a mainly individual endeavor, with the data generation and analysis at an individual level. The HCI community is exploring health tracking as a collective activity to involve families and friends in the data analysis process [74, 78]. We augment this line of work by highlighting the need for this plurality to exist even at the data generation stage, to fully capture social, cultural, and environmental aspects of care for a more complete account of patient-centered care management.

We present findings from an interview study with 18 patients and families, and 8 doctors, that we conducted to understand the patients' prescribed- and lived- cardiac disease management approaches. Cardiac diseases are chronic conditions requiring medical or surgical intervention as well as lifelong lifestyle management and health tracking activity. Our study takes place in Bangalore, India; conducting this research in an urban Indian context enables us to study emergent technology-enabled health tracking practices and their sociocultural situatedness. We explore our participants' engagement with health tracking technology and data generation—the data that is tracked and that which is not—as they are embedded within larger ecologies of collaborative care. Exploring the effects of social and cultural norms on health tracking in this way affords a window into engaging patient empowerment narratives to more effectively provide patient-centered care. While patient empowerment initiatives have primarily foregrounded information provision and patient choice [61, 77], their realizations in healthcare settings with different social and cultural norms, like in India and other regions in the Global South, have only been touched upon [49]. Through this paper, we further develop this narrative by examining how appropriately supporting health tracking can provide alignment towards patient empowerment in an understudied culturally unique context.

Our contributions to CSCW research are two-fold. First, we contribute evidence for the sociocultural situatedness of patient-centered care. This understanding could suggest the path forward for better data collection practices and more inclusive design of health tracking technology. Second, we enrich and complicate the patient empowerment literature that currently proselytizes information provision as a means of empowerment.

2 RELATED WORK

We situate our research in conversation with existing work in HCI that explores patient-centered care through health tracking and collaborative caregiving. We then provide an overview of patient empowerment approaches within this literature and present the research gap that this research seeks to fill.

2.1 Health Datafication and Self-Tracking

In HCI, health datafication has been extensively studied within the field of personal health informatics (PHI). Here, researchers study the processes by which individuals collect and reflect on data about themselves to understand their behavior [15, 51, 81], and gain insights related to their health (e.g., [3, 10, 19, 44, 52]). This includes research ranging from patient-doctor interactions [16, 17, 41, 72, 103], to self-improvement with health tracking [14, 99], to personal informatics tools

and practices in managing chronic health conditions like diabetes (e.g., [18, 21, 79]) and asthma [42].

Despite the ostensible benefits of individual personal tracking of health data surfaced and studied by this research, however, researchers also acknowledge barriers to this tracking including: a lack of time and motivation both among doctors and patients [2, 16], privacy concerns [25], inability to analyze data, and multiple incompatible streams of data [50]. They identified a need for data narratives that capture the complexity of human emotions and sociocultural contexts around this data [46]. Consequently, research has moved towards more contextualized tracking, like in the ‘lived informatics’ model that considers people’s behavior with, and adoption and usage of, self-tracking tools [26]. Increasingly, research has argued the need to expand personal informatics beyond the individual to truly understand people’s behavior around health data. Puussaar et al. [78] present social sensemaking as an approach towards this end, finding that sharing and analyzing self-tracker data among social networks improves sensemaking by contextualizing the data. Similarly, Pina et al. [74] study the effects of caregivers monitoring others’ health data and reflect on what it means to design for such contexts.

These approaches to self-tracking situate the individual at the center of their tracking, while recognizing that informal caregivers [60] also play an important role in the process. Lupton, on the other hand, approaches self-tracking as a “profoundly social practice” and presents the sociocultural and political dimensions of self-tracking[53]. This argument has gained traction in the PHI community [66] with more attention shifting towards its interpersonal and social nature [95]. For example, Murnane et al. [67] present an ecological model of PHI, based on Bronfenbrenner’s Ecological Systems Theory model [9], that extends beyond the individual to encompass closely related social ties, institutions, and sociocultural contexts as layers that influence self-tracking. Recent works have also explored the design of methodologies to incorporate peers’ observation data in self-tracking activities [4, 5].

Having identified research on the collaborative nature of self-tracking, we delve into research that explores chronic disease management as a collaborative practice.

2.2 Chronic Disease Management and Collaborative Care

Chronic disease management literature has extensively studied the importance of sociocultural context in care. Theories of care have been studied in the context of healthcare to analyze and explain its interplay in the social interactions that occur around healthcare [84, 91, 102]. Technology can play an important role in enabling care across these different healthcare contexts. Studying parental interactions with NightScout, a Type 1 Diabetes tracking tool, Kaziunas et al. surface the social and emotional impact of tracking children’s care on the caregivers [46]. Schorch [84], for example, presents the context of informal caregivers in domestic home care, and their roles in the healthcare of others. Tixier and Lewkowicz [91], studied the importance of social support for these informal caregivers and the role technology could play in that. Research has not just focused on the role of informal caregivers in the context of domestic home care [60, 84], but also on studying the care-needing individuals themselves. Self-care refers to the activities that people requiring care of some nature undertake to manage their care as a part of their everyday life [69]. Nunes et al. [70] explore opportunities for technology in self-care, suggesting focus on patients’ everyday life experience, and existing everyday collaborations. Building off this work, Berry et al. [6] argue that most recent research prioritize either the individual or the caregiver in tracking, and propose designing technology that supports both parents and caregivers as equally important users of tracking technology.

Our research aligns with this perspective on health tracking and extends this body of literature by presenting findings of how aspects of health tracking such as activity logging or meal logging,

although prevalent in the context of study, were not fully utilized for improved care management. Additionally, recent research argues that available self-tracking tools do not effectively capture data that are important to users and that currently collected data are not very useful to clinicians [80, 103], and we present sociocultural dimensions of health that preclude tracking altogether in patient-doctor interactions as well as patient-caregiver interactions. In reflecting on these barriers to datafication, we contribute towards an understanding of the challenges that underlie the geographic divide in data generation trends around the world.

2.3 Patient Empowerment

Extensive literature in HCI addresses the issues of patient empowerment through the lens of improving information engagement (e.g., [37, 40, 55, 58, 61, 72]). The focus of this research is to improve the way patients engage with different information streams during in-hospital engagement with doctors as well as post-hospitalization. Haldar et al. [33], for example, study the information needs of hospitalized patients and find that extant patient portals—technology giving patients access to their health information—do not meet patients' information needs in ways including preparing for at-home care. They also emphasize how current technology amplifies provider-centric values that are enforced on patients over truly empowering patient-centric values, following similar critiques raised by Skinstad et al. [88]. Mishra et al. [62] study collaborative tracking of health data by doctors and patients as a way of empowering the patients during their stay in hospitals. They argue that patients' engagement with their care takes the form of individual engagement about treatment and care instead of relying on a doctor or healthcare professional to monitor it for them. Pollack et al. [77] present the challenges faced by patients in transitioning to self-management of care, post-hospitalization, and identify a lack of knowledge, resources and self-efficacy as factors that could lead to breakdowns of care.

A common thread across this body of literature is the notion that the empowered patient is an informed patient, with consequent efforts to more effectively provide relevant information to the patient. Empowerment, however, can take other forms. Morley and Floridi [64] argue for a shift in perception of mHealth devices from being 'empowering' to being 'digital companions', showing current challenges to the empowerment narrative as well as the ethical and conceptual advantages of a companionship approach. Prior work has argued that empowerment need not take the form of more information to make more informed choices—the logic of choice—but should instead take the form of better care and delegation of responsibilities of care to caregivers—the logic of care [63]. In this paper, we further this conversation on the limits of current empowerment approaches by showing that patients exercising agency in the information they choose to engage with, if at all, is a critically important aspect of patient empowerment.

3 METHODOLOGY

Our goal was to gain a deeper understanding of the care management practices, with and without the use of technology, of people with cardiac diseases and the nature and frequency of their interactions with their doctors. In order to do so we recruited, through purposive and snowball sampling [85, 92], and interviewed 18 patients from middle-income backgrounds (P1–P18), along with their immediate family members, who had been diagnosed with cardiac diseases. We also interviewed 7 cardiologists and 1 cardiac surgeon (D1–D8) to understand their interactions with patients and their families during the diagnosis phase as well as in follow-up consultations. The participant recruitment started with purposive sampling of patients who had recently been diagnosed and treated for any cardiac diseases. Following these initial interviews, we conducted snowball sampling to include other patients within their social networks, their doctors and their colleagues, and other patients of these doctors.

3.1 Data Collection

With institutional review board (IRB) approval, we collected data for our research in May–July 2019 in Bangalore, India. Our patient-participants included 18 patients who had been diagnosed with a heart disease but had not yet received surgical treatment, as well as those who had received surgical treatment. They included patients with congenital heart diseases that presented themselves in adulthood as well as adult-onset heart diseases (*e.g.*, rheumatic heart diseases [98], atherosclerosis [97]). We chose to study these diseases because their treatment involves medical and/or surgical interventions as well as lifelong lifestyle management and health tracking. Patients with these cardiac diseases therefore constitute a group that is required to periodically track their health and interact with their doctors regarding this data. The urban Indian context allowed us to explore smartphone and wearable technology-enabled health tracking in an infrastructurally constrained healthcare system [12, 49]. Consequently, this demographic provides a window into the different personal, interpersonal, and ecological factors that influence this tracking and subsequent patient-doctor interactions.

The patients' ages varied from 20 to 74 years, with an average age of around 50. The patients were mostly male (12) despite concerted efforts to maintain gender balance. We conducted patient interviews in their homes (13), workplace (1), and a doctor's clinic (4) (in the absence of the doctor). In these interviews, we asked participants questions about their diagnosis, interactions with their doctor, at-home care practices, as well as technology usage for assisting in cardiac health management. More details are presented in Table 1.

We interviewed the eight cardiac specialists¹ from three major cardiac care hospitals in Bangalore, one government-run, and two private. The doctors varied in experience, ranging from 3 years to more than 30 years practising medicine. Many govt-hospital doctors also worked in private hospitals before or after their govt-hospital responsibilities, and could reflect on the difference in approaches they took to interacting with patients in these different settings. These interviews were mostly conducted in doctors' workplaces (7), while one was conducted in a doctor's house. Additionally, we participated in one counselling session at a hospital's Cardiac Rehab center. This was not audio-recorded and the first author maintained notes of the topics discussed in this session. In these interviews, we asked the doctors about their workload, approaches to interactions with patients and their families, and interactions with technology like online health resources and personal fitness trackers.

Interviews were conducted by the first author, audio-recorded with the participants' consent, and later transcribed. We also maintained handwritten notes for all interviews. In cases where participants preferred not to be recorded (1), we only took handwritten notes. Interviews with cardiac patients and their families lasted between 30 minutes and 2 hours. Interviews with doctors lasted 25–60 minutes. Most interviews were conducted in English and some were in a mix of English and Kannada, as per the participants' preference. All participants' names have been anonymized in the paper.

3.2 Data Analysis

All audio recordings were transcribed. The authors periodically discussed interviews to identify interesting themes and inform future interview questions. We used an inductive, interpretive coding approach to this data [59]. These initial themes included "mutual care", "technology non-usage", and "sensemaking". As the interviews progressed, we iterated over the data to produce higher-level themes including "information ecologies", "gender dynamics", and "personal informatics". Finally,

¹We have not included a table for doctors' demographics as that data are not used in our analysis

Table 1. Participant Demographics (Patients)

Participant	Gender	Age (in years)	Family Members in Interview	Time since Diagnosis (in years and months)
P1	M	74	Wife	1y 6mo
P2	M	39	-	1y 10mo
P3	M	62	Wife	2y
P4	M	65	Wife, Daughter	2y 6mo
P5	F	49	Sister	5y
P6	M	55	Wife	7mo
P7	M	54	-	5y 4mo
P8	M	49	-	1y 8mo
P9	M	61	Wife	3mo
P10	M	59	Daughter	3mo
P11	M	55	Wife, Son	4y
P12	F	20	-	3mo
P13	M	59	-	1y
P14	M	71	-	42y
P15	F	42	-	19y
P16	F	29	Husband	13y
P17	F	31	Husband	1y
P18	F	20	Mother	1mo

we abstracted out to four main themes that we present in this paper: *technology use, attitudes towards information, patient-doctor interactions, and cultural situatedness and collaborative caregiving.*

3.3 Limitations

We clarify that our participants had a middle-income background, and our findings may not extend to more socioeconomically disadvantaged backgrounds in the area. Future work could certainly look at a more diverse group of participants, as our findings suggest as well. We also struggled to find a gender-balanced sample, among both doctors and patients. Among the former, there were few female doctors available. Among the latter, despite our best efforts we were unable to find more willing participants for our research. We do acknowledge these limitations in our study and recommend that future work take a deeper look at underlying factors for the imbalance we perceived.

4 FINDINGS

Our findings convey the technological, personal, interpersonal, and ecological factors that influence the adoption of health tracking behaviors in our context of study. This includes the usage of health tracking technology, attitudes towards health information, dynamics of patient-doctor interactions, and factors like culture and gender.

4.1 Technology Use for Generating Data

Recent literature in HCI finds significant adoption of health tracking behaviors, such as step tracking and meal tracking, most of which are enabled by technologies being built into smartphones by default [29], and also analyzes motivations for such tracking [14, 81]. Some researchers identify challenges like inflexible tracking tools [17] and incompatibility between doctors' needs and tools'

capabilities [80, 103] as issues with existing tracking systems, and suggest harnessing personalized insights from data as the way forward in chronic disease management [22]. Below we describe our participants' use of technology for health tracking, focusing on their expectations from such technology as well as concerns and factors that influenced their adoption of this technology.

4.1.1 Current and Potential Affordances of Health Tracking Technologies. All participants we interviewed had smartphones that they used regularly, including for health tracking. Many owned wearable fitness tracking devices such as FitBits, Garmin trackers, and Apple Watches. Their use of these devices for health tracking ranged from monitoring heart rates and daily activity levels to setting and tracking fitness goals. Additionally, many participants regularly used blood pressure and blood sugar measuring devices at home.

In addition to generating the above data, some participants informed us that they were already recording and communicating their health data to their doctors using various mobile applications. For example, P7 spoke excitedly about a new app that his doctor had advised him to use to track his health and share his data with the doctor. Exclaiming that he measures everything he does, he said, “[I like] just the fact that someone does this for you and [does not] even charge a rupee. Now I don’t need anyone motivating me. I want [to achieve set targets].”

The doctors we interviewed acknowledged that there could be value in personal tracking data towards understanding and making sense of their patients' health, and speculated about the feasibility of integrating self-tracked data into routine diagnostics. For example, D2 said:

“... they have all smartwatches now right? So they are monitoring their heart rate. Many of them are monitoring. They... will show me on their watch, this is what their heartbeat is, this is what... so it’s quite fascinating to make a diagnosis from their side. He helped me make a diagnosis. So that’s good... I think he can transmit those information to you if you have a computer or a... he can send it to your mail [to make this easier].” (D2)

Likewise, our patient participants also had thoughts regarding the affordances of health-tracking technologies. P2 expressed his preference for one where context was retained, that is, where he could provide his medical history to a device and receive personalized feedback and recommendations:

“I put in the wearable ‘look, I have had a XYZ procedure [sic]’, the wearable knows it. So tomorrow, if I ask a question, ‘I’m finding it too tiring, what should I do?’ it should know that I’m an XYZ treatment patient, and tell me, ‘okay you know what, since you had your surgery, probably you want to slow it down, drink a glass of water [or] whatever’. That would be fantastic!” (P2)

Not only was P2 inclined to adopt such a tracking technology, he also remarked, “the privacy concern definitely will be there! But... look it’s... it’s not something that I have... if you ask me... I’m okay with it.” His view was that a device could only truly be effective if there was no withholding of information. Proposing the design of an artifact that was tailored to his needs, he said, “The wearable takes in my data. I am honest to my wearable. ... But yeah, for that I need to be honest to my wearable, right?”

Certainly some participants (like P2 above) were more enthusiastic about the potential for tracking technologies to be beneficial for their health, but our interviews revealed a general willingness among patients and doctors to embrace the use of technologies for health tracking, even when it was not always known what advantages these might afford. There were also many reservations that our interviews surfaced, however, which we discuss next.

4.1.2 Reservations towards Health Tracking. Our participants did not identify as digital natives, and using technology for tracking health did not always come naturally to them. For example, P1—a recently diagnosed cardiac patient—was asked to track certain aspects of his health and present

them to his doctor in subsequent consultations. When asked if he had tried using tracking tools for managing the data he was collecting, P1 responded, “*Everything is in my head. I don’t see why I should use technology for something I can do by myself.*” Painstakingly maintaining written logs was his preferred approach. Here we note an example of tracking behavior and generation of data but without the use of technology. In another example of non-use of health tracking technology, P17 reported that she did not need to track her health anymore given that she was now keeping well.

Tracking was also occasionally viewed as potentially unnecessary, depending on specific health needs. For example, a doctor participant provided some insight on why tracking could be avoidable:

“No I don’t feel like [using technology for personal health tracking]. Like, if any risk factor is there, then we might try [using it]. But if no risk factor is there...I get my routine blood sugar test, kidney function tests done...once a year. I don’t believe in unnecessary evaluation and investigation” (D7)

Even when participants did use health tracking technologies, this use did not always align with their health management needs. Thus, instead of engaging in cardiac health monitoring, participants would more generically track meals or weight-loss. Other participants who used tracking technologies expressed difficulty in appropriating them for monitoring their cardiac health. Explaining how the ability to monitor heart rate, without the ability to customize its use, exacerbated P16’s heart rate fluctuation, P16’s husband said, “[*If it goes above 100, again she gets worried and heart rate goes to 120-130, and I ask her why she’s worried...She [has] palpitations...I’m going to change the settings of that [so that she can’t check heart rate very often].*”

There are thus several reasons—we found—that may impact the adoption of health tracking technologies and consequently impact the generation of health data. Individuals might be more comfortable with non-digital modes of tracking, see no reason for tracking in periods of good health, rely on non-digital medical tests to monitor wellness, engage in tracking not relevant for their health condition, or simply find it stressful.

4.2 Attitudes towards Health Information

Having examined our participants’ range of views around using tracking technologies for generating health data, we now turn to their attitudes towards health information.

4.2.1 Reactions to Online Information Sources. CSCW and HCI research have deeply investigated the potential for online sources of information to support health management (e.g. [8, 15, 101]). Our participants recognized that there were numerous online sources they could trust like WebMD, Mayo Clinic, among others, in addition to less authoritative sources such as online health communities, Facebook groups and Reddit subs, as well as individuals’ contributions in the forms of personal blogs and articles. In fact, several participants shared that blog posts (of strangers) expressing lived experiences acted as sources of inspiration. For example, one participant (P2) followed the preparation guidelines for a 5KM run, post-surgery, via a personal blog of a marathon runner who had trained and run after surgery. In addition to being a source of inspiration, this blog served as a step-by-step guide to gradual recovery and rehabilitation to normal activity. Summing up the value of such resources, P14 said:

“The experience of (a) patient is more important than the guidance of doctors. Of course it’s also required, but if a patient explains his circumstances, that could have been much more [helpful]...” (P14)

Despite the existence of the above sources of information, participants generally struggled to find reliable content online. One challenge that surfaced in our interviews, for example, was that

existing blogs, Facebook groups, and medical websites typically targeted older adults, unresponsive to the trend of younger adults contracting cardiac diseases.

Participants also hesitated to engage online for fear of discovering information that could leave their mental states adversely affected. For example, P2 shared that information found online could be overwhelming:

“The one thing which I did was I didn’t look, I didn’t search internet before I went to the surgery. What this surgery means, I didn’t look. Because the internet gives you way wayyyy too much information you don’t need to know. And yeah, I just said, ‘Look, if this is what it is, this is what it is’. Let me read about what is this in the internet after surgery. I don’t want to psych myself out.”

Participants said they were afraid of inciting negative reactions. For example, P1 noted, *“I share my opinions one-on-one, but on social media [if] I say something, 5 people will like it, 5 people won’t. [Those] negative responses hurt.”* This fear of encountering negativity not only impacted information-seeking practices, it impacted participation of participants in online fora (even where anonymity was possible).

Many participants thus expressed that they generally preferred engaging with information, best practices for care, and/or health advice through word of mouth, and on their personal social networks, bypassing less personal/more authoritative online resources.

4.2.2 Engagement with Health Information Online. In addition to attitudes regarding online sources of information, there were other factors that shaped online engagement as well. Time made a difference, particularly as it pertained to the stage of illness, and balancing information across caregivers also played a role. Regarding the former, participants experienced different information needs along different stages of the disease and/or recovery. As one participant (P2) noted:

“...I knew, right after my surgery [if] I come home and I start looking at it, I would... you know... it would be more difficult to get through the process. So I thought ‘Okay, I’m not going to look at this for the next 3, 4, 5 months whatever. After some time, I will look into this, what is this procedure about.’ ” (P2)

Spacing information-seeking over time was one approach; another was the delegation of information-seeking roles to different caregivers. Even when information was necessary, spacing out and effectively filtering the information (via caregivers) allowed our patient participants’ care to be managed appropriately. For example, P10 said that the only information he had read about his treatment, until the day of the interview, was about a pill he had been prescribed a day before his surgery. He further went on to say, *“They (the family) look after everything, I won’t worry too much. They also didn’t show me what it says and stuff. Then I might get confused and emotional.”* His daughter explained:

“That moment is very critical for us. We don’t want him to get more emotionally affected because of what we talk or understand of the surgery... So we didn’t want to stress him out with lot of information... We just wanted him to be in a cool and calm way so that this phase passes.” (P10’s daughter)

Apart from spacing out information-seeking across time and caregivers, some participants actively rejected health information for various reasons. Surgery, for example, was a scary prospect to many, particularly since it necessarily involved an invasive procedure on an externally healthy-looking body. As a participant’s mother (P18), who reluctantly accepted that her daughter needed surgery, put it: *“We thought, without [surgery], she would at least be as she is now. We didn’t think beyond the [surgery].”* This fear of surgery, in many cases, also translated to a fear of encountering difficult-to-consume information regarding the required treatment and care. Some doctors expressed

needing to assess the situation and gently, over multiple sittings, introduce the need for surgical intervention since it could otherwise scare away patients. We delve further into this in the next section.

4.3 Patient-Doctor Interactions

Patient-doctor interactions have been studied by CSCW and HCI research in the past, in the context of improved collaborations and information exchange (e.g., [23, 73, 75]), and a more informed, active patient. Chandwani and Kulkarni [11] have studied patient-doctor interactions in the Indian context, and commented on the shifting power dynamics between the patients and doctors, with growing internet adoption. In this section, we present our findings on how patient-doctor interactions have evolved to incorporate the use of health tracking technologies and respond to increased access to health data.

4.3.1 Outsourcing Decision-Making to the Doctor. Some participants who tracked their health data also chose to leave the analysis, sensemaking, and decision-making tasks to their doctors, despite the fact that the tracking technologies they used were designed to allow individuals to track and understand their own health. This was in general acknowledgement of the notion that doctors were better positioned to make sense of the data, make changes to treatment if necessary, and ultimately provide better care. P7, for example, expressed that he had a good set of doctors that he trusted, so he did not need to do anything else for his care. Justifying his decision, one participant who regularly and meticulously collected data about his blood glucose levels said:

“Each time I go meet a professional, I leave it to the professional... if it is medicine, I go to a doctor and tell him ... ‘You decide, in this situation, with this data, what do you need to do next?’ ” (P8)

This approach of handing off decision-making to the doctors is reflective of the existing power dynamic in traditional patient-doctor interactions in India that places high importance on trust between the doctor and patient [11]. To exemplify this, P13 expressed how he tried different doctors for his surgery before deciding on he could trust based on their initial interactions. He also noted how a doctor’s candor regarding the difficulty of his surgery dissuaded him from seeking care from that doctor.

“So I came to Bangalore and approached Hospital 1... They were saying ‘we can take a challenge’, but I thought it is not a [situation] where ‘challenges can be taken’. It is a heart problem... So I approached Hospital 2. I was very satisfied with them. They said, ‘no, it is a case of surgery, stents cannot be placed. And placing a stent may be difficult for you, so better you go for surgery.’ So I was satisfied with their conclusion and I went for a surgery in their hospital.” (P13)

Our doctor participants expressed how decision-making conversations with patients ultimately resulted in the doctors choosing the optimal treatment. While they did list potential treatment options, they also explained to the patient what the best possible course of action, according to their best judgement, was:

“We can’t offer this and this and this. There could be multiple treatment options, but what is best for the patient we will offer.” (D2)

Patients’ interactions with doctors frequently appeared to convey an expectation that doctors could heal any problem they faced. One doctor participant, D8, expressed how he worked hard to play down this notion and manage expectations:

“They try to come and tell us ‘you are like God... you save our baby’. That’s the time you’ve to cut short that conversation. They’re expecting you to do something you MAY not

be able to do. [I tell] them ‘we’re not God. We’re doing God’s work...’ We can do the best that we can for your child but there are things that are beyond our control, you have to understand that. You calling me God is not a good thing.” (D8)

Doctors were generally cognizant of this power dynamic, and did not seem to prefer it, but leveraged it as necessary to enforce care management when patients appeared reluctant to seek care. This dynamic is markedly different from that studied previously in the Western context [24, 34, 43].

4.3.2 Google Doctor. In this section, we present how health tracking and patient-doctor interactions interface and the tensions they foreground. Preliminary work [11] suggested that Google-informed interactions are modifying patient-doctor relationships in India. We advance this finding by uncovering what being Google-informed means, and how it affects care provision and the dynamics of patient-doctor interactions.

The existence of information sources online eased some of the information provision burden faced by doctors. On this, P2 expressed: *“Beyond that, I have not asked him any other question. I was just dependent on Google for information, and for the wearables for the analytics and measurement of things.”* One effect of this information-seeking practice was that consultation time could be used efficiently for more pressing questions. This was not always the case, however, for several participants commented on the unverifiable nature of information available online, and spoke of how they approached their doctors to verify information before applying to their care practices. A patient, P15, said this of her propensity to internalize “scary” information about her diagnosis and approach doctors for consolation and verification: *“I’ll Google and come to some conclusion and go and talk to them. That may irritate some doctors. I know [it does].”*

Google-informed patients, although more aware, also challenged existing power dynamics by approaching doctors to verify information. While on the one hand, patients are ostensibly just reaffirming the validity of the information Google provides them, doctors perceive this as a questioning of their authority on the matter. As one doctor put it:

“[patients ask] questions which are irrelevant, repetitive. At the end, may not have the same importance. It takes you away from the primary focus. Many of the questions will be on the secondary focus.” (D3)

While D3 said that answering questions from his patients needed him to respond calmly and show concern, other doctors did not necessarily react the same way to patients’ questions. Another doctor (D2) said his approach to addressing persistent questions with finality was to direct them towards prevalent guidelines on addressing their condition.

“... if he’s more persistent... we’ll go to the guidelines. Like we teach our postgraduates, we say, ‘This is the guidelines. This is what the world is following. This is what we’re doing.’ Then [the patient] is more convinced. So ‘we’re going to do what everyone does anywhere in the world’. That’s it.” (D2)

Patient-doctor interactions and their dynamics must be considered when examining the design or use of health tracking technologies. Though the data is predominantly generated by the patient, there is a significant role that the doctor (as seen above) is expected to play, which is typically not factored into the technology design.

4.4 Cultural Situatedness and Collaborative Caregiving

As the literature on care (e.g., [62, 77]) points out, caregiving is both collaborative and culturally situated. Within hospital contexts, this translates to collaboration between and among the healthcare providers and the family members of the patients. Outside hospital contexts, it translates to negotiations among family members, other informal caregivers, and cultural practices within which

the care provision occurs. We now present our findings on how cultural and ecological factors play a role in care provision.

4.4.1 Gender Dynamics. We encountered the gendered nature of health management several times in our research. Not only did gender appear to influence who suffered from heart disease, it shaped doctors' interpretations of their patients' experiences, and treatments that could take place, as well as conversations that could (or could not) occur.

One female participant (P5) introduced us to a commonly held bias regarding heart disease, remarking that her doctor had informed her at the time of diagnosis that *"heart disease is predominantly for men."* This belief, if widely held, would impact patients and caregivers by preventing women from getting themselves regularly checked, for instance.

Doctors also appeared to believe that symptoms of cardiac disease were processed differently across genders. One doctor participant (D8) noted, *"I think [women] are typically more tolerant to what they undergo. I don't think they voice their concerns as much..."* Another doctor (D7) expressed that several people came into the hospital each day with purportedly cardiac symptoms, but only 5% of those were women. This was incommensurate to the gender split the doctor said there was among patients he diagnosed as having cardiac symptoms: typically 70% male, 30% female. Probing further about why such a discrepancy might exist, D8 offered an explanation about why and how women might incorrectly attribute their symptoms and not seek medical help early enough:

"Somehow women have the ability to underplay [their symptoms]... [They think] 'I walked a kilometer more than I did yesterday, [that's why] I'm feeling this'... One more thing is, initially [cardiac disease] starts out being something that presents... due to exertion and then it progresses... to when it appears when you're at rest. So most of the time... women do house work here... men do outside work more often. So their symptoms play up more than women." (D8)

The downplaying of cardiac symptoms naturally impacts the health of a patient, while also advancing incorrect biases around the gendered nature of cardiac disease. Consequently, this could further marginalize female patients due to insufficient data about their care needs.

Treatment of cardiac patients also appeared to vary across genders. Consent for surgery, for example, can be gender-imbalanced. D8 expressed how consent-seeking involved more individuals than the patient undergoing surgery, requiring an older male member of the family needing to provide consent:

"... it is very strange. If you see abroad, it's the patients' consent which is foremost. Here... we take the attender's (caregiver's) consent too. It's funny, but it's true. So for us, consent-taking will be a process in which the family, extended family, the decision makers in the family are all involved. We try most of the time, at least probably because of our culture where... it's still a patriarchal society right? So most of the time we're trying to have a male attender when we are explaining the risk to the patient or explaining something later." (D8)

There was stigma associated with being a cardiac patient, particularly for women, and it could impact their ability to identify a matrimonial match, since cardiac care management was seen as being a lifelong process. This meant that there was the additional need to keep such a health condition to oneself, as a woman, as P16 and her husband informed us:

"That's a common thing in India. If you have any kind of surgery and you start telling people, people will start bragging about it... cross-talking about it... all those stuffs happen. That's the reason she kind of avoided it before marriage." (P16's husband)

“People will ask many questions like... why [will] this girl get [heart problem]... especially for girls they’ll ask many questions.” (P16)

This gendered norm was corroborated by other participants as well, like one participant who is yet to disclose her earliest diagnosis and treatment to her husband since it had been kept a secret until they were married. Even in cases where the woman was not the one suffering from cardiac disease but played the role of a caregiver, as with P10’s daughter, the parents expressed concern that their daughter’s prospective in-laws may not appreciate these caregiving needs, motivating them to keep things quiet:

“She was only thinking it might affect me because I’ve to take care of everything from the house. Mentally she’s like ‘I’m depending on my daughter which I’m not supposed to do... We both are dependent on you... What will your in-laws say?... What will society say?’ ” (P10)

Extensive HCI research has reiterated the social ramifications of health conditions on female members of the household (e.g., [35, 68]), supporting our finding that health tracking must also recognize the role that gender plays.

4.4.2 Within—not Beyond—the Home. Recent literature on the social nature of collaborative care and personal informatics [67, 78] shows the important role played by members outside the individual’s immediate family and household. We find that, in our context of research, the caregivers are mostly immediate family members with several reasons to not go beyond the family. Having already presented how gender dynamics play a role in who an individual’s caregivers are, and how that affects rehabilitation, this section further addresses some of the concerns participants had with sharing information beyond the home.

Many participants spoke of reasons why they did not want others from their social networks to be aware of their diagnosis, surgery, or rehabilitation, until they were ready to share that information. While P2 spoke of his reservations about this during rehabilitation, P13 expressed how informing others, and their realism, negatively affected his process:

“I do not want visitors home. I do not want sympathizers home saying, ‘Oh my God! What happened?’ ” (P2)

“When I were to undergo surgery, I spoke to one or two friends who had undergone the surgery and somebody said, ‘Oh, you’re undergoing this surgery? It’s very painful’, so that was a shock to me.” (P13)

Consequently, most participants chose to keep the news of their surgeries and diseases within the confines of their homes until they were comfortable sharing it, at least partially, with other trusted persons beyond the household. This was made possible since a large amount of care and support came from within the home, as we have highlighted above, with parents, children, spouses, and siblings playing key roles in rehabilitation. This fully precluded the need to go beyond the home during the immediate rehabilitation phase, with attempts to engage others on these diseases occurring only at later stages of recovery.

As mentioned above, there was also a gendered difference in the comfort levels participants experienced when sharing information about cardiac disease with those outside of their homes. Most male participants said they would talk to their friends, relatives, and colleagues about the surgeries they had had, the female participants were far less forthcoming. P16 explained her reticence regarding her surgery:

“Who [all] are very important to me in my life, they know. Why [should] others like my friends and [distant] relatives... know? How will they help?” (P16)

Other female participants corroborated this notion as well, expressing discomfort around sharing their health conditions outside of their households, in personal conversations as well as on social media. P15, for example, said she had thought about writing online about her experiences with wrong diagnoses several times but did not do so because she was uncomfortable with the idea of “*tell[ing] everyone that I have this problem.*”

4.4.3 Surveillance Care. Even within the family, care could be seen as surveillance sometimes. Kaziunas et al. [46] present this aspect of NightScout, with children’s schools being opposed to it as the over-involvement of parents proved to be a distraction for teachers. They also present the parents’ perspective, however, which was that there was good reason to be constantly anxious about the NightScout readings. We observed a converse effect of reverse parenting among some of our participants, where spouses and adult children of participants used their self-tracking data to confirm adherence to healthy lifestyles and care requirements.

When patient participants were, for any particular reason, unwilling to track their own health data using technology themselves, these practices were frequently enforced on them by their children. P11’s son, for example, said:

“[I know he walks 7 KM] because I have an Apple Watch, and I tie it on his wrist when he leaves. So when he comes back, I know what’s his distance. He used to tell me 7km, but I didn’t believe him on that. So few days later I started giving him the Watch. So when he gives the Watch back to me, I knew exactly [how] the 7km was [traversed].” (P11’s son)

P6, who otherwise enjoyed tracking and analyzing his health and claimed to have reversed his diabetes through regular blood sugar monitoring and diet manipulation, gave up on using his wearable tracker since “... it told me what my heart rate was, how much I have walked... both these things were not too much of help for me. I wasn’t too regular on using it...” His daughter, on the other hand, presented another side to this, saying that she once scolded her father, “*There’s only 1000 steps. What have you been doing all day?*” suggesting that she attempted to hold him accountable to his activity, which may have resulted in eventual non-use.

Wearables were not the only means of surveilling individuals, as one participant expressed. Living close to his workplace meant that his (P13’s) wife did not have any logistical problems in caring for her husband.

“And now my wife doesn’t leave me alone. She doesn’t want me to go alone to places at longer distances. I am sure I won’t have any problems but she is afraid... it’s a good thing that she’s always with me. She’s taking more care of me now... At work, she lets me go alone because distance is not much... [but] she is always connected to me” (P13)

As discussed in this section, ecological factors—culture, gender, etc.—play a key role in promoting and/or prohibiting tracking behaviors, and must be taken into consideration in the design of tracking technologies.

5 DISCUSSION

We described the various personal, interpersonal, and ecological factors that shaped how our patient participants tracked (or did not track) their health, and how far technology played a role in supporting these behaviors. We now focus on what our findings mean for devising data-driven insights for better healthcare. In particular, we reflect on what our findings suggest for moving forward on health tracking data-oriented technologies, and what they mean for patient-centered care and patient empowerment—as a whole.

5.1 Reflections on Situated Health Tracking

In the emergent climate of big data solutions, AI, and machine learning, the prevalent narrative is that collecting more data about humans and their actions would lead to better insights into human lives as well as the ability to enhance these lives further. These approaches have met with widely acknowledged and significant successes while also causing equally significant inequalities [28, 104]. Underlying these inequalities is an important, much-repeated problem: there is insufficient diversity in data for these technological solutions to be just (e.g., [47]). This problem is relevant for health tracking applications as well in which the design predominantly targets technology-savvy, internet-equipped individuals in the Global North. In less technology-savvy, newly connected contexts, however, there are quite different sociocultural practices that technologies may need to contend and coexist with, as we found in our research. Naturally, there would be differences within Global South settings as well—not all contexts in the South are as familiar yet with technology use as are our research participants from Bangalore, although they are moving in that direction. Regardless, our research makes the case for being more culturally aligned with disease management practices. This becomes especially critical if we look at contexts such as mental health or menstrual health, where stigma is more pronounced, and the role of others (family/doctors included) would need to be understood with greater sensitivity. We elaborate below.

5.1.1 The Role of Culture. Emergent HCI research in the Global South has explored how culture influences technology design, uptake, and retention (e.g., [7, 31, 45, 87]). Present day health tracking technologies, however, have not been explicitly designed for these contexts. For instance, most existing health tracking technologies are designed for individual data collection and reflection, with aspects of social sensemaking [78] through gamifying health goals [82]. These technologies are appropriate for users in contexts where healthcare predominantly foregrounds the patient as the decision-maker, making individual choice paramount to effective delivery of healthcare.

Caregiving, however, is culturally situated, and subject to power-, gender-, and cultural dynamics that influence decision making and patient-doctor interactions as we presented in our findings. Chandwani and Kulkarni [11] studied these dynamics within the Indian context, finding that physicians held mostly negative opinions of internet-informed patients—reiterating the large divide between patients and doctors—and suggesting that doctors could play the role of ‘warm experts’ as an intermediary between patients and the vastness of information online. Additionally, there exist vast networks of informal [90] and community health [39] infrastructures that complement formal infrastructures that are not adequate in and of themselves. In contexts that are particularly deprived of adequate care delivery, and technological solutions could ease some of the burden on the constrained health infrastructures, there is an even greater need to pay attention to culturally specific needs.

Tracking mechanisms must allow therefore for multiple, shared streams of data collection that multiple informal caregivers, with different stakes, can contribute to. As our findings suggest, this would provide a means for capturing a more complete, nuanced view of the patient’s health. This might also allow for capturing information actually relevant to doctors during consultations, providing support to existing information collection during building patient-history. More ambitiously, this could contribute informal streams of data to health data infrastructures.

5.1.2 The Role of Gender. Literature situated in the Global South has discussed previously how gender norms influence how people adopt and use technology (e.g., [45, 48]). In contexts where there exist strong gendered structures, technology usage is restricted, monitored, or otherwise hampered [1, 45]. Even in critical healthcare, we found that across the spectrum, from experiencing symptoms, to diagnosis, to consent for surgery, to post-operative care there was gendered structures

that impacted how different genders had different experiences. As we showed in our findings, differences exist even in how freely women conversed about, and accessed information regarding, their health conditions.

Technologies for ‘personal’ health tracking would be subject to these same gender dynamics, potentially resulting in skewed adoption due to stigmatization. Even if adopted, they would be subject to concerns about digital privacy of ‘personal’ health data due to the common practice of sharing mobile devices within households (as previously identified in HCI research [1, 45, 83]). Personal health tracking technologies are, therefore, not designed for such contexts despite already having entered them. Being cognizant of unique, context-specific device usage practices is crucial to optimizing design. Shared usage of devices, for example, lends itself well to our earlier recommendation for including caregivers’ contributions as sources of an individual’s health data. In addition, designing technology that encourages conversations, and sharing experiences, while ensuring desired levels of anonymity and privacy, would go a long way towards correcting biases and preconceived notions about cardiac health that we described in our findings.

5.2 Reflections on Patient Empowerment

In our study, we learned how patients engaged with each other, with data, and with their doctors in managing their health. We also found how they used—and disused—healthcare technologies based on how they fit into culturally and socially situated preexisting practices of care. Here, we reflect on how these practices play into the discourse around “patient empowerment” and how technologies for patient empowerment, as they are currently being conceptualized by the CSCW and HCI communities, do or do not achieve the same goals in contexts like ours.

5.2.1 Is an Informed Patient an Empowered Patient? In the Global Development context, economist Amartya Sen defines empowerment as amplifying the agency of people to improve their lives [86]. Patient empowerment signified a shift in healthcare dynamics as a move away from paternalistic approaches to more active, involved patients enabling them to take more control of their lives. Funnell et al. [30] in 1991 proposed the concept of “empowering” patients through education of their diseases, to promote their overall health and more optimally use available resources. WHO defined patient empowerment as “a process through which people gain greater control over decisions and actions affecting their health” in 1998 [71]. Since then, this idea has expanded drastically to reform Western approaches to healthcare. What started off as educating patients gradually grew to include patients in other forms of patient engagement, including, for example, a more discursive form of consultations and active involvement in decision-making [24]. Jethwani and Sperber [43] argue that this shift was also a result of increased access to medical information, through formal and peer-to-peer sharing resources due to a proliferation of technology. While there is no universally accepted answer addressing how to empower a patient [32], there have been approaches to explaining and summarizing the forms it takes as well as factors that affect “empowerment” [13]. In an increasingly datafied society, empowerment is enabled through increased access to information. A recent article that polled Twitter users on what an empowered patient means [24] puts forth seven essential components of empowerment: information, health literacy, digital literacy, self-efficacy, mutual respect between patients and doctors, shared decision making, and a facilitating environment. They further argue that empowerment is a non-binary and non-linear process where what in one context was empowering could be disempowering in another.

Research on health informatics has increasingly foregrounded patient empowerment as a priority. Patient empowerment, from this vantage point, takes the form of *more* information (e.g., [61, 77]) and *more* involvement in patient-doctor interactions (e.g., [33]). The underlying argument here is that information is necessary for empowerment. This approach champions encouraging patients to

seek out and make informed choices about their care, thus empowering them. Mol [63], however, discusses the *logic of choice* to argue that patients, however well-informed, may not be the best people to make decisions about their own care. She further argues that care is collaborative, and the burden of care rests on the network of caregivers including professional caregivers in hospitals and informal caregivers at home: the *logic of care*. Choice also may not be fully autonomous in certain contexts, potentially at the expense of care [39]. As care research (e.g., [53, 60]) has shown, care requirements and provision are fully situated in the cultural context. Consequently, it becomes imperative to reconsider and refocus patient empowerment efforts on the sociocultural context of care as well as the people involved in the provision of collaborative care.

The intent of patient empowerment, as we have summarized, has always been about giving patients more control over their health. Gathering and analyzing more data about one's self is one way to be empowered. Others take the form of more choice in decision-making regarding health, equity in power between doctors and patients during interactions, more information regarding their health, and approaches to self-management that also has the benefit of reducing burden on the doctors [56]. While patient empowerment is a WHO-prescribed guideline for the world, both uptake as well as the form taken by patient empowerment efforts have mainly been studied in the Western, Global North context which are historically more technology-rich contexts. In recently burgeoning technology-usage contexts, however, we found that the meaning and approaches to patient empowerment look different.

As we showed in our findings sections around engagement and disengagement with data and information (for example, P8 who expressed his desire to leave the health analysis and data with his doctor) *deferring to the expertise of the doctor is, in and of itself, a form of empowerment*. This both actively follows from Mol's argument for the logic of care [63] and also provides a counterargument to the approach of an 'informed' patient being empowered. This level of trust in doctors—enough to leave healthcare fully in their hands—is historically and culturally situated in India [11, 89]. Consequently, the onus of health tracking too has rested on the doctors, with patients having little autonomy over the data they need to collect and how to learn from it.

Personal health tracking technology seeks to change that dynamic, by potentially enabling patients to contribute to a better understanding of their health for themselves, but also add other streams of health data to these records. However, as we show in this paper, building on literature [11], this causes a tension in existing norms of patient doctor interactions that truly brings into question the direct transferability of this technology to contexts like ours. A potential approach could involve including doctors and caregivers as stakeholders in designing such personal health tracking technology. These could serve a dual purpose of educating and empowering patients through information and additionally allowing doctors and caregivers to collect—and contribute—data explicitly to inform their regular diagnostics and care provision.

5.2.2 How Much Data do we Need? In this “datafied” world, the focus of most commercially available products invariably goes to data generation. Be it search engines, social networks, or general internet usage, the underlying motivations of these technologies is to generate and collect data about people's technology usage practices to inform the design of more convenient, useful technologies. In a similar vein, HCI research on patient empowerment too has taken the approach of generating and utilizing data about health to enhance patients' engagement in their care.

While these approaches are feasible in technology-rich contexts, as shown by several works (e.g., [27, 46, 60]), they are invariably untenable in contexts where data generation is, in itself, infeasible and not standardized. In our context of study, there is no standard shared 'health record' infrastructure across hospitals, sectors of healthcare [12], and healthcare providers. Treatment records are provided to patients in paper form, and patients are expected to carry these papers

to any subsequent consultation with the same, or other, doctor. This not only introduces a single point of failure, it also precludes an important tenet of prevalent patient empowerment research: patient-caregiver collaboration using data [62, 76]. So, we should question how, and where, these approaches work best, as well as consider approaches to patient empowerment that depend lesser on standardizing health records and increase focus on an assets-based approach [57] to designing solutions in such contexts.

As we move towards an increasingly datified society, data generation is paramount to keep pace with advancing technologies that pervade all facets of society. Undoubtedly, data is required to make these technologies successful. However, our findings surface important considerations in contexts where data generation can be infeasible and unreliable. For one, sociocultural barriers prevent sufficient expression of, and engagement with, information online leading to marginalization of certain voices and a consequent absence of diversity in data. Without this diversity, ongoing technological advances further marginalize these data and people [100]. This creates several issues especially in the healthcare context. For example, Tuli et al. [94] present user engagement with an online platform for menstrual health education, Menstrupedia, showing how there is a significant mismatch between questions being posed (that are few) and number of viewers of available answers (quite high in comparison). Taboo and stigma, in this case, play a significant role as a barrier to data generation, and become important factors in silencing many voices online. With no technology to appropriately curate these voices, the already sparse resources tend to become sparser for people attempting to access information relevant to them.

6 CONCLUSION

CSCW literature is increasingly exploring the socioculturally situated nature of health tracking. We extend this work by highlighting the technological, personal, interpersonal, and ecological factors that influence health tracking. In this paper, we presented a qualitative inquiry with 18 patients with cardiac diseases and 8 doctors in Bangalore, India to reveal how health tracking practices are informed by the individuals' attitudes towards health information, the dynamics of patient-doctor interactions and sociocultural norms. We argue that our findings have implications on patient-centered care and patient empowerment, as well as devising data-driven insights for healthcare.

ACKNOWLEDGMENTS

We are grateful to our participants for making the time for these interviews and sharing their experiences. We also thank Anupriya Tuli, Azra Ismail, Mohit Jain, Sachin Pendse, and Vishal Sharma for their invaluable support and feedback. Finally, we thank our anonymous reviewers for their helpful feedback and encouragement throughout the review process.

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Received January 2020; revised June 2020; accepted July 2020