"We are half-doctors": Family Caregivers as Boundary Actors in Chronic Disease Management

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Computer-Supported Cooperative Work (CSCW) and Human–Computer Interaction (HCI) research is increasingly investigating the roles of caregivers as ancillary stakeholders in patient-centered care. Our research extends this body of work to identify caregivers as key decision-makers and *boundary actors* in mobilizing and managing care. We draw on qualitative data collected via 20 semi-structured interviews to examine caregiving responsibilities in physical and remote care interactions within households in urban India. Our findings demonstrate the crucial intermediating roles family caregivers take on while situated along the boundaries separating healthcare professionals, patients and other household members, and online/offline communities. We propose design recommendations for supporting caregivers in intermediating patient-centered care, such as through training content and expert feedback mechanisms for remote care, collaborative tracking mechanisms integrating patient- and caregiver-generated health data, and caregiving-centered online health communities. We conclude by arguing for recognizing caregivers as critical stakeholders in patient-centered care who might constitute technologically assisted pathways to care.

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

Additional Key Words and Phrases: caregivers, patient-centered care, qualitative, chronic diseases, India

1 INTRODUCTION

Recent research on patient-centered care in Computer–Supported Cooperative Work (CSCW) and Human–Computer Interaction (HCI) is increasingly taking an ecological perspective by looking beyond the patient and healthcare provider to recognize other stakeholders in care. This perspective has allowed for an understanding of the broader sociocultural influences on care [11, 67] and the role of healthcare infrastructures [39, 40], accounting for constituent stakeholders such as nurses [54] and community health workers [48, 101]. The caregiving contributions of family members and "trusted others" (*e.g.,* [11, 21, 32, 62, 78]), in particular, have been extensively studied in both clinical and home settings, to highlight their influence in care management and leverage this influence towards improved care provision. Unpacking caregiving burdens [20] has also allowed for a deeper understanding of the care coordination challenges they face [88]. Our research extends this growing

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body of literature as we center familial caregiving—caregiving practices within the household, and uncover the potential for technology-mediated caregiving.

Caregivers have predominantly been studied as ancillary stakeholders responsible for assisting clinical and home care in patients' care journeys. Prior CSCW research has foregrounded the variety of supporting roles "informal caregivers" perform during hospital stays [62] and in the home [41]. Caregivers' potential to improve health outcomes is yet understated as a result of primarily being viewed as supporting actors in care. Caregivers' capacity to take on more empowered roles in care has only recently garnered scholarly attention, with research situating them as 'proxies' in remote care [34]. We research familial caregiving practices to make a case for positioning caregivers as more central stakeholders, or *intermediaries* [55, 83] in care, arguing that such a shift in perspective more accurately reflects their agency to impact better health outcomes. Our research highlights how positioning family caregivers as intermediaries—capable of making informed decisions in service of their patient's care—opens up avenues for research and technology design towards better leveraging and supporting familial caregiving in the delivery of patient-centered care.

In this paper, we study caregiving family members as *boundary actors* [57] in patients' care ecologies, and surface their decision-making responsibilities in the different social groups they interact with. Our research poses the question: *In what capacities are family caregivers involved in a patient's chronic disease care journey, and how can their caregiving activities be better enabled and supported?* To address this question, we conducted 20 semi-structured interviews with family caregivers for people with chronic health conditions in urban India. These interviews focused on caregivers' involvement in patients' care management at home, interactions with healthcare providers, and resources sought out over the course of care provision. The focus on chronic health conditions afforded us a window into caregivers' experiences at various stages of the long-term care-seeking journey.

We begin this paper by situating our research in a body of related work on collaborative and technology-mediated care, and also offer background on research relating to digital healthcare interventions in the Indian context. We then describe our research design and interview protocol. Our interview findings highlight how caregivers participated in their loved ones' care in intermediating roles and across social worlds. Our contributions to HCI are threefold. First, we contribute empirical evidence for repositioning caregivers as central, decision-making stakeholders in patient-centered care. We argue that this positioning could better support caregivers and create a path forward for improved health outcomes for patients. Second, we enrich the research on patients' treatment-seeking pathways, offering that caregivers could comprise technologically assisted pathways to care. Finally, we provide design recommendations for supporting caregivers as intermediaries enabling patient-centered care.

2 RELATED WORK

Our research draws on prior HCI work on collaborative and technology-mediated care, drawing attention to the current understanding of caregiving burdens and challenges, and how technologies have been designed to address them. We also draw on current research on the shifting landscape of healthcare in India to identify how these changes are highlighting familial caregivers' roles and responsibilities. In this section, we situate our work in conversation with ongoing research in these spaces, and provide an understanding of *boundary actors* [57] before we use this construct to analyze the roles and contributions of our study participants.

2.1 Collaborative and Technology-Mediated Care

Caregiving has been the subject of study across disciplines for several years. Strauss et al. theorized caregiver work in chronic care as *"trajectory work"*, arguing that a disease's trajectory included not

only the symptoms and its consequent medical care, but also the organization of stakeholders—healthcare providers and family members—around the treatment of the disease and its impacts on them [93]. This framing provided the basis to study chronic disease management as not only involving the patient and the doctor, but also other stakeholders. Subsequently, researchers introduced this perspective to the HCI and CSCW communities, providing the framework of computer–supported cooperative care to unpack the roles of technology in older adults' care at home [27].

As technology adoption has steadily increased in various facets of chronic care: in the home, in healthcare, and in communication, so too has research on its influence on reconfiguring relationships among stakeholders. One foray into this area of research came from Miller et al. who provided a framework for understanding the various roles *"informal caregivers"*—family members and other non-professional caregivers—play in a patient's care in clinical settings by defining five roles they play as *"companion, assistant, representative, navigator, and planner"* [62]. In post-clinical at-home settings, Nunes made a case for *"mundane self-care technologies"* arguing for a greater shift towards self-care from patients and caregivers, and reduced dependence on doctors in long term at-home care [70]. Identifying family members as primary caregivers in diabetes care, Hentschel et al. studied care management behaviors in India with the household as the unit of analysis [43], reflecting a paradigm shift in chronic disease management literature that has increasingly focused on other stakeholders in care (*e.g.,* [58, 94]). Further, Murnane et al. theorized an ecological perspective to chronic illness tracking, based on the Ecological Systems Theory model [13], that extends beyond the individual to encompass closely related social ties, institutions, and sociocultural contexts [67]. Responding to this paradigm shift, recent research has also revisited theories of care to understand its interplay with these social interactions around healthcare [86, 98].

Caregiving carries with it several responsibilities and burdens and has a growing body of research contributing an understanding. Literature from the health and nursing sciences have extensively studied informal care in this light, particularly around dementia and other health conditions that necessitate patients' dependency on their caregivers. Labelling these effects as caregiver distress [28], and caregiver burnout [95] prior work has identified the psychological, financial, and mental and physical health ramifications experienced by family caregivers [12]—akin to a chronic stress experience [87]. In classifying caregiver challenges in performing their responsibilities, Chen et al. uncovered difficulties in balancing caregiving burdens with other aspects of their lives like their physical, emotional, social, and reflective selves [20]. Yamashita et al. extended this line of work, focusing on the lived experiences of caregivers of people with depression to design technologies for their wellbeing, finding a need for anonymous spaces to find a community of caregivers [103]. They further studied how tracking caregivers' activities and care recipient's moods could support caregivers in coping with their responsibilities [104]. Along similar lines, unpacking parent interactions with the Type 1 Diabetes management tool, Nightscout, Kaziunas et al. surfaced the social and emotional effects of tracking children's care on their parent-caregivers [56]. Other research on parent-children dyads also found tensions parents experienced in balancing their parenting and caregiving responsibilities [89], recommending tools that integrated the two as a viable approach to lessening burdens on parent-caregivers. Extending this research to a network of caregivers, where care coordination becomes necessary, Tang et al. found that difficulties arise in the form of maintaining awareness of caregiving needs, coordinating responsibility handoffs among caregivers, and easing tensions between patients and caregivers [96]. Building on this work, recent research by Schurgin et al. in the US context looked into the care coordination challenges of caregivers, and provide additional situational and mediating factors that inform caregivers' experiences navigating these challenges [88]. In sum, this body of literature has progressively extended our understanding of the sources of caregivers' burdens that affect both their own physical and mental health, and their ability to provide care for others.

Several research approaches have incorporated technology design to help caregivers in ameliorating caregiving challenges. For example, early research on assistive technologies for people with dementia identified design and user experience requirements that could encourage adoption, like generating positive emotions through usage, and either augment or be a better alternative to existing caregiving workflows [4], with the support of family and professional caregivers [44]. Tixier and Lewkowicz, presented the value of technology-supported social support for informal caregivers [98]. Another approach to reducing individual caregiver burdens has been a focus on inter-caregiver collaboration in chronic disease care (*e.g.,* [81, 85, 96]) and respite care (*e.g.,* [63]). Shin et al. proposed a collaboration platform for caregivers of children with autism for continuity of care between home and school [90], such that the stresses of care coordination are reduced.

A common thread across this body of literature is the ancillary positioning of caregivers in chronic care and care management technologies. Within this frame of reference, prior work has drawn specific focus to caregivers, recognizing care burdens and proposing technological solutions to provide support, like online health communities [49, 97]. Recent work has begun to shift perspectives to see caregivers, and care provision, in a different light. Schurgin et al. recommended designing for the dyadic relationships in the care network, rather than for individual users, as a way forward in navigating care coordination challenges [88]. Shin et al. proposed an assets-based approach to designing technologies for caregivers, drawing attention to the situated knowledges gained from care coordination and provision [91]. With this paper, we aim to contribute to this discussion. We argue a need for further investigation of healthcare contexts where caregivers play a significant and central role in decision-making around care access and management and could be supported through technology interventions. We contribute an understanding of their situated challenges, strengths, and resources in such contexts, which might shed light on future directions for research and development to better support caregivers in their responsibilities.

2.2 Healthcare and Telehealth in India

In resource-constrained healthcare contexts, the appeal of telehealth stems from increased reach of quality healthcare to rural and other particularly under-resourced regions [31] as well as lower costs of care [60]. The first rollout of telemedicine in India, as well as its successes and shortcomings, has been widely documented (*e.g.,* [19, 24, 37]). Years after the initial deployments, Chandwani and De examined the norms of teleconsultations and how they differed from regular, in-person consultations, proposing how telehealth could best be employed [16]. Recognizing a research gap in unpacking the sociotechnical nature of these telemedicine deployments, Chandwani and Kumar unpacked the human infrastructures supporting telemedicine deployments in rural India, identifying the variety of "seamful" ways in which human actors facilitate telemedicine [18]. Recent and currently ongoing events, like the COVID-19 pandemic, have reinvigorated telehealth adoption in India. The pandemic severely impacted healthcare systems in India by delaying chronic disease care [69], and further straining limited resources [2]. These developments have revived discussions about the potentials for telehealth as sustainable avenues of care seeking in the future [50, 64, 82]. In this time frame, Bhat et al. studied the ways in which patients and doctors devised ways to facilitate telehealth when scalable infrastructures did not exist, and their experiences in these consultations [10]. Raj and Srikanth proposed an assisted telemedicine model for rural healthcare in India leveraging three sets of stakeholders: doctors, frontline health workers, and patients [80]. Our work extends this body of literature by critically examining the role of caregivers in facilitating telehealth in the urban Indian context.

HCI research has increasingly examined the cultural dynamics of Indian healthcare to understand the stakeholders involved, their interpersonal relationships, and their engagement with technologies for healthcare. Chandwani and Kulkarni reported on the dynamics of patient-doctor interactions

in India, noting the long-standing power imbalance between patients and doctors. They found that the increased access to health information on the internet was changing this existing power imbalance, as doctors needed to adapt how they exercised their expertise in interactions with internet-informed patients [17]. Building on this work, Bhat and Kumar critically examined the role of sociocultural factors in health tracking for cardiac disease care [11], uncovering the crucial roles played by family caregivers in distributing and managing information needs of their loved ones. Other works have also shed light on the efforts of stakeholders instrumental in last-mile care delivery, such as frontline health workers (*e.g.,* [6, 48, 101]) and nurses [54]. Specifically focusing on caregiver challenges, Tuli et al. designed a system, Harmony, to address caregiver needs in severe mental illness management [99]. A subsequent study by Deb et al. critically reflected on the viability of mental health apps that incorporated caregiver needs in India [30]. Engaging with and extending this prior work, we ask how caregivers can be better understood as critical intermediaries in care access, and how an understanding of their duties could inform better health outcomes for their loved ones.

2.3 Boundary Actors

Star and Griesemer introduced the concept of *boundary objects* to understand how groups that belonged to different social worlds collaborated despite having differing world views. They defined boundary objects as objects that possess the ability to maintain a common identity among social groups, while being able to adapt to the individual requirements of each of these groups [92]. In HCI, this concept has been used in a variety of contexts, including design workshops [75], job onboarding materials [14], in patient-provider collaboration with patient-generated data [26], and in studying technologies for home care [1]. Extending this concept, and building on prior work that considered action researchers in their communities as active *boundary subjects* [46], Keshet et al. proposed the idea of *boundary actors* to include humans serving as boundary objects between multiple social worlds [57]. They noted that the biggest departure from Star and Griesemer's definition was that humans introduced and were affected by the power imbalances in those social worlds, unlike non-human objects. Viewing them as actors, then, allowed for analyses to take into account these politics of interactions. Arnon et al. have since adopted this concept to understand nurses' roles as *boundary actors* in integrative medicine, the combination of conventional and complementary medicines [3].

We employ this lens in our analysis of caregiving responsibilities of family members because we recognize that they straddle multiple social worlds in this role. Within the home, they live in multi-generational households with their own power and cultural dynamics and still derive some authority as primary caregivers of their loved ones. Yet, their lack of training and expertise in professional caregiving shifts the balance of power in interactions with healthcare providers. Family caregivers, in these situations, fall on the boundary between these two worlds as they intermediate between them. This conceptualization of caregivers as boundary actors affords us a framework to deconstruct caregivers' experiences and challenges in ensuring care for their loved ones, and identify directions for future technology design.

3 METHODS

The goal of our study was to gain an understanding of the capacities in which family caregivers are involved in a patient's chronic disease care journey, towards identifying how their caregiving activities could be better enabled and supported through technology. We conducted 20 semi-structured interviews with individuals from middle-income backgrounds in urban India who also serve in caregiving capacities in their familial contexts. We present details on our study context, data collection, and data analysis methods below.

3.1 Study Context

We conducted our study with caregivers living in urban India. Our study criteria consisted of participants of age range 18 to 55, with incomes ranging from INR 2.5 lakhs[1] per annum (LPA) to INR 8.5 LPA *(approx. USD 3,400 to USD 11,500)*, living in urban or semi-urban areas of Bangalore, India. We also filtered for the health condition of the care recipients—type 2 diabetes, cardiac disease, pulmonary disease, or other non-communicable chronic diseases. Caregivers of patients with such chronic, non-communicable, diseases were recruited since their long-term care requirements included regular follow-ups with doctors and daily-to-weekly care management to prevent disease exacerbation. This allowed for us to study caregiving as a dynamic, lifelong process.

We focused on caregivers in the rising middle-income demographic because they have financial resources to assess how they utilize healthcare and technology for managing caregiver tasks [35]. India is one of the fastest growing economies and digital consumer markets. The country is experiencing a shift from a low- to middle-income economy with more wealth to absorb mobile devices and healthcare costs. According to a report by McKinsey & Company, India had 590 million internet subscribers, 1.17 billion wireless-phone subscribers, 354 million smartphone devices, and 12.3 billion app downloads in 2018 [51]. According to the World Bank, more than 62% of healthcare expenditures were paid for out-of-pocket in India [7]. In addition, chronic diseases (*e.g.,* cardiovascular disease, diabetes) are among leading causes of death and disabilities in India [72, 73]. Therefore, we aimed to further study health and chronic disease management in India to better understand the role caregivers play as facilitators of care and avenues for innovation.

3.2 Data Collection

With Institutional Review Board approval from Microsoft Research, we conducted 20 semi-structured interviews via Zoom audio calls in June-July 2021. Participants were recruited through an agency that recruits for qualitative and quantitative research studies across India. Potential participants were recruited via a combination of methods such as leveraging existing contacts through internal databases as well active recruitment methods. Interested participants who met eligibility criteria were then informed about the purpose of the study and what to expect, and given time to ask questions. Participants who volunteered to take part in the study were verbally read the informed consent, and provided with a copy of the consent form via WhatsApp, email, text or other mode of preference as/if requested by the participant. The research team only scheduled the interviews after the participants had provided their consent to the recruiting agency. All participants were living in Bangalore, India at the time of the interviews. All participants were caregivers for family members with a range of chronic health conditions detailed in Table 1. Their age range varied from 18-30 (2) to 41-50 (4) with a majority of our participants falling in the 31-40 (14) age range. Their annual household income ranged from INR 3-4 LPA *(approx. USD 4,080 - 5,440 per year)* to INR 6-7 LPA *(approx. USD 8,160 - 9,520 per year)*, with a median of INR 4-5 LPA *(approx. USD 5,440 - 6,800 per year)*. Most participants lived in multigenerational households which typically included the caregivers, their older adult parents or parents-in-law, and their young children. Our study included 12 female (F) caregivers, and 8 male (M) caregivers. More details about the participant demographics can be found in Table 1.

To confirm participation, verbal consent was again obtained from each participant prior to the interview, followed by verifying demographic information. We asked all participants to recount their day-to-day activities that they consider as "caregiving responsibilities'' with prompts such as "cooking, cleaning, managing medications, and setting up appointments with doctors." We then asked them about the factors that influenced their decision-making during the occurrence of major

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[1]'One hundred thousand' (100,000) is represented as 'one lakh' (1,00,000) in the Indian numbering system.

Table 1. Participant Demographics.
Acronyms: Cardiovascular Disease (CVD), Chronic Pulmonary Disease (CPD), Nonspecific Interstitial Pneumonia (NSIP)

P_ID	Age	Gender	Income (LPA)	Occupation	Health Condition	Patient
1	31-40	F	4-5	Teacher	Aplastic Anemia	Son
2	31-40	M	4-5	Own business	Asthma, NSIP	Parents
3	41-50	M	4-5	MNC Employee	T2 Diabetes	Mother
4	31-40	F	5-6	HR	T2 Diabetes	Mother-in-law
5	41-50	F	4-5	Homemaker	T2 Diabetes	Father
6	41-50	F	4-5	Homemaker	T2 Diabetes, Hypertension	Father-in-law
7	31-40	M	4-5	System admin	T2 Diabetes	Parents
8	41-50	M	5-6	BPO Manager	T2 Diabetes	Mother
9	31-40	M	6-7	Sr. Sales Mgr	T2 Diabetes	Mother
10	31-40	M	5-6	Own business	T2 Diabetes	Mother
11	31-40	F	5-6	Homemaker	T2 Diabetes	Mother-in-law
12	31-40	F	4-5	Homemaker	Arthritis	Grandfather
13	31-40	F	4-5	Accounts exec	T2 Diabetes, Hypertension	Mother-in-law
14	18-30	M	3-4	Manufacturing	Cardiomyopathy	Mother
15	31-40	F	4-5	Hommaker	CVD	Mother-in-law
16	31-40	F	4-5	Homemaker	CPD	Father-in-law
17	31-40	F	5-6	Accountant	CVD	Mother
18	31-40	F	5-6	Own business	CVD	Mother-in-law
19	18-30	F	4-5	Associate Consultant	CVD	Mother-in-law
20	31-40	M	4-5	Account Assistant	CPD	Mother

and minor health events, including at what stage they reach out to their doctors. We also asked participants to recount instances where they intentionally avoided or delayed care for themselves or their family members. Finally, we asked them about their experiences with aspects of telehealth like remote consultations, blood tests and reports, and engagement with health information. All participants were compensated INR 700 *(approx. USD 10)* for their participation. All participants' names have been anonymized.

3.3 Data Analysis

All interviews were conducted by the first author. They were audio-recorded with the participants' consent and later transcribed by the recruiting agency. The first author also maintained handwritten notes for all interviews. The interviews lasted 55 to 70 minutes. A majority of the interviews were conducted in English with some being in mixes of English and Kannada, and English and Hindi, as per the participants' preference. The interviews were transcribed, and translated to English as necessary, soon after they were conducted. The first and second authors periodically discussed interviews to identify interesting themes and inform future interview questions. We used an inductive, interpretative coding approach to this data [61]. These initial themes included 'expertise in remote care', 'health tracking', and 'time constraints.' As the interviews progressed, we iterated over the data to produce higher-level themes including 'at-home responsibilities', 'online

information seeking', and 'patient-doctor interactions.' Finally, we abstracted out to three main themes that we present in this paper: 'Facilitating interactions with healthcare professionals', 'Gaining expertise in care at home', and 'Collaborations with other communities.'

3.4 Limitations

The timing of our interviews during the ongoing COVID-19 pandemic introduces some limitations to the study. To a large extent, participants were working from home, with children attending school virtually. This may have resulted in recency biases [22] in our participants' interview responses. Second, our study looked at a variety of chronic health conditions—that have some common long-term care requirements—as a window into the everyday practices of caregivers. Consequently, our approach takes a necessarily abstract view of the care needs for these particular health conditions, and future work could look into caregiving for each of these conditions individually to gain a deeper understanding of their situated caregiving needs. Further, all participants we interviewed had been engaged in caregiving already; it is likely that our findings would have been enriched by adding perspectives around barriers to caregiving as experienced by individuals just about to embark upon the caregiving journey. This could be a focus of future research.

4 FINDINGS

We conducted this study to enhance our understanding of how family caregivers are involved in caring for their loved ones suffering from chronic ailments. Through the course of our analysis, we noted the various social worlds these caregivers were a part of, and their responsibilities across the different worlds. We found that caregivers were facilitators in patient-doctor interactions, collaborators and stewards in the home, and curators of information in their physical and online communities. Our findings below detail how caregivers intermediated their loved ones' care by straddling the boundaries and navigating the unique dynamics of each of these social worlds.

4.1 Facilitation: Interactions with Healthcare Professionals

The first boundary that caregivers lie on is between healthcare providers, like doctors and physio-therapists, and the patients. One of the primary roles family caregivers play is facilitating consultations and other interactions with healthcare professionals throughout their loved ones' healthcare journeys from care access to care management. The caregivers we interviewed were uniquely positioned to do so, having higher technology and health literacies than their older family members. They acted at this boundary by being proxies for the other: providing care in the absence of healthcare professionals, and advocating patients' care in their presence. We describe the ways in which caregivers intermediated, translated, and facilitated care for their loved ones navigating the power differentials between patients and doctors that have been documented in prior work [11, 17].

4.1.1 Choosing and Contacting Doctors. Caregiver roles in the healthcare journey began even before the first consultation with healthcare professionals. At the onset of symptoms suspected to be related to chronic ailments, caregivers were tasked with identifying potential doctors to reach out to for their loved one's condition[2]. In doing this, they either reached out to a family doctor[3] for diagnoses and referrals, or to their social networks or online platforms to receive recommendations for doctors. Some participants had existing and ongoing relationships with doctors for prior health conditions, either for the same family member or someone else in the family. These relationships and goodwill were generally built over time, as patients sought continuing care for their health

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[2]We unpack this decision-making in a 4.2.
[3]Doctors, of any specialization, that the families had close relationships with: as long-term care providers, (extended) family members, or trusted community members [10].

conditions. P16 explained that *"since he has been suffering from this one for quite a long time, so the doctor has become more like a family member to us. . . We have developed a very good relationship with the doctor."* This continued engagement afforded trust between the doctors and the families, and consequently allowed for easy access to care for new conditions, as P11 described:

> "First thing would definitely be my family doctor. If he can diagnose, he usually gives the medicine. If he is not able to diagnose, or he feels that this requires attention of a specialist, he refers some specialist and that is how we go about it. . . We trust him. He has been our family doctor since more than 25-30 years." (P11, F, Diabetes)

In this way, caregivers drew on existing relationships they, or other family members, had with doctors to facilitate care when necessary. This was not always possible, however, as myriad reasons could render these family doctors inaccessible during crisis moments. In such circumstances, their approach was to leverage other available resources, like online healthcare plaforms. P9 described one such instance when he was forced to rely on online platforms, saying:

> "15 to 20 days back when I was calling up my family doctor, he did not pick [up] and after some time, he switched off his phone. . . I ended up checking with my Practo app also [to find a] doctor on call. . . at least at that point of time, at 5:30 or 6 in the morning, I was having the chat option [to get a consultation]."
> (P9, M, Diabetes)

Practo[4], and similar online health platforms like Tata 1MG[5], formed an easily accessible resource for caregivers to leverage for their loved ones. They did, however, express some misgivings around using these platforms as the primary portal for healthcare access. Returning to the importance of trust in their doctors, participants noted that user reviews of doctors and healthcare facilities on such platforms were not trustworthy. Consequently, they relied heavily on other measures of quality like the reputations of the platform, healthcare facility, or doctors as they made decisions about using these services. In P11's words, *"[if it is a] not well-known doctor, then you are not sure who that actual person is. . . if it is some XYZ doctor I do not know anything about, how do I trust this doctor?"* Word-of-mouth recommendations from known and trusted individuals also served as a viable approach to seeking out good care.

Arguably the greatest latitude in choosing doctors was afforded to caregivers at this stage: the initial consultation. Given the long-term nature of chronic disease care, our participants tended to spend time getting multiple doctors' opinions and consultations to assess not only their style of consultation but also their comfort levels communicating with the doctor. P14 described his experience finding a suitable doctor in this way:

> "We went to three doctors for the same heart issue. We took three decisions from three doctors in three different hospitals, but finally we are continuing with one doctor out of the three. . . All three doctors gave the same tablets. There are no changes in the prescription, nothing. . . He is very kind and answers whatever questions we ask. He answers very patiently. Some of the doctors do not listen what we are asking and they will give whatever they want. So, he is very satisfactory." (P14, M, Cardiomyopathy)

This account points not only to how they perceived these consultations *in situ*, but also factor in decision-making about whether this patient-doctor relationship could be a sustainable, long-term one. This is particularly salient given the nature of family doctor relationships and how they span generations in a family. In identifying doctors they could trust for their loved one's health, they were also laying foundations for a long term care relationship other members of the family could

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[4]Practo: Say Hello Doctor! 24/7 Video Consultations—https://www.practo.com/
[5]Tata 1mg: India's Leading Online Pharmacy & Healthcare Platform—https://www.1mg.com/

leverage. Consequently, these relationships were constructed jointly by the patients and their caregivers, highlighting the strong decision-making role caregivers had on this boundary.

4.1.2 Consulting with Doctors. In this section we take a deep dive into the specific roles caregivers played during patient-doctor consultations. Prior work in the Indian healthcare context has drawn attention to the power-imbalanced interaction dynamics of patient-doctor interactions [11, 17]. Caregivers are typically merged into the cumulative 'patient', viewed as supporting stakeholders for both the patients and the doctors. We extend this line of work to draw attention to the intermediating roles caregivers play within this interaction by being on the boundaries of these worlds.

Caregivers' responsibilities included a variety of tasks like logistical support (scheduling appointments, accompanying their loved one to the doctor's clinic, and taking notes during the consultations), presenting medical history, reporting on medication adherence, and participating in decision-making. In doing so, caregivers acted as the patient's 'representatives' [62] and 'proxies' [34] in these interactions. However, indirect effects of the COVID-19 pandemic led to additional responsibilities falling on the caregivers in facilitating consultations. First, it reduced the frequency of in-person consultations as healthcare infrastructures were strained. Further, telehealth became a viable alternative to in-person healthcare. As a result, the caregivers needed to have (or develop) the technological proficiency to set up a teleconsultation for their loved ones. The strains on caregivers were introduced as a result of this shift, and allow us to unpack their responsibilities as boundary actors in these interactions. In aiding doctors, some caregiver time during consultations was spent providing technical and diagnostic support by taking pictures or videos to capture how patients were presenting symptoms. Compounding matters further, P13 explained how sometimes these diagnostic support tasks received no real feedback from doctors further adding uncertainty to the overall consultation experience. She said:

> "It was very hard because we were trying to do video calls and show pictures, like take some snaps and send to him: enlarge it and highlight those spots and things in those lines. So, it was like a lot of work plus, we still do not know if it can be easily understood what it is, right? Like, it is one thing to see from naked eyes versus doing it over pictures." (P13, F, Diabetes)

These tasks, however, came at the expense of their responsibilities to the patients: as their 'proxies' asking questions on their behalf. Coupled with the lack of physical interactions with doctors, this change contributed to a negative perception of the teleconsultation experience. As P15 noted:

> "I would say [it is] because of the habit that you had a practice of going and meeting the doctor and then there is self-satisfaction that 'yes. I did visit the doctor'... All that [teleconsultation] experience was great but somewhere in my mind is that 'it could have been better if we would have gone there.' " (P15, F, Cardiac Disease)

A key boundary object [92] that caregivers managed on behalf of the patients and doctors was patient medical records. Currently, there is no centralized health record infrastructure in India, with only recent efforts in this direction [5]. Largely, health records were maintained as paper-based files in the possession of the patient or their caregiver. They were expected to carry these files to all subsequent consultations to facilitate continued care. In practice, this involved the caregivers keeping meticulous record of paper-based prescriptions and diagnostic reports for use in subsequent consultations. They noted that only recently, with the shift towards remote care, have doctors and diagnostic laboratories started providing digital versions of these documents. This allowed for caregivers to curate and archive this data into more manipulable and easily stored digital formats, that reduced dependency on the paper-based reports. One participant explained her use of Excel sheets to record her son's biweekly test results to identify trends in the reports. She noted that

"even doctor was very happy with this work...The doctor is having only the [diagnostic] reports...but he was following our Excel sheet because everything was mentioned and for him it was easy." A complication of this largely paper-based practice became apparent to the caregivers when they needed to have a teleconsultation with a new doctor for their loved ones' health. Exacerbating the earlier constraints on caregiver time in consultations, caregivers had to expend more time verbally bringing doctors up to speed on the patient's medical history. Explaining why this led to reservations about teleconsultations, P2 explained:

> "In my parents case we have not changed doctor...If we will go with the other doctor then just we have to explain each and everything from the starting, so it will take one or two hours to explain...the history and everything so then he understands that 'okay this is the problem. Okay fine.' He just sees the reports and...he will reach at that point: okay, no problem. We are starting the medication. So that is why..." (P2, M, Asthma)

Analyzed in this way, we draw attention to the specific, instrumental responsibilities caregivers had in providing care for their loved ones. Despite playing a supporting role in consultations with doctors, a blurring the boundary between the home and the clinic in remote care foregrounded their intermediating role in care provision.

4.1.3 Diagnostic Tests and Physiotherapy. Given their loved ones' chronic conditions, the caregivers regularly facilitated diagnostic blood tests to track their health. Depending on the conditions, the frequency of these tests ranged from every 2 weeks to every 6 months. The infrequent nature of these tests meant that caregivers could not factor these time commitments into their daily routines, causing frequent disruptions to schedules when they became necessary. P17 expressed:

> "So many tests I have to keep track every time like, 'when is it that I have to get it done?'...Sometimes instead of three months, her *HbA1c*[6] I may get it done in four months or five months...Every time taking the patient to the lab, getting the test done...*HbA1c* - any time I can go to the lab; *FBS*[7] or *PPBS*[8] - it is even more troublesome. [If] I have to go in the morning, [then] previous night I have to note the time she had dinner...[After collecting blood,] I have to note down what time she had breakfast and immediately within two hours I have to give blood for the testing...All these small, small things it is very difficult." (P17, F, Cardiac Disease)

Introducing additional complications to this cumbersome process was P17's perception that her mother was not acting in her own best interest. Recognizing a pattern, P17 needed to intervene inhabiting her boundary identity between her mother and healthcare professionals, in order to ensure health outcomes were not negatively affected by her mother's actions. She noted the differences between the *HbA1c* test and a regular blood sugar test explaining that her mother had learned to game the latter. She said:

> "what she does is: if she comes to know that tomorrow I'm doing that *FBS* or *PPBS*...[then for] two days, she tries to avoid all those things, which are adding to her blood glucose level so that [the] reading will come very low. After that, she will say, 'my blood sugar level is under control, I can eat anything.' That kind of a strategy she is following." (P17, F, Cardiac Disease)

Contrary to patient-doctor interactions, a pandemic-instigated shift towards remote care allowed for some easing of caregivers' logistical burdens in this regard as diagnostic testing practices also changed. Multiple participants reflected positively on the availability of home testing, *i.e.,* having a

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[6]A blood glucose test measuring the average blood glucose level of the past 3 months.
[7]Fasting blood sugar test - measuring blood glucose levels after 8-12 hours of fasting.
[8]Post-prandial blood sugar test - measuring blood glucose levels within 2 hours of a meal.

diagnostic lab employee visit the home to collect blood. In availing this paid service, caregivers could forego the time and energy sinks of transporting their loved ones to different parts of the city for care. P11 explained:

> "The doctor has his clinic at one place, the diagnostic center was at another…It was tiring, but now we have figured it out where we can just call a person home also. They can come and take the fasting [blood sugar] one and all…They do take home visit charges but then it is a little [inexpensive because we use it infrequently]" (P11, F, Diabetes)

Once completed, caregivers took charge of scheduling follow-up appointments with doctors who could change prescriptions or identify abnormalities in the reports. Over time, caregivers developed an expertise in sensemaking around diagnostic reports and began to enact changes based on diagnostic reports themselves. This further points to caregivers' positioning on the boundaries between patients and healthcare providers: able to glean knowledge from the latter, to affect improvements on the former. P14 noted that blood reports were *"easy. They will give the normal range and the range she is having. I think they will bold the letters if it is not normal, the range…We will get it. Anyone can understand the irregularity in the results."* With a further understanding of how their dietary and exercise habits could positively influence blood report readings, participants also expressed making intentional changes to diets to make targeted efforts towards bringing abnormal levels under control.

Home care for chronic conditions like cardiac diseases and arthritis involves rehabilitation and physiotherapy. These treatments, however, did not readily translate to remote care as they involved the presence of a trained instructor to coach the patient on form and prevent injury. During tele-physiotherapy, in the absence of these trained professionals, caregivers' boundary identities were highlighted as they could step in to intermediate on behalf of their loved one. In P12's case, this involved several interactions with a physiotherapist where she first learned the exercises herself, following which she taught her grandfather to perform them. In her words:

> "Actually you can say [I have] a major role because what physiotherapy exercises they were telling us, first I had to learn it, since he was not able to grasp everything online. It was not easy for him because it is a new [experience]…not only [for him] even this technology is new for us also…So I had to learn that, I had to observe it. I had to ask him so many doubts, 'Sir, how to do this? Will it be very painful? Will [he] be able to do it at this age?' I had to learn everything and after learning slowly…I had to teach my grandfather that. It was not very easy, so I had to take a major role in learning." (P12, F, Arthritis)

We note that P12 had to invest several extra hours of work in ensuring her grandfather ultimately got the benefits of physiotherapy for his condition. Learning the exercises to a sufficient degree to be able to safely teach her grandfather showcases her importance at the boundary: the ability to be coached by the healthcare providers ensuring the best health outcomes in the patients. We note here that this constitutes an exemplary model for caregivers. Aligned with current research [70], this coaching model provides a caregiver-mediated path forward for patients' self-care.

4.2 Gaining Expertise: Caregiver Responsibilities at Home

Having presented how caregivers facilitated professional healthcare for their loved ones, we draw attention to how they provided care in the home. We note here that the boundary we focus on is between the caregivers and the patients. Creating this distinction allows us to unpack caregivers' roles as they are situated in the power dynamics of the household they inhabit. Noting that they leveraged existing caregiving and health tracking technologies, we focus on their key care

responsibilities and how they performed them while managing expectations of expertise as informal healthcare providers, and navigating cultural expectations placed on them.

4.2.1 Existing Chronic Disease Management. Caregivers assisted with several day-to-day activities like cooking to specific dietary needs, managing medications and assisting in adherence, and ensuring regular follow-ups with the doctors. All of these activities at home—accompanied by prior experience mediating consultations—allowed for P7 to reflect on how she had now *"become half-doctor"* herself. Despite the demanding nature of these responsibilities, they were generally managed by a single caregiver in a household, with minimal support from other members of the household. This lack of support worked to isolate caregivers in their roles, leading to heavy decision-making responsibilities in care. As P12 described it:

> "I am the main caregiver for all of them at home including my kids, my husband, and my grandfather. It is me who decides regarding all the responsibilities and all things at home." (P12, F, Arthritis)

Relatively fixed tasks, like medication adherence, became part of a caregiver's daily routine over time. They used a variety of signifiers, like pill boxes, smartphone reminders, and meal timings, to ensure that medications were consumed in a timely manner. The more dynamic tasks, like diet modification and exercise regimens, required mindful consideration on a daily basis to ensure better health for their loved ones. Participants explained that they regularly searched online for recipes of new foods to prepare in accordance with their loved one's dietary needs. Negotiations around dietary restrictions and food cravings were a routine part of the caregivers' practices, corroborating prior research on diabetes care in India [43]. For many participants, these responsibilities—time-consuming as they were—became a part of their daily routine and they ceased to consider them as 'additional' responsibilities. P16 said, of this:

> "Well, had you asked me a year ago, I would have a list of [issues], but if you ask me now, I enjoy it thoroughly. So, there is nothing that I could [do to] make it easier because I have mastered myself so well in it. My time management is so good…So, my day goes very smooth I have no complaints at all, no issues at all…It is just perfect as I said because I do get my free time in the afternoon so I have my 'me time' also…Maybe I was not so well planned when it all started but right now if you ask me…I do not see any changes to make it is all sorted." (P16, F, Pulmonary Disease)

Chronic disease management also meant that caregivers were in charge of administering medical care and tracking the health of their loved ones. Some of these practices included using a glucometer to monitor blood sugar levels, assisting with insulin injections for loved ones with diabetes, using nebulizers to provide oxygen, and massages for pain relief from arthritis. Again, we note the indirect impacts of caregivers' presence in the healthcare provision world on their responsibilities at home. Importantly, however, we found that this boundary identity had negative effects on the caregivers in the home with regards to care provision. We found that our participants expressed misgivings about some responsibilities stemming from their perceived lack of expertise in caregiving. For example, P3 expressed apprehension about using finger-prick glucometers at home because *"we are just scared of that thing. I understand that…it is very easy to do at home…the pen is also much easier because when you shot with the pen it does not hurt a lot compared to what we have when taking out blood…but still she feels little bit uncomfortable doing it"*. He continued that this fear also affected other responsibilities that he was not trained to perform:

> "The main challenge about caring a family member is…we are not doctors or we are not caretakers to give professional caring to them…Sometimes like we are little scared

> to give them injection also because the skin and everything right, so that is why like the professionalism is not there in us." (P3, M, Diabetes)

Within the home, caregivers were indeed experts in providing care to their loved ones as they best understood their personalized needs. Discomfort around invasive procedures, like drawing blood and injecting insulin, as expressed by P3 might stem from a preconceived notion around a need for professional training to perform these tasks. Despite gaining expertise with experience, P3's admission to a lack of professional training points to underlying assumptions about what expertise in home caregiving entails.

Blurring the boundary between caregiver and care recipient in the household, a final aspect of at-home care responsibilities involved preventative care for hereditary chronic conditions like high blood pressure, diabetes, and cardiac diseases. Along with other family members, caregivers themselves were susceptible to these hereditary conditions in the short- or long-term. Their caregiving behaviors, then, involved some part of preventative self-care. Our participants concurred, expressing that they were concerned with delaying its onset and taking preventative measures like maintaining a more active lifestyle, and controlling their diet similar to their older family members. P11 said:

> "Since it runs in the family, even my husband would be at risk sooner or later. So it is better if we also have that control [of blood sugar levels]…He goes for a very long and brisk walk…he is well aware of the situation…so that you can delay these lifestyle diseases." (P11, F, Diabetes)

In some families, however, these preventative measures stopped short of regular health checks and testing. Even though the participants acknowledged the benefit of having yearly health checks, their resistance stemmed from financial considerations, the mental toll an unexpected diagnosis would have on them, and the complications it would introduce to the distribution of caregiving work at home. This highlighted their caregiving priorities when their own health was impacted.

4.2.2   New Symptoms and Health Conditions. When family members had new minor illnesses, like the common cold, caregivers were involved in providing immediate care while deciding on potential next steps including when to reach out to doctors. Our participants overwhelmingly expressed a common decision-making process in these situations, reiterating their influence in this social world. The first step involved home remedies, drawing on their prior knowledge and that of elders in the family. In case there was no improvement in health in the short-term, they used over-the-counter medicines that they had available at home for these situations. If even that did not cure the patient, they would contact their family doctor to seek professional care, as P4 described:

> "Generally, if it doesn't subside within two or three days, then I wouldn't wait for it to go high. So, I would wait for two days with home remedies, with proper food and whatever precautions I can, but again, beyond that, I think we need to consult the physician." (P4, F, Diabetes)

When the caregivers suspected that the symptoms were related to the chronic condition their family member had, they would handle the situation differently. If they were unsure of the immediate care needs, they would directly contact their doctor. Largely, however, they tended to manage the condition themselves as they had gained this expertise, over time, on the boundary between patients and healthcare providers. Participants caring for family members with Type 2 Diabetes and hypertension explained that they would modify diets to be more restrictive, hypothesizing that the symptoms were caused by a relaxation of dietary needs. We note here, and expand in the next sub-section, that caregivers were empowered to do so within their household. Being seen as the main caregivers and experts in care, they had leeway to make decisions on behalf of their loved

ones in these circumstances. P2, who cared for parents with NSIP, explained how he had arrived at a good level of preparedness for sudden complications in his parents' conditions with the support of his doctor. He said:

> "Actually, doctor told me the full procedure how to cure if there is any emergency time like suddenly if she got some asthmatic attack like problem in breathing and anything else like that so doctor told each and everything to us means what is the step-by-step procedure you can take at home and if it will not work then please call me and come to hospital then we will cure her." (P2, M, Asthma)

4.2.3 Navigating Expectations and Cultural Norms. Caregivers' involvement in their loved ones' care needs to be situated within their family dynamics and the broader cultural norms informing them. When asked about burdens they faced in being caregivers to their family members, the participants summarily denied viewing care as a burden, but instead as a cherished part of their life. P6 explained *"It is a necessity and it is not responsibility...and it is important in my life...I am doing it happily."* In our participants' households, caregiving tasks were seen primarily as a responsibility of the women in the house. Despite there being other members living in the same household, P12 pointed out that *"Since there is no other lady at home, all work and everything is totally entirely on me."* Even in interviews with our male participants, we noted that historically gendered roles were strongly adhered in their households. Here, the male caregivers were primarily responsible for the financial aspects of care while the female members of the house, sometimes the patient themselves, were in charge of diet management and medication adherence. P16 described her 'old-fashioned' household where she was the primary caregiver to her father-in-law as *"I am the younger daughter-in-law so I was basically the youngest in the family. Expecting somebody to [listen] to me was very challenging; that too when it comes to a family that is very old-fashioned where the daughter-in-law's do not talk...in front of the father-in-law."* She went on to explain how caregiving changed this family dynamic over time, giving her a greater voice and more authority in household affairs as:

> "I have reached an era now where I can dominate on my father-in-law. 'Daddy, I have made this for you and you are going to eat it.' So that has been a tough journey. My mother-in-law had to see that I was taking over everything when it comes to Daddy's [care]." (P16, F, Pulmonary Disease)

We noted that care provision, sometimes, came at the cost of the caregivers' own health. In such situations, caregivers admitted to avoiding care for themselves as they prioritized their family members' needs. The justifications were varied, including recognizing that seeking care for themselves would affect existing routines and potential financial considerations. P20 noted that his financial resources were stretched thin by the parent's care needs. So, when he needed to receive medical attention for his own health, he chose against it:

> "...I had a stomach infection...the doctor referred some tests and I got diagnosed with some condition...he asked me to consult a specialist and I did not go through with it because I felt it is expensive...I thought, 'why I should go again and he may suggest other tests to know...exact conditions [and] later on giving treatments?' [instead of] shelling the amount, I can spend it for my mother." (P20, M, Pulmonary Disease)

Other participants also recounted experience with either avoiding self-care, or experiencing disruptions in their caregiving routines as they took time off for self-care. P16, for example, noted that, she *"could not risk being away from home"* as it would disrupt her father-in-law's care. She recalled a recent instance of how a hand sprain affected the family's daily routines because there was no one else to take on caregiving responsibilities. She concluded with *"No matter what, daddy is my*

priority. I am a person who gets very frequent migraines...but even the worst migraines, I make sure it is not affecting daddy's routine."

4.3 Collaboration: Caregivers in their Communities

The final boundary that caregivers lie on is between external communities, both physical and online, and the patients. This boundary loosely encompasses informational and social resources caregivers can access and leverage in supporting their care provision. We present how caregivers leveraged community knowledge outside of their household like extended family members; from online communities like Facebook and WhatsApp groups; and online informational resources like Google and YouTube to fill knowledge gaps and augment their caregiving. In doing so, we draw attention to their decision-making around when and whom they reached out to, and how they used it towards better care for their loved ones.

4.3.1 Family Members, Friends, and Neighbors. Our interviews focused primarily on caregivers who lived in the same household as their family members who needed care. There were multiple scenarios in which the participants involved other extended family members in their decision making and caregiving process. The motivations included wanting to share the responsibility of care, and sharing expensive equipment across multiple households. P15 described why she chooses to involve more family members in her decision making as:

> "...those are the things...where I cannot take the decision and I need to talk to my husband, and I need to talk to my other sister-in-law...They also want me to take a second opinion from other doctors to check if this is all fine...I am individually involved there, and sometimes it is risky to take the whole in-charge (responsibility) and I would also want somebody else [to] advise me." (P15, F, Cardiac Disease)

Decision making around their loved ones' care was a responsibility caregivers did not take lightly. When unsure, they involved more family members to allow for collective decision making was a preferred approach. The approach extended beyond decision-making, to also include collective caregiving practices. While being primarily responsible for care within their own households, they also supported other caregivers in their extended families, bringing to light how the caregivers created informal support networks with other individuals at the boundaries of their own families' health. P9, for example, described how she and her sister shared a glucometer as:

> "My sister's in-laws also have this problem, so we both keep exchanging it...She lives within my colony only...[We exchange it] once in 3 days or once in 4 days. As of now, I think yesterday, my sister has taken it and gone...It is mine only, but because her mother-in-law [has] come over, she has taken it." (P9, M, Diabetes)

When reliance on extended family members for support was not a viable option, participants described an alternative support network they had created, consisting of friends and neighbors to assist in ensuring continued care for their loved ones. The support network, in this case, was to ensure the care of their own loved ones indicating how caregivers were leveraging their boundary identities outside the home to ensure care within the home. P20 explained how his friends filled caregiving gaps for when he needed to be away for work. P2's parents needed constant monitoring and time-sensitive interventions in case of emergencies. For such situations, he had enlisted his neighbors to provide this support. He explained:

> "...actually look, my parents are my responsibility. So we have to do this, but sometimes if we are not available for any moment...due to any work or any pressure...my neighbors are also aware about these procedures" (P2, M, Asthma)

Finally, the participants reported having used, or at least considered using, home health care services to assist in their caregiving. P10, for example, mentioned that they signed up for 'Nightingale' services to have doctors visit their homes for consultations. However, they stopped short of including professional caregivers (like home health aides [71] or nurses) into their home support network. Justifying this distinction, P3, who also used 'Nightingale' services, brought up a lack of trust in complete outsiders entering the home. P14 noted financial as well as emotional reasons for not recruiting external help:

> "[I would not prefer that] mostly because of financial issues. We have to afford them…I think there is no substitution for the caregiver. I am not [going to be] satisfied if someone is there in my position and if they give care to my mother." (P14, M, Cardiomyopathy)

4.3.2 Online Communities and Online Resources. With the increasing ubiquity of online interactions, caregivers spent more time in online spaces, like medical fora, blogs, and video archives in their capacity as patients' proxies. Online communities, on Facebook and WhatsApp, served as another resource that caregivers leveraged when they had questions and needed community guidance. Engagement behaviors in these spaces varied, with most participants being passive information seekers in these spaces. That is, their engagement was limited to observing interactions and learning new ideas. Only few reported being more active members of these communities by contributing back to them. Active information seeking largely took the form of Google and YouTube queries. All participants reported having used Google at some stage of the caregiving journey for activities like looking up recipes to cook, information on side effects of medications, and making sense of diagnostic reports. A characteristic of these spaces that caregivers had to contend with as they attempted to leverage it towards care, was its immeasurable vastness. Going online to search for health information typically led to participants being bombarded with information that they then had to critically evaluate. Describing challenges he faced in the process, P7 said:

> "sometimes what I do I just Google it…and check it what is the use and what is the benefit…when you go to YouTube [and search for] this, you get lot of information and the thing is that we get confused like, 'who is saying right [things] and who is saying wrong [things]?' …So, sometimes the thing is that get misinformed. [We wonder] whether to listen to them, or whether to not listen to them. So, that is the crucial headache for us…See sometimes we cannot depend upon Google also because they are not doctor." (P7, M, Diabetes)

In seeking information from online resources to care for their loved ones, one of the primary intermediary responsibilities caregivers described was that of assessing the veracity of the information they found. The participants noted that there was a lot of health misinformation online that they had to filter out before incorporating useful information into their daily routines. We note here that this spotlighted their presence on the boundary between all three social worlds they navigated. They needed to leverage their health expertise towards sensemaking of information in online spaces, all in service of their caregiving responsibilities. Examples of misinformation they came across included spurious home remedies, unverified medication recommendations for COVID-19, and super-foods for people with diabetes. Alternatively, participants indicated reaching out to *"experienced persons, some elders in your family" (P10)* as basic and trustworthy sources of information. These individuals would have been through similar illnesses, P10 explained, and their lived experience would serve as accurate information.

By and large, the mechanism caregivers employed to receive trustworthy health information was directly reaching out to individuals they considered as more expert than them, reaching across their social boundaries. These individuals included their doctors, and elders in the family. P1 said,

"sometimes doctors will tell us not to see on the internet, so much wrong information. It is very true actually... whatever I was having doubt when I search on the internet, [when] I used to consult the doctor, he used to clarify the doubts about information I had." Verification with doctors, however, introduced latency in their ability to act on this information because these topics were not included in off-schedule conversations with doctors. As a result, much of this expert verification was only possible in routine quarterly consultations, delaying adoption of potentially useful behaviors. Through viewing caregivers in this light, as boundary actors between between their own communities and the patient, we surface the ways in which caregivers draw on these resources at their disposal to assist in care intermediation.

5 DISCUSSION

Our findings offered insights into how caregivers played instrumental roles in intermediating care for their family members suffering from chronic ailments. From facilitating and participating actively in patient-doctor interactions, to tracking patient health while navigating cultural expectations at home, to using online resources and online communities for support along the way, we shed light on their lived experiences in these different worlds. We identified how caregiver presence in these worlds was shaped by power relations, how these caregivers manipulated these relations towards better care for their loved ones, and where they faced challenges in doing so. Drawing from these findings, we now argue the benefits of viewing caregivers as central stakeholders, potentially empowered to effect change in a patient's chronic care. In support, we leverage the lens of *boundary actors* [57] to unpack how caregivers acted as intermediaries along the boundaries separating their loved ones, healthcare providers, and online spaces in enabling improved health outcomes. We then provide design recommendations for technologically supporting caregivers in intermediating patient-centered care. Lastly, we posit that situating caregivers more prominently in the patient's care ecologies uncovers promising insights towards strengthening patients' pathways to care.

5.1 Navigating Boundaries: Patients and Healthcare Providers

Our study shed light on how caregivers were directly involved in intermediation work along the boundary between patients and their healthcare providers. They were effectively proxies for doctors in the home, providing care and monitoring patients' health. They were proxies for the patients in consultations, advocating for the patients' health. From health tracking and self-management (*e.g.,* [11, 45, 55, 78, 100]), to having remote consultations with the doctors [10, 34], caregivers played critical roles in facilitating patients' engagement in their own care. As these remote care activities became more sophisticated and technology-dependent, caregivers took on newer responsibilities to keep abreast of these changes. This was particularly true in light of the COVID-19 pandemic, and heralded shifting trends in healthcare interactions in the future. In our participants' remote consultations, our findings showed that a lack of experience, and a perceived lack of expertise as a result, in intermediating on behalf of the doctors may have led to unsatisfactory experiences. With a rapid shift to remote care, caregivers received neither training nor feedback on performing new tasks during consultations, like capturing audio and video recordings of medical history and symptoms. The lack of a feedback loop, compounded by the learning curve associated with their new roles in teleconsultations meant that caregivers spent additional time and resources intermediating the interaction. As a result, they found themselves unable to do justice to their roles as boundary actors between patients and healthcare providers during remote consultations.

Our findings highlight specific situations that could be addressed through design interventions. Designing for caregivers who are making a switch to remote care could include *educational training content, technology assistance, and expert feedback mechanisms* to enable them to upskill to go along with these shifting trends in healthcare. Training content could cover topics like assisting

during patient-doctor consultations through better videography, and hands-on home care tasks, like administering insulin injections, where caregivers are untrained. Such training content with a feedback mechanism could serve to ameliorate any concerns arising from a perceived lack of expertise among caregivers. Mobile technologies could be designed to assist in these new roles, leveraging augmented reality or computer vision methods to signal focus areas to caregivers. Involving experts, like doctors, in the design of these artifacts could both leverage their expertise and add authenticity to this training and feedback content, and also allow for lesser doctor involvement in the patients' self-care in the long term [70].

Within HCI, and in the personal health informatics community in particular, collaborative health tracking has been proposed as a means to include caregivers (*e.g.,* [11, 55, 78]), and other interested stakeholders (*e.g.,* [8, 9, 79]), in a patient's care. Recent work found that caregivers perceived a greater value in manual tracking as it led them to more intentionally observe their loved ones' self-care mechanisms, and consequently allowed them to care better [104]. In a later work, the authors noted that allowing caregivers from different families to share such tracking data with each other engendered both a sense of community for the caregivers, and allowed for new means of caring through sharing other patients' care journeys [105]. Our findings pointed us to the different ways in which caregivers manually collect, curate, and manipulate this data on behalf on the patients, to inform their consultations with doctors. Crucially, caregivers' practices were not restricted only to data collection, but also included sensemaking within their ability as a *proxy* for the healthcare providers. That is, they reviewed their loved ones' medical reports and intervened in the form of changing diets and lifestyle regimen to address abnormalities identified in the reports.

Our findings identified existing pain points in patient health tracking as well, with caregivers managing unstructured data like infrequent glucometer readings; and paper-based reports that required manual data entry for any form of data analysis. Caregiver-focused design interventions to address these pain points could include improved collaborative tracking mechanisms that integrate patient-generated health data [33] with caregiver-generated data and diagnostic lab data to inform better insights into the patient's health. The value of this integration in clinical settings have been extensively studied in the past, primarily in aiding communication among patients, caregivers, and doctors (*e.g.,* [45]), as well as doctors' care provision [11]. However, leveraging caregivers' boundary identities as proxies for doctors, we argue that such integration would allow for caregivers to take consistent data-driven decisions towards their care responsibilities like frequency of testing and patient-doctor interactions, and modifications to diet and lifestyle activities. A further benefit of progress in this direction would be workflows to digitize diagnostic reports and integrate them as a part of a patient's compiled medical record. Such digitization could open up information visualization research and design avenues to create visualizations tailored for assisting caregivers—reading and making sense of reports currently—in performing their responsibilities, and allowing for improved health literacy among patients and caregivers. These could also serve support communication and collaboration in clinical interactions, going beyond current practices.

5.2 Navigating Boundaries: Internet-Assisted Caregiving

Technology integration into care interactions has seen a gradual rise in prominence in the Indian healthcare context, and has effected changes in the interaction dynamics among stakeholders in care. Chandwani and Kulkarni studied patient-doctor interactions in India in 2016, and identified the tensions that stemmed from patients being internet-informed and bringing counter-questions to these conversations that traditionally had a uni-directional information flow from doctors to patients [17]. With internet usage rising among the masses, they recommended changes to doctors' roles in patient-doctor interactions: away from being the sole experts in the room, towards being 'warm experts' who contextualize and verify patients' queries that originated from online information

seeking. Building on this work, Bhat and Kumar identified the roles family caregivers played in mediating this online activity by taking on information seeking responsibilities from the patients and providing relevant information when necessary [11]. This, they found, afforded lowered tensions in patient-doctor interactions likely due to their presence on the boundary between these two stakeholders. Extending this work, our findings showed that caregivers were constantly involved in online information seeking in service of their caregiving needs. This knowledge gathering influenced every aspect of the patient's care journey. We argue that the internet, reported by prior work as an inconvenience in patient-doctor interactions, is increasingly an inextricable component of these relationships. With all three stakeholders—patients, caregivers, and doctors—needing to contend with this changing dynamic, caregivers' responsibilities on the boundaries of these worlds comes to prominence.

We presented the many ways in which caregivers are leveraging their boundary identities: their expertise akin to healthcare providers, their knowledge of the patients' health and day-to-day lived experiences, and their presence in multiple physical and online communities outside the home towards care provision for their loved ones. We identified the prominent roles technology played in mediating and altering the dynamics of these interactions, particularly as remote care became an increasingly widespread experience. Of particular interest is a fast growing sector of online health products targeted at supporting patients in their care-seeking and management. Among several similar platforms, Practo, Tata 1mg, and others are positioning themselves as one-stop shops for healthcare online in India, offering ways of locating doctors, schedule teleconsultations, fill prescriptions, search for health information, and engage in discussions in fora with other patients and doctors. Our findings directly showcased how patients' use of these platforms was frequently mediated by caregivers who were more technologically savvy and were better positioned to communicate the patients' healthcare needs. The design gap, then, is that caregivers' needs are underrepresented in the designs of these patient-focused technologies.

Centering caregivers in the design of these online health technologies brings alternate considerations to the fore. Drawing on our findings, we recommend designing caregiver-centered online health communities, like online fora that afford caregiver collaborations and streamlined interactions with healthcare providers in a group setting. The former would enable access to communities of caregivers for similar conditions and create learning environments for new members of the community. Challenges impacting existing online health resources, like those of mistrust and misinformation (*e.g.,* [10]), would still need to be addressed within such communities. We propose that involving doctors (or other medical/health experts) in the community might directly address these concerns and the existing bottlenecks our findings identified in care provision, as the caregivers could more quickly verify, validate, and act on new information. In making these recommendations, we draw attention to the fact that such caregiver communities already exist, comprising primarily of caregivers' social and professional networks as we showed in our findings. We argue that larger scale online communities stand to contribute more towards information triangulation and cross-cultural knowledges around caregiving.

5.3 Identifying Design Pathways: Revisiting Patient-Centered Care

Traditionally, patient-centered care aims to improve quality of healthcare provision [47] by means of increased patient engagement and the use of information and communication technologies in care delivery [29]. Centering patients in this paradigm provides them a greater responsibility in making choices regarding their care by leveraging information technologies. Within HCI, research on patient-centered care has largely focused on personal health informatics (*e.g.,* [23, 25, 52]) and patient engagement technologies (*e.g.,* [42, 65]). These approaches, however, also carry implicit assumptions about the roles of other stakeholders in the care management. Increased patient

involvement in care has come with diminishing long-term responsibilities for healthcare providers [36], with recent research pushing for further control residing primarily with patients [70].

Recognizing other stakeholders in the ecologies of care, researchers have also studied the roles of family caregivers in *supporting* patient-centered care (*e.g.,* [97, 98]). Labeling caregiver responsibilities during a patient's hospital stay as 'companion, assistant, representative, navigator, and planner,' Miller et al. provide a rich description of the different ancillary roles caregivers played [62]. Similarly, Gutierrez and Ochoa studied the culturally situated supporting role caregivers of older adults—as assistants, monitors, and helpers—in Latin America [41]. In unpacking these supportive roles and their effects on caregivers, researchers have focused specifically on caregivers' day-to-day experiences, identifying gained expertise, social isolation, and caregiving burdens as major components of their experience [86], and the different ways they strike a balance between care provision and other aspects of their lives [20].

Our research seeks to complement this body of work by recommending a shift in focus to caregivers as *intermediaries*, as opposed to ancillaries, within a patient's ecologies of care. We expand on the recent framing proposed by Foong et al., who studied family caregivers as *proxies* to patients during remote home assessment for occupational therapies [34], and Shin et al. who proposed an assets-based approach to incorporating caregivers' knowledge and expertise into technology design [91]. We further build on Schurgin et al.'s discussion of care coordination challenges, where they proposed a shift in perspective from 'designing for the user' to 'designing for the relationships' in mediating care coordination [88]. We predicate our argument on the basis that caregivers are strongly intertwined in the patient's care management, and that therefore patient-centered care must not minimize their presence in the care ecology. Our findings showed how caregivers were not only facilitators in patient-doctor interactions and at-home care, but also actively involved as *decision-makers* in their loved one's care across the different phases of the care seeking journey. They were responsible for decisions around initiating contact with doctors, choosing doctors, and enabling quality care in the consultation. Patient-doctor interactions, like every dyadic interaction, have unique, socioculturally defined power dynamics associated with them. In the Indian healthcare context in particular, prior research has found them to be significantly skewed, with the doctor—the expert—having much more power in the relationship [11, 17]. Caregivers' prominence in this dyad—at the boundary between these two parties—is crucial, yet it remains typically invisible as they are absorbed by the cumulative 'Patient'. Initiating a shift from this perspective, prior work has presented the manifestations of patient empowerment in this context by identifying the ways in which patients and doctors leverage caregivers in patient-centered care [11]. Disentangling caregivers from this cumulative 'Patient,' to instead view them as powerful, intermediating stakeholders in the patient-caregiver-doctor triad could open up avenues for envisioning patient empowerment approaches that more impactfully leverage caregivers' positioning in the patient's care ecologies (as evidenced by prior HCI work in the US context [49]). Next, we propose one approach in this direction.

5.4 Identifying Design Pathways: Supporting Caregivers as Pathways to Care

Given the caregivers' positioning in their families and the healthcare system as *intermediaries* in care, we argue that they could comprise an untapped pathway to care for their loved ones. Pathways to care, or treatment-seeking pathways, have primarily been studied to identify the various ways in which patients are able to access healthcare [38] that include navigating referral-based healthcare infrastructures [59], and more informal healthcare contexts in India leveraging neighborhood doctors [15] and with financial and caregiving support from friends and family [74]. Much of the focus has also been on factors that hinder access to care and how they can be diminished. The research identified various sociocultural barriers to care seeking like gender

[59, 66, 77], stigma around mental health [76], and financial constraints [84]. These works point to a range of reasons that *patients* with chronic diseases like tuberculosis and diabetes employ in delaying care or avoiding it altogether. We note from our findings, however, that though self-care was avoided, caregivers considered themselves duty-bound to ensure their loved ones received care when required. We showed how this sense of duty potentially stemmed from sociocultural expectations on caregivers to provide care for others in the family. We propose that viewing, and empowering, family caregivers as pathways to care could result in improved care adherence and better overall health outcomes.

Our findings summarized responsibilities, expectations, and burdens that fell on caregivers within our context of study. Caregivers took on at-home management responsibilities like tracking, maintaining health records, medication adherence, and home treatments. They also carried the burden of societal expectations on them to make affordances for caregiving. Further, caregiving was associated with a strong gendered stereotype with our findings indicating that women inherited at-home caregiving responsibilities primarily by virtue of their gender. Additionally, caregivers generally bore the financial responsibilities for their loved ones' care, which we found was sometimes at the expense of their own health. However, within the bounds of these cultural expectations, we found that caregiving itself sometimes became an act of resistance against this imposition. Caregivers leveraged their responsibilities to question and break cultural expectations and increase their agency in the home. Taking on caregiving and stewardship (*e.g.,* [68]) roles for their elderly family patriarchs counterbalanced the previously uni-directional power relationships. We draw specific attention to these relationship dynamics that caregivers contend with in their boundary roles. These overarching power dynamics affect caregivers' experiences and decision-making as they balance self-care and care for their loved ones. Long-term studies of these relationships could allow for a better understanding of how best to support and design technologies for caregivers in patient-centered care. This could point to sociocultural factors incentivizing care seeking for their loved ones, highlighting the potential of caregivers in serving as pathways to care.

One design approach towards supporting caregiver-pathways to care would be introducing health educational campaigns and preventative health tracking initiatives for non-communicable chronic diseases with language targeted at caregivers. As earlier stated, cardiovascular diseases, diabetes and other metabolic conditions are the leading causes of death and disability in India [72, 73]. Interventions recognizing and acting on caregivers' decision-making agency could potentially mobilize care seeking better than those addressed directly at the patients who have existing barriers to delay care seeking. Such an approach could not only lead to better health outcomes for the patients in the family, but also aid in identifying undiagnosed health conditions, as well as promoting preventative practices among other members of the family including the caregivers themselves.

Promoting caregivers as central actors in patients' treatment-seeking pathways does indeed bring up multiple important considerations. *First*, it could serve to potentially reconfigure the autonomy and agency of both caregivers and patients in patient-centered care. Accenting and designing technologies for caregivers as decision-makers could, if done wrong, diminish patients' agency in their own care. Indeed, the introduction of new technologies into any context introduces changes to power dynamics within it [102]. Designing to support caregivers as intermediaries, therefore, should involve a deliberate balancing act of ensuring patients' agency in care is not diminished while caregivers are supported. In our design recommendations, for example, we have focused technology design towards learning experiences for caregivers—removing barriers to caregiving and potentially enhancing the care provided. *Second*, positioning caregivers as intermediaries could potentially introduce additional responsibilities in their loved ones' care. As described in the related work, prior research has extensively documented the challenges caregivers currently face in balancing care work with other aspects of their lives [20, 53], reconciling the emotional effects of

caregiving [56], and care coordination [88, 96]. Proposing additional responsibilities on caregivers, therefore, might serve to exacerbate these burdens. In response, we point out that this related work has focused on bringing caregivers' invisible labor to light (*e.g.,* [20]) to inform the design of technologies to support them [62, 88]. Such an approach centers and problematizes caregivers' burdens and challenges. As an alternative, changing perspective and taking an assets-based design approach could help provide a different understanding of caregivers' lived experiences, and create new avenues for technology design. Recent research has taken this very stance—highlighting caregivers' situated knowledges, and making a case for system designs that leverage them as assets in support of caregivers [91]. So, by situating caregivers as intermediaries—with a focus on designing technologies to support responsibilities they are already performing—we envision that technology-mediated futures to care access could exist (*e.g.,* caregivers as pathways to care) without introducing new burdens on caregivers.

6 CONCLUSION

CSCW and HCI research on informal caregiving has foregrounded caregiver burden in clinical interactions and at home, uncovering caregivers' ancillary role in patient-centered care. We extend this research by investigating healthcare contexts where caregivers may be found to play more prominent, decision-making roles in care access and management. Our interview study presented in this paper was centered around caregivers of patients with chronic diseases in urban India, and we used the lens of *boundary actors* to highlight their care provision responsibilities and how they navigated the boundaries separating patients, healthcare providers, and online communities. We discussed the diverse responsibilities caregivers had across these boundaries as they enabled optimal care for their loved ones, sometimes at the expense of their own wellbeing. We also uncovered the challenges they experienced in caregiving, and how they could be better supported in those activities. Our research led us to argue for viewing caregivers as critical decision-making intermediaries in patients' care ecologies, and for proposing that they could be engaged and empowered as patients' pathways to care. We also provided design recommendations for sociotechnical environments to further support and enable familial caregiving.

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