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Mobile Health and the Social Organization of Care in the Global South: Beyond Technological Fixes

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Abstract

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The notion of a global “care crisis” has recently loomed large in public consciousness, drawing attention to the longstanding problem of how our care infrastructures are increasingly overburdened and unsupported. The chronic underinvestment in paid and unpaid healthcare work has been made especially clear in light of the shocks of the COVID-19 pandemic. In response to this crisis, transnational agencies, national governments, hospitals, and non-governmental organizations (NGOs) have sought to leverage increasing smartphone and mobile internet use globally to create “technological fixes” that restructure work, time, and space with the aim of meeting care needs with limited resources—this in contrast to investments that could increase resources but ultimately compromise on capitalistic aims of profit and efficiency. In this dissertation, I examine multiple types of fixes that have gotten significant traction in global health, including digital payments, personal chat apps, and semi-automated chatbots, focusing on contexts within India and Kenya. I describe care workers’ and health organizations’ experiences with these technologies and how they integrate with larger health infrastructures. Drawing on feminist social reproduction theory, I tease out ways that these technologies meet real and urgent care needs, while also belying the mere redistribution, short-term valuation, and narrowing of care work that takes place by and through

technological fixes (often most affecting those with the least power in a given context). Taking this dilemma seriously, I argue for the responsibility of researchers and practitioners to combat dominant narratives of technological fixes for the care crisis, even as we seek to support care work through design. Thus, this work considers how we might center futures of care work in which societies make concrete investments in care workers and care infrastructures, not for efficiency's sake but for the needs and aspirations of care workers and the sustainability of our care infrastructures.

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DEDICATION

To each of us fighting for the right to care and be cared for.

Chapter 1

INTRODUCTION

The notion of a global “care crisis” has recently loomed large in public consciousness. It has signaled the many ways that our means and capacities for care are being depleted, whether it is maintaining our health, providing shelter and safety, fostering community, or sustaining the natural and built environment [168]. Decades of increasing privatization, low wages, and reduction of public resources for healthcare, childcare, and education have organized societies in such a way that care infrastructures are inaccessible or overburdened, with little incentive to operate in more sustainable ways despite demographic shifts suggesting that care needs will only increase [136, 168]. It is especially unsurprising then that the COVID-19 pandemic, an acute crisis of its own, resulted in severe intensification of work for paid and unpaid care workers all over the world. Those most impacted by the care crisis across the world have consistently been women, particularly those at the bottom of race, caste, class, and other social hierarchies [619]. But as feminist scholar Nancy Fraser argues, “care crisis” is a misleading term for this decades-long, intentional gutting of our care infrastructures, and one that belies the multiple manifestations of care crises throughout history [168]. Rather, the current crisis is one of and by capitalism. Capitalism as a social organization requires care work to produce workers and maintain buy-in, but its drive towards accumulation is precisely what undermines the conditions needed for sustainable care work [168]. Thus, to think about the care crisis and the wellbeing of care workers and care recipients, means to grapple with the ways that it is subject to exploitation, and the struggles towards providing care for all.

In response to capitalism’s crisis tendencies, societies often come up with what schol-

ars have called a “fix” [204, 530]. As Harvey explains, the assumption behind fixes is that “something (a thing, a problem, a craving) can be pinned down and secured,” alluding to how society reorganizes itself to address crises through ways that seem permanent but often only alleviate pressures temporarily [204]. In the context of the care crisis, Dowling draws our attention to care fixes [136], or attempts to “solve” parts of the care crisis by reorganizing and displacing care work, whether it is technologically, geographically, or financially. This is in contrast to actually resolving the tension between care and accumulation by reducing focus on profit and efficiency, and instead meeting the demands of many care workers across the world for better working conditions, social protections, and other policy-level changes [7, 70]. The conversation around technological fixes for the care crisis in healthcare has become more prominent with the rising uptake of smartphones and mobile internet globally, development of artificial intelligence (AI) and data-driven technologies for healthcare, and pressures to digitize healthcare due to the COVID-19 pandemic. Technological fixes by themselves are not necessarily inherently good or bad but can become part of design narratives that suggest how we should go about addressing the care crisis and who or what care work can be displaced to [136].

Design narratives on the role of technology in healthcare work have been divergent. On one hand, there are claims that technology can reorganize care workers’ time, freeing up or reducing time taken by certain tasks so it can be spent on something else. In the development space, transnational and third sector organizations such as the Gates Foundation, USAID, and World Health Organization (WHO) have increasingly funneled funding and programming towards addressing the burden of women’s unpaid care work, time poverty, and gender equity in the health workforce [172, 580, 64]. Technologies proposed to aid these efforts especially in the Global South include digital financial services, conversational agents, or diagnostic and predictive tools intended to reduce work burden, and offer pathways to more efficient health systems and increased access to quality health information and care (e.g., [580]).

Critiques of technological fixes for care work insist on understanding how technol-

ogy engages with the complex, situated process of caring, and asking the “who” questions [389]—that is, who do technologies ultimately serve and who decides which ones get designed or adopted? Scholars have argued that it is important to remember that the need for technological fixes arises out of chronic underinvestment in human and material resources in healthcare [136], and in many cases, technological fixes justify further underinvestment (e.g., [324, 49, 277, 207]). For example, prior work has shown how for decades, in trying to get women into the workforce while also addressing care needs at home, the World Bank has prioritized time-saving technologies and programs to get men involved in care work, over maternal leave and childcare policies since the latter have less productivity benefits [49]. Technological fixes can also actively engender harms. Early work in the field of Computer-Supported Cooperative Work (CSCW) and plenty of research since then has demonstrated that technology ranging from electronic patient records to predictive tools are often unaligned with existing workflows in nursing, community health, and home care (e.g., [592, 237, 343]). Technology can also reduce autonomy and create the need for workarounds [108], whether through monitoring or attempting to funnel complex workflows through inflexible interfaces. These technologies often serve the needs of administrative actors more than care workers [542, 592, 453], speaking to the ways that deployment of technology takes advantage of the devalued and expansive nature of care work to push organizational needs onto women care workers.

Considering these multiple and divergent roles technology plays in the politics of care, it has become necessary for researchers, designers, and practitioners to think about how we organize care within societies, by whom, for whom, and how technology interacts with the structure and stability of this organization. This brings to light questions around political aims—even if technology might meet immediate care needs, what is the role of researchers and practitioners in long-term investment into resources for care work? This line of inquiry is also valuable simply because the politics of care is a starting point for thinking about equity and wider anti-systemic struggle [54]. If care workers

are mostly women, understanding the effects of technology in care work means understanding the effects of technology on women's working conditions. If care work is foundational to human survival, understanding the role of technology in care work shapes how human rights, like healthcare, food, and water, are provisioned.

My dissertation work takes steps towards grappling with this question by examining how emerging technologies are shaping the work of (mostly women) healthcare workers in multiple, distinct sites within India and Kenya. I examine two threads of the development project. I start with *digital financial services*, focusing on the use of digital payments in community health systems. I then delve into the increasing popularity of *chat-based health interventions*, looking at the use of chat apps for healthcare communication and provision. These interventions range from organizationally mandated and worker-driven adoption, to small-scale research pilots, to scaled services integrated with public health infrastructures. I attend to workers' experiences, organizational priorities around the use of these technologies, and how these interventions are sustained within health systems. This allows me to uncover how technological fixes, despite seeming to fix or pin down problems in one frame of view, still unevenly impact work burden and care needs beyond that frame, opening up a discussion of the responsibility of technology researchers and practitioners in futures of care work.

In the rest of this chapter, I offer context for healthcare infrastructures in India and Kenya and how centering perspectives from the Global South develops the conversation on technology and the politics of care. I then describe the theoretical framing this dissertation draws upon. I end with a summary of the contributions of this dissertation to conversations on futures of care work and a roadmap of the remaining chapters.

1.1 Care Work in/for Global South Contexts

In the fields of Human-Computer Interaction (HCI), CSCW, and Information and Communication Technologies and Development (ICTD), where my work is aligned, relatively

early research in the Global South on healthcare and labor sought to support specific tasks that care workers are assigned, for example the data collection or information dissemination responsibilities of community health workers (e.g., [122, 124, 377, 288]). In adjacent fields, such as Science and Technology Studies (STS), much of the research has focused on exploitative relations between the Global North and Global South. As liberal feminist movements encouraged the participation of women in the Global North in the paid labor force, we've seen extensive work on care chains, where the care burden in Global North contexts is being displaced to low-income, migrant, and women of color, in turn destabilizing care within these women's communities and countries [435, 643]. We also see a focus on reproductive technologies and global capitalism, such as commercial surrogacy and human milk banking (e.g., [590, 432, 405]), and their role in commodifying bodies, particularly of vulnerable populations. However, as Amrute and Murillo argue in "Computing in/from the South", moving beyond developmentalist frameworks and the binary of exploitation and resistance in relation to the Global North is important for understanding women's varied struggles and social hierarchies within Global South contexts [23]. Raghuram also discusses the need for studying care at local levels, as situated in local economic and political systems, culture, and social stratification, to more completely understand care at a global level [465]. More recently, there has been growing interest in the politics of care work and technology within contexts across the world. A CSCW workshop that colleagues and I held in 2021 [258] drew a significant number of researchers looking at power dynamics and organizing efforts of care workers in domains like health, home care, domestic work, and education, diversifying from seminal work on professionalization of nursing in the Global North and signaling the urgency of building transnational solidarities across the struggles of care workers.

Focusing in on healthcare work in India and Kenya offers the opportunity to understand the very different but shared struggles of care provision in multiple contexts within the Global South. Health systems in these countries must be historicized in processes of colonialism and neoliberalism. Structural adjustment programs have directed

Global South countries post-independence to implement measures like user fees and use their budget towards servicing debt, rather than social programs, resulting in greater privatization of healthcare, a weak health workforce, and continued underinvestment [488, 30]. Both India and Kenya have had chronically low health expenditure as a percentage of GDP, and provision of care is split across public, private, and third sector institutions and financing [570, 99, 387]. Both countries have decentralized healthcare systems, with variations in implementation across states or counties, but with a tiered structure of public facilities covering primary, secondary, and tertiary care. In India, government facilities, including maternal health services, are free for all citizens. However, a range of issues including staff and supply shortages lead a significant portion of the population across urban and rural areas, especially those who are upper- or middle-class, to seek care at private facilities. The government provides insurance schemes to cover secondary and tertiary inpatient care for sections of society such as low-income earners. In Kenya, low-income groups also tend to rely on public healthcare more, and user fees have been abolished for public primary care and for maternal health. Insurance is provided by the government across formal and informal sectors with progressive contribution rates, but overall it covers a small part of the population [266]. Both countries employ community health workers, who fill in gaps in the public health system by engaging their communities to support the uptake of health practices among families.

Both countries face a shortage of healthcare workers, including nurses and doctors. In Kenya, health workers are unevenly distributed across counties and rural and urban areas. There have also been regional and national strikes by nurses and doctors as a result of poor working conditions, mismanagement of the transition to decentralized healthcare implementation, and unmet conditions of bargaining contracts [593]. Similarly, India faces health worker shortages and uneven distribution across states, exacerbated by international migration of doctors, nurses, and medical students [256]. In both countries, women are most highly represented in professions lower in the healthcare hierarchy such as nursing and community health work, receive no or lower pay, and

endure lack of respect in the workplace and within their communities.

The threads of technology interventions that I examine in this dissertation—digital financial services and chat-based health interventions—capitalize on the market forces, regulation, and increasing uptake of smartphones and mobile data that have made apps and platforms critical infrastructure in India and Kenya. The financial inclusion assemblage [516], composed of development agencies, companies, and universities, among others, has been driven by the idea that uptake of financial services among the poor is key to development. In healthcare, digital payments, such as bank payments and mobile money, have been proposed to pay health workers faster, potentially reducing the queuing times for payments and easing the logistics of payments at scale in health systems (e.g., [484, 37]). Personal chat apps, especially WhatsApp, have also become more pervasive, leading to not just the everyday appropriation of chat apps for healthcare communication and provision but also business solutions for managing semi-automated two-way communication and client information [1, 2]. This infrastructure has culminated in the use of chat-based health interventions at scale among hospitals, NGOs, and development agencies. Chat has been proposed to integrate work communication with health information systems [209, 2] and support automated information dissemination and behavior change, while allowing health workers and organizations to more easily reach care recipients [580]. However, empirical research on how these technologies are being utilized and how they are actually shaping paid and unpaid care work is nascent. To address this gap, this dissertation centers around the following research questions:

- What emerging technologies are being introduced in or for paid and unpaid care work in health in parts of the Global South and why? How are they designed and implemented and why?
- In the context of already strained health infrastructures, what are care workers' experiences with technology interventions in their work? What are some of the cultural, political, and economic factors that contribute to these experiences?

- What are some considerations for designing sociotechnical systems for more sustainable care infrastructures that meet the needs and aspirations of care workers and care recipients?

1.2 Studying Emerging Technologies in Care Work

To think about the tensions between why technology is deployed in care work and care workers' experiences, I draw on Michelle Murphy's work on the logic of population, contrasted with the notion of distributed reproduction. In *The Economization of Life* [392], Murphy analyzes the ways in which states and transnational and non-profit organizations create regimes of valuation in which lives are valued differently and managed accordingly so as to achieve particular rational, economic aims. Her analysis draws on the connected histories of the rise of GDP as a (flawed) measure of economic activity, coercive postcolonial family planning efforts, and "Invest in a Girl" campaigns that position girls' education as investment into their future utility to their communities, nations, and global development. By tracing this history, Murphy points out how these managerial forms of "care" are not inevitable, but rather constructed. She points to certain concepts that help in this construction and naturalization, including *epistemic infrastructures* and *phantasmagrams*. Epistemic infrastructures are processes of knowledge production that are used to justify and consolidate material realities, such as standards, technologies, funding flows, affective orientations, and power relations. Phantasmagrams account for the ways that materials, figures, and practices are affectively charged, which helps them create imaginaries and feelings, having effect beyond their "rational precepts" [392].

Following this account of how logics of population have become extremely pervasive, Murphy shows that the care infrastructures formed on the foundation of "population" have been narrowly concerned with "*the governance of quantity and quality, foreclosing questions of the infrastructural distribution of life chances, pasts, and futures,*"

[392]. She argues that instead, we might expand our relationship to care through the notion of distributed reproduction, or “*the extensive sense of existing over time that stretches beyond bodies to include the uneven relations and infrastructures that shape what forms of life are supported to persist, thrive, and alter, and what forms of life are destroyed, injured, and constrained,*” [392]. The juxtaposition of population and distributed reproduction allows me to ask the following questions to analyze my findings: What rational plans and aims do organizations have? How are they justified and animated? How does this all compare to care workers’ lived experiences with technological change? What can we learn about the design and impact of technologies for care work by centering distributed reproduction?

In the following chapters, I draw on a range of qualitative methods—interviews and focus groups, observations, analysis of chat records and other artifacts—to describe healthcare workers’ experiences with technologies across four sites. In chapters 2 and 3, I describe technology adoption in two contexts: the top-down use of digital payments to pay community health workers in rural Kenya [257] and the bottom-up adoption of WhatsApp for communication in nurses’ work in a hospital in urban India [261]. In chapters 4 and 5, I continue following the thread of chat-based health interventions in two contexts: facilitated WhatsApp-based peer support for youth living with HIV in urban Kenya [259], and a semi-automated chatbot for maternal and child health information serving families across six states in India. These sites allow me to consider the use of interventions in a range of organizational contexts such as public health infrastructures, private hospitals, research pilots, and NGOs. Considering these are all key actors in health systems, examining each context helps bolster understanding of how factors such as funding flows, profit incentives, organizational culture, and strategies to manage workers compare and contrast as they help justify and shape technological fixes. In each case, I also attended to the specificities and conditions of different types of paid and unpaid care work, including that of community health workers, nurses, parents, and care workers who engage with beneficiaries virtually. Looking at different types of

care work helped uncover how experiences with technology interventions are shaped by varied personal motivations and stakes, situated practices, cultural meanings, and resources available for work, while still drawing attention to repeated dynamics of the devaluation of feminized care work and what implications they necessarily have for technology design in this space. Finally, the studies also enable me to think about the effects of scaling technology interventions by examining adoption at the level of small communities, as well as large organizations and infrastructures. Understanding these dynamics is crucial, as scale and efficiency are often ways to do more with limited resources, but present tensions with the situated practice, relationality, and conditions of care work.

1.3 Outline and Contributions

In my examination of technology interventions in healthcare work, I describe the tensions between the rational aims and even benefits of deploying technology, and the ways that technology acts as a mere fix, obscuring the continued overburdening and inequities that care work is subject to. Ultimately, I argue that maintaining sight of structural issues affecting care work is important to combat dominant narratives of technological fixes for the care crisis and stand in solidarity with political struggles towards greater valuation of care work.

Chapter 2 sets the stage for the tensions between organizational and worker perspectives and the importance of attending to distributed reproduction in understanding the effects of technology interventions. We describe a qualitative study of a community health infrastructure in a county in southwest Kenya, where local health organizations pay health workers' salaries via digital payments, backdropped by ongoing issues with missing and delayed payments. We describe how digital payments benefit organizations in terms of logistics, but have varied and uneven impacts on health workers, affecting those at the bottom of the healthcare hierarchy the most. We also highlight the logic of population in how workers at the bottom of the hierarchy are positioned in ways that

justify unpredictable pay, further contributing to challenges of working amidst missing or delayed payment. We end with a discussion of how centering distributed reproduction helps account for the widest impacts of technology interventions, and ways that the externalities of interventions can be collectivized, rather than placed on workers.

Chapter 3 starts to look at chat interventions in healthcare, and in contrast with Chapter 2, examines a case of worker-driven adoption. We conducted an ethnographic study of the adoption of WhatsApp in nurses' work in a large multispecialty hospital in urban South India. We uncovered how chat is embedded in the uneven power relations of the nursing hierarchy, serving the communication needs of senior nurses but creating off-shift, invisible work for those lower in the hierarchy. We also tease out the logic of population in the hospital's desire to monitor and control hospital communication due to privacy concerns and how this contributes to dynamics of invisible work. We end with a discussion of how centering the situated practice of feminized care work and the power dynamics that it is subject to complicates even worker-driven adoption of technology interventions.

Chapter 4 goes on to examine chat-based interventions for easing patient-provider communication in the context of a six-month research pilot, offering the opportunity to reflect on the relationship between care, scale, and the valuation of care work as interventions are integrated into public health infrastructures. We analyzed interview data and chat records from a six-month pilot of chat-based facilitated peer support for youth living with HIV in urban Kenya. We describe the labor of the facilitator in fostering a supportive environment for youth, and how this nurtures the link between youth's aspirations and behavior such as adherence. We discuss opportunities to scale such interventions but also draw on distributed reproduction to resist a sole focus on scale-thinking and center the working conditions of care workers and sense of community that was essential to the intervention.

Chapter 5 then explores chat-based health interventions at scale, further demonstrating that the valuation of care work matters greatly to the success of technology in-

terventions and that being responsive to the complexity of care work is essential. We conducted a study of an NGO's patient education service, where parents are trained by nurses on maternal and child health caregiving at district hospitals and can then register for a WhatsApp chatbot where dedicated nurses can answer questions. We describe how opportunities for more decent and valued work garner the nursing labor that makes this intervention possible. This chapter also centers the unpaid care work of parents who use the chatbot, unsettling the rational behavior change goals of the intervention to visualize the appropriation of the chatbot to navigate structural complexities and inequities within the health system. We further critiques that call for recognition of the relational work that makes technology work, and describe takeaways for being responsive to the structural aspects of caregiving.

In chapter 6, I draw on the studies as a whole to summarize the contributions of this dissertation: a rich description of women's care work in parts of the Global South, the role of technological fixes in complex health systems, and an expansion of the relationships within research and practice that are relevant to futures of care work.

Chapter 2

DIGITAL PAYMENTS IN COMMUNITY HEALTH AND THE COSTS OF EFFICIENCY

In 2018, my lab was funded by the Gates Foundation to study digital financial services. First launched in 2006, the Gates Foundation's financial inclusion initiative centers on including the poor in formal financial services, partially through digital payment infrastructures that are physically accessible, usable, affordable, and advantageous compared to cash. These systems ostensibly enable people to save, take out loans, or buy insurance, presenting pathways to economic empowerment via entrepreneurship and being able to handle financial shocks. For example, the United Nations Better than Cash Alliance, a partner of the Gates Foundation, claims that the introduction of digital payments single-handedly put a stop to health worker strikes in Sierra Leone during the 2014 Ebola virus epidemic [37]. Investigative reports show that it was, of course, a much more complicated story of lack of back pay, continued strikes, and the overall deprioritization of hazard pay for frontline workers in the public health response [524, 352].

It was an opportunity to better understand the realities of digital payments in care work then, when Medic Mobile, an NGO operating in parts of East and West Africa and South Asia, approached us to conduct an exploratory study of community health workers' experiences with digital payments in rural Kenya. Medic Mobile creates and supports open-source technology projects that aid care coordination, community health feedback loops, and more. As an NGO that works with and pays health workers, their interest was in understanding the relationship between payments and worker motivation and potential opportunities for design to support community health. In one particular conversation with Isaac, the research lead at Medic Mobile, I was trying to gain more

context for the community health ecosystem in the county where we would be conducting the study, and I learned a crucial piece of information. He noted that missing or delayed payments, from the county Ministry of Health (MoH) or NGOs, are common in the area even with digital payments and that it would be important to consider this in the study design. I began to think not just about *how* digital payments were being used, but *why*: What does it mean to be using digital payments in the midst of such significant payment issues? What was this technology supposed to accomplish then and who does it serve? How do digital payments interact with the challenges of work without pay?

In this chapter, we consider these questions through an investigation of how community health workers responded to the changes and precarity brought about by mandated use of digital payment methods by employers and ongoing payment delays. We interviewed staff from the MoH and NGOs, community health volunteers (CHVs, who were “paid volunteers” in this context), and contracted/salaried workers, such as community health assistants (CHAs) and nurses. We explored how and why the MoH and NGOs set up workflows for digital payment methods, in contrast to previous cash-based payments. We also attended to workers’ perspectives on digital payments and how they coped with the stresses of payment delays and missing payments. Drawing on notions of population and distributed reproduction, we look at the extent to which digital payments support organizations’ rational aims of managing cash flows and human resources. We also attend to the varied infrastructures, identities, and relationships that converge to shape health workers’ everyday experiences with digital payments, positively or negatively. We find that while organizations use digital payments to address fraud and safety concerns and move large amounts of money around faster, some costs of using digital payments are then borne by health workers, particularly CHVs who are paid a low stipend, or those who live in more remote areas. Drawing on the role of epistemic infrastructures and affect as Murphy suggests, we also consider how the discursive and material production of some workers as contracted and salaried and others as volunteers, shapes the challenges and recourse that workers have with digital payments

amidst payment delays.

Through these findings, we connect to the growing body of work in HCI and CSCW on designing to support resilience and struggles towards wellbeing by leveraging community assets. Within this rich body of work, studies have focused on the actions that people take to be resilient [330, 239, 240, 283, 472], how technology design can support those actions [591, 333], and how resilience, particularly innovation, among marginalized populations should be recognized and legitimized within CSCW and HCI [11, 240, 625]. However, prior work has hinted at the cost of resilience as well. Studies of the frustrations behind necessity-driven entrepreneurship [225], the competitiveness and undervaluation of repair work [11], or the gendered nature of creative infrastructural action [239] all begin to point to how enacting resilience can have both positive and negative impacts. Literature on resilience [50, 113] calls for greater attention to the broader impacts of being resilient, as well as how “the gains and losses of adaptation, and being part of a resilient system, are distributed within society” [113]. By centering the specificities of care work in community health and an understanding of distributed reproduction in the implementation of technology interventions, we describe takeaways for how we can think about the complexity of assets and the design of more sustainable infrastructures, of care work and beyond.

2.1 Related Work

Scholarship in HCI and CSCW has focused significantly on the role of technology in resilience, adaptation, and struggles for wellbeing in periods of change or disruption. I discuss this work, highlighting critical perspectives on attending to the uneven costs of adaptation, and situate it in literature on adoption and use of digital payment methods, the politics of labor in community health, and technology use in Kenya more broadly. This study contributes to understandings of how care work in particular is made to absorb the costs of adaptation, and how the design of sociotechnical systems might ac-

count for this.

2.1.1 Understanding the Complexities of Resilience

Hart et al. discuss numerous definitions of resilience in research and note that there is little consensus other than that it “assumes adversity and is relative to it” [201]. Theoretical literature on resilience has primarily been in the domains of human development, ecology, policy around disaster response, and sociology. Work in human development often views resilience as an individual trait, studying how individuals achieve positive outcomes (say, psychologically or academically) in response to change or adversity, such as losing a job, experiences of domestic violence, or poverty [514, 403, 424]. Seminal work in ecology [596] and disaster response [342] has theorized about resilience beyond individuals, encouraging a focus on resilience of entire systems and at different scales. Because our study is focused on resilience among socioeconomically diverse stakeholders, we draw on critical perspectives where there is a serious acknowledgement of structural factors in how members of a community can and do work towards wellbeing in response to change and adversity [191, 201, 419]. These definitions shift the analysis from individual traits, or even individual strengths as in prior HCI work [591], to the “navigation” or “negotiation” of resources, and the availability of resources, to work towards wellbeing [201, 191]. These definitions of resilience consider the roles of groups, organizations, and institutions, as they are stakeholders in a community and influence structural factors. They also discourage looking at whether wellbeing has been “achieved” in response to change and adversity as this can ignore efforts to be resilient and presumes a single desired outcome. Instead, we are encouraged to take a process-oriented perspective to look at how efforts to be resilient play out and are distributed among diverse groups within a community [50, 113]. Finally, these definitions mean we must necessarily view resilience in context, acknowledging that there is no one way to be or become resilient.

Studies in CSCW and HCI have largely studied how technology plays a role in various forms of resilience, and they prompt further questions around how to grapple with the broader and sometimes negative impacts of being resilient. Studies of resilience to disaster, displacement, and war have described the unpredictable nature of resilience, and the ways technology might present new, positive courses of action during periods of change [12, 331, 333]. Studies also look at how vulnerable and socioeconomically marginalized populations form and maintain valuable social ties and manage resources, such as by turning to community savings groups or relying on intermediated mobile phone use [71, 107, 132, 183, 500]. Expanding on innovation as one aspect of resilience, prior work also studies repair, creative workarounds, and appropriation of technology [11, 240, 283, 489, 630, 625]. In the Kenyan context, Wyche and colleagues' studies of repairers in rural Kenya and Facebook use for income generation point to how local knowledge and innovation should be leveraged towards appropriate technology design [630, 625]. However, prior work has also studied contexts in which resilience, while furthering wellbeing, has negative implications as well. For example, Jack et al. study how the resourceful creation of a sales network in Phnom Penh, Cambodia was subject to gendered notions of labor [239], while Jackson et al. and Ahmed et al. highlight the competitiveness of repair work that results in gatekeeping against new apprentices [11, 240]. We delve deeper into how to think about the negative impacts of resilience and how the navigation of resources might be supported to make resilience more sustainable.

Assets-based approaches in CSCW and HCI are underpinned by assets-based community development (ABCD). ABCD is an approach to community development formulated in the context of low-income neighborhoods in the United States. It encourages moving away from a focus on deficits to identifying or mapping assets within a community [345]. In HCI and CSCW (e.g., [95, 234, 260, 437, 620, 634]), research taking assets-based approaches have helped bring attention to the navigation of resources and constraints in struggles for the wellbeing of communities and how they might inform design. Karusala et al. use the vocabulary of leveraging, extending, and supporting

care, an asset in their context, through technology design [260]. Cho et al. draw from the method of appreciative inquiry, or interviews that focus on the successes of participants, to identify assets, and further suggest creating user personas inspired by assets [95]. Wong-Villacres et al. suggest attending to and comparing the everyday struggles *and* resistance among different marginalized populations in order to highlight assets and constraints for technology design [620]. These works have named non-material assets, like care, solidarity, and social networks, as well as material assets like mobile phones, internet connectivity, and electricity [260, 235, 620, 95, 437]. Indeed, a purposefully broad definition of assets allows us to include anything that might be “engines of community action” [344]. However, there is less understanding of the complexities of actually leveraging assets, in technology design and beyond, and care work in particular presents a case where work, capacities, and limits often go unacknowledged. Indeed, Mathie and Cunningham note that acting on assets is particularly complicated in communities characterized by uneven power relations among members [345], and Mathie et al. have pointed to the need to learn from the process of leveraging assets in order to better understand the possibilities and limits of ABCD [344].

2.1.2 Resilience in the Study Context

Resilience in the context of this study is in part how workers (and organizations themselves) responded to mandated technology adoption. Looking at payment methods, a recurring theme is having to respond to the switch from cash to digital. Employers and governments are often the ones pushing for such change [152, 564], and workers and citizens on the other end of the transaction, as well as the overall design of payment processes, are expected to keep up. CSCW and HCI have looked at cases such as the impact of demonetization in India, the removal of cash payments on London buses, and the adoption of mobile money-based loan repayments by Indian auto rickshaw drivers [421, 429, 459]. Studies find that digital payments generally benefit the organization

more than payment recipients' wellbeing [13, 14, 59, 133]. Meanwhile, much work from both stakeholders is required for adoption, with studies looking at factors such as trust, integrating with the wider financial ecosystem that users participate in, and the points of inflexibility introduced by digital payments [282, 349, 421, 444, 459, 494]. Notably, M-Pesa, a mobile money system operated by the mobile network operator Safaricom, has received widespread adoption in Kenya, largely because of its alignment with practices that users were already exhibiting in sharing airtime [38]. About 70% of the population in Kenya has a mobile money account with M-Pesa [425], and it is used widely in under-served areas in particular [239, 383]. Prior work in HCI has found that M-Pesa payments are a part of family communication [411], and has noted the range of challenges that rural Kenyan women face in using M-Pesa and associated services [627, 629]. Adoption of bank accounts and associated mobile banking and bank agents is less widespread particularly in rural areas [140]. In this context, our study of the switch to digital payments contributes to our understanding of the scaffolding role of organizations and of how workers responded to the change.

Resilience in our context is also in response to ongoing payment delays and the resultant unpredictable income. Community-based public health organizations often rely on both salaried workers and volunteer frontline health workers. Prior work in numerous sub-Saharan countries including Kenya documents how, while frontline health workers join the role for self-development and community involvement [552], issues such as inadequate or inconsistent payments, or no compensation at all, result in decreased motivation to work [180, 322, 555]. This is worsened by the additional personal costs that health workers sometimes must incur over the course of their work [192]. Bringing attention to political aspects of the issue, Maes also finds that the discourse of the "pricelessness" of frontline health workers has also been used by public health organizations as a reason to not pay them at all [321]. An overburdened healthcare sector in general also means that formal workers face difficult working conditions, low wages, and payment delays [232]. In Kenya, there have been repeated organized strikes by formal

health workers (largely nurses and doctors) since devolution of health administration to local governments, including an extended strike in 2017, the year before our study [413, 414, 315, 232]. We examine perspectives on working conditions and modes of resistance from workers of different contracted and salaried status, and align with prior work in CSCW and HCI examining the oft-neglected labor of workers [130, 231, 474, 542], including in health systems [235].

2.2 Methods

The community health ecosystem we studied consisted of the county's local Ministry of Health (MoH), the health workers they employ, and NGOs or “partners” working in the area. We describe the field site and payment flows among actors in detail, and then explain our process of data collection and analysis. This study was approved by our university's institutional review board.

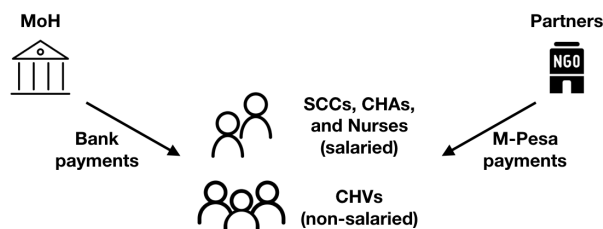
2.2.1 Field Site

There are multiple types of health workers in the county; they work under and are paid by the MoH but also receive payments from partners (as shown in Figure 1) for research or training activities around healthcare provision or mobile health interventions. Community Health Volunteers (CHVs) are frontline health workers who visit homes in their villages and refer residents to hospitals when needed. CHVs are managed by field community health assistants (CHAs). There are also nurses who work at dispensaries and hospitals. Finally, there are sub-county coordinators (SCCs) who manage the CHAs in each of the county's six sub-counties. The MoH pays all health workers through bank payments. Nationally, CHVs are indeed volunteers and non-salaried, but in the county where we conducted our study, they receive a monthly stipend of KES 3000¹. SCCs, CHAs, and nurses are salaried and paid monthly, receiving salaries from the MoH rang-

¹KES refers to Kenyan shillings; at the time of the study, KES 100 = USD 1

ing from KES 60,000 to 75,000 per year. Health workers of all types sometimes work with partners. They receive smaller payments of KES 500 to 1000 for these activities, often through M-Pesa or sometimes cash, depending on the partner. However, the reality was that payments from both the MoH and partners could be delayed, as we will detail in the findings.

Figure 2.1: Stakeholders in Field Site



2.2.2 Data Collection

Our study began as a collaboration between academic researchers with expertise in HCI and digital financial services (Naveena and Richard) and Medic Mobile, a health organization working with the county's MoH on mobile health solutions (co-founded by Isaac). We worked with local Medic Mobile staff and the MoH in setting the objective of the study and gaining approval for the study design. Naveena carried out the study over the course of two weeks in May 2018. During this time we conducted semi-structured interviews and focus groups with health workers and staff from the MoH and partner organizations. We spoke with 25 CHVs via 15 interviews and two focus groups of five participants. We also interviewed five CHAs, three nurses, and two SCCs. We also spoke with five staff members of four organizations (including the MoH) who could speak to their organization's payment processes.

We aimed for diversity among health workers in the recruitment process. Naveena worked with Medic Mobile's local field project manager in the county to recruit health

workers, some of whom the project manager had worked with in the past (health workers often worked with more than one partner, so they were able to describe their experience with multiple organizations' processes). We used purposive sampling to recruit health workers of each type from diverse backgrounds. Participants lived varying distances from the county's major towns (which were also financial centers), and had a range of digital and financial literacies. Workers' ages ranged from 25 to 65, with most participants in the 30 to 50 age range. Twenty-five of 33 health workers were women; this reflects the fact that most health workers in the county are women.

We sampled widely for partners as well. Among the four we studied, three were non-governmental organizations—CARE Kenya, Medic Mobile, and Kenya Community Health (KCH). The MoH was a government entity and managed all the health workers in the county. Medic Mobile was the smallest organization, with CARE Kenya and KCH operating at a larger scale. Both Medic Mobile and CARE Kenya had switched to digital payments while KCH was using cash and intended on switching to digital payments in the future. We recruited staff members of these organizations through snowball sampling, starting with Medic Mobile, as this was how we could begin engaging with more organizations operating in Kenya and directly contact individuals who would be able to speak to the organization's financial decisions.

Interviews were conducted at hospitals and dispensaries that health workers often reported to or gathered at; Medic Mobile's field project manager accompanied Naveena on each interview. In interviews and focus groups with health workers, we asked questions about how they are paid, preferences around payment, and any challenges they had in receiving payments. We sometimes received conflicting information about how processes worked—we triangulated information through multiple interviews but took conflicts as a signal of different interpretations and availability of information. For some participants, asking about payments may have been associated with criticizing or speculating about one's employer. As a result, before each interview, we ensured that participants knew this was an exploratory study to constructively learn from health workers'

experiences with payments, negative or positive, and that all data and identities would be anonymized. In interviews with representatives of public health organizations, we asked about the design of their payment processes, motivation for their design choices, and experience with implementing them. We obtained participants' verbal consent to participating and having the interview recorded.

Most interviews were audio recorded, unless they took place over phone, in which case we took detailed notes (as was the case with two partners' staff who could not meet in person). Interviews ranged from 30 minutes to an hour. Naveena conducted the interviews in English, which most participants had intermediate or high fluency in. In cases where participants were not fluent or comfortable with English, Medic Mobile's field project manager interpreted Swahili and English.

2.2.3 Data Analysis

The process of data analysis started by iterating on the interview protocol as we interviewed participants. After data collection, Naveena transcribed each interview, using English translations of interpreted interviews. She then followed inductive interpretive analysis as described by Merriam [366]. Starting with open coding of the transcripts, Naveena labeled phrases with codes, such as "traveling far to withdraw from the bank" or "calling about missing payments as a group". Over several iterations, the research team (based on conversations and reading through field notes) agreed upon a set of high-level codes such as "adopting bank payments" and "coping with missing payments". These codes brought out a set of themes that spoke to the resilience of workers and, in part, organizations, around which we structured our findings.

2.2.4 Self-Disclosure

We recognize that the collection, presentation, and discussion of the data in this paper is shaped by our identities. All data was collected by Naveena, a woman of Indian ori-

gin, whose prior research has been conducted in parts of India and the United States. While health workers were familiar with working with partners, the presence of Medic Mobile's field project manager (who lived in the county and had previously worked with some of the health workers we interviewed) during interviews may have affected how participants described their experiences with Medic Mobile, but also helped us establish rapport. Data analysis was led by Naveena in conjunction with Isaac and Richard, both white males from the United States with extensive research experience in global health in east Africa and south Asia. We also note that the differences we saw as relevant in the data, such as the difference between salaried and unsalaried workers, became salient because of the set of questions we chose to ask and the topic we explored with participants.

2.3 Findings

We present our findings on how a community health infrastructure responded to changes and challenges in care work on account of digital payments and missing payments. We draw out the advantages to the MoH and NGOs in efficiently and safely managing financial flows, in contrast to a new equilibrium where health workers, particularly CHVs, took on the challenges of using digital payments in a cash economy. We also describe how health workers dealt with delayed and missing payments, and how differences in contracted and salaried status and the government's management of expectations of payment shape how health workers are able to cope.

2.3.1 Adopting and Adapting to Digital Payments

In looking at adoption of digital payments, we focused on the MoH's introduction of bank payments to CHVs in 2010, and partners' introduction of M-Pesa payments to all health workers in the early 2010s. We found that introduction of bank payments required scaffolding and collaboration, while M-Pesa payments were integrated more

easily, though they still presented a deviation from cash. We also found that over time, adaptation for CHVs in particular manifested as lower engagement with banks as compared to M-Pesa, and as the use of digital payments despite ongoing confusions.

Setting Up Bank and M-Pesa Payments

In 2010, Kenya's national government began a multi-year process of devolving health administration to county-level governments, so the county MoH became charged with paying its staff with funds from the national government. At the same time, the county's leadership decided that CHVs would start receiving a stipend as a *"token of appreciation"* (CHV8), notably becoming the first county to pay its CHVs. S1 shared that they chose to use bank payments as per policies around disbursing public funds, and because they were easier to audit. Salaried staff (CHAs, nurses, and SCCs) had already been receiving bank payments previously. Setting up bank payments involved having all CHVs create bank accounts, a year-long process in which workers *"really faced a lot of challenges"* (S1, MoH), due to different constraints arising out of CHVs' varying degrees of financial literacy and remoteness from the town center. Uptake of banking among some CHVs, particularly in urban areas, was already high, but adoption was slower and more difficult for CHVs from more remote areas. Many CHVs had to apply for a national identification card for the first time (at the time of bank payments being initiated), obtain identification photos, and pay the additional cost of transportation over long distances to town centers to submit materials and open an account in person. At the same time, the MoH and workers who managed CHVs were able to scaffold the process. For example, once CHVs opened accounts, they also had to submit their account information to the MoH to get paid. Among CHVs who were less familiar with banks and their workflows, many submitted incorrect account numbers, or ATM card numbers instead of account numbers, which resulted in complaints of missing payments. In response, the MoH liaised with banks to gather correct information, asking CHVs to go to their bank and specifi-

cally request their account number, while CHAs and SCCs were charged with sensitizing CHVs to different types of numbers.

Despite the effort and missing payments this process involved, there were some immediate perceived benefits to opening a bank account (beyond the prospect of receiving a stipend). While many CHVs perceived banking to be *“too complicated”* (CHV6), some CHVs, particularly those who lived near the town center, remembered the opening of bank accounts as an introduction to a resource that they could choose to leverage. CHV2 described how *“when we were told that we would be paid through the bank, each one of us had to go and open an account. That means it gave others opportunity at least to go there, open accounts, and know what it is to use our banks.”* From there, CHVs saw opportunities to learn new financial practices and procedures, as CHV5 shared: *“Some of us had never even entered in the banks. The procedure of withdrawal, maybe they didn’t know, so they’re given the opportunity to save for themselves.”* However, this did not necessarily hold over time, as we discuss below.

The partners we interviewed, along with the majority of partners operating in the county, had generally switched from cash to M-Pesa in the early 2010s to pay health workers travel stipends for participation in research or training activities. Organizations we talked to were motivated to switch to mobile money as they scaled up in operation. M-Pesa offered the ability to quickly make bulk payments to a list of recipients. NGOs could also avoid potential issues with the risks of withdrawing and moving large amounts of cash or even NGO staff taking a cut of the funds for themselves. For both organizations and health workers, collecting workers’ M-Pesa information to send out payments later was a much simpler and less disruptive process compared to setting up bank accounts. True to accounts of the widespread popularity of M-Pesa use throughout Kenya [425], most health workers had already used M-Pesa in the past to, say, receive or send money to family, as found in [411]. Additionally, M-Pesa was designed in a flexible way that supported adoption. As staff from CARE Kenya described, *“...the transaction doesn’t require a smartphone. You can do it on any feature phone and also maybe if you*

don't have yourself, then your trusted beneficiary—if a CHV is a lady and she doesn't have a phone, she uses the one from her husband, and vice versa” (S2). Thus, M-Pesa as a mandated method of payment aligned more with existing forms of technology access.

We also noted power dynamics in the way health workers, particularly CHVs, perceived the need to adapt to new payment methods. Health workers often paid for daily purchases such as food and clothing in cash, as that was the main form of currency in surrounding areas. CHVs who ran side businesses such as selling vegetables or sugar were also paid in cash for these goods. Ultimately, cash was the currency that could actually be used in health workers' daily lives. As a result, even though workers acknowledged that digital payments meant not being required to queue for cash, partners needed to convince them that using M-Pesa had its benefits:

“They [health workers] are open to getting M-Pesa, but the problem is people will always prefer cash. But you know, you as the activity organizer, have to tell them the benefits of why you're doing that [...] Then they know very well that is the mode of payment that they will get.” (S2, CARE Kenya)

This did not mean that workers were entirely convinced that M-Pesa was best for receiving payments, as much as they felt that they did not have a say in how partners paid them. CHV12 shared his perception that *“...they have their own ways of working operation. So you can't get in and start telling them that you should do this and this and this. If you do that, they can even say no, we are not dealing with you people, we are going on another site.”* In fact, CHVs from remote areas mentioned how useful it would be to get paid in cash during trainings with partners. CHA2 explained that *“maybe a CHV has come from far, she or he has used transport, and then maybe she borrowed that money from someone else, so it's good if you just pay them cash instead of M-Pesa.”* Here, we can see how resilience through adaptation, while certainly being a conscious choice, is also laden with what workers perceive to be the relative costs of not adapting or of demanding changes—in this case, the income that comes from working with partners.

Sustaining Digital Payment Use in a Cash Economy

As digital payments became the official method of compensation, health workers needed to adapt these methods to their daily lives. How health workers felt about each payment method was related to factors such as place of residence and work status, combined with how well the features of digital payments aligned with their priorities.

Most evidently, receiving bank payments was much more disadvantageous for CHVs because their work status meant that they were paid much less than salaried health workers. As CHV17 shared, *“It [bank payments] is not ok, because the stipend is so little, then it goes to the bank account, the bank account also slash it and then it becomes less. I’m supposed to get 3000 and I’m getting 2500.”* Though CHVs accepted that this was the process for getting paid, many CHVs wished they were paid through M-Pesa instead. Most CHVs preferred M-Pesa payments because they had much lower transaction fees (KES 27), which some partners covered themselves (Medic Mobile, for example, did not at the time of the study but aimed to be able to do that in future). Here, we see organizations taking on constraints for workers, in part because M-Pesa levies relatively manageable fees. One exception to the preference for M-Pesa was that M-Pesa required Safaricom and was not interoperable with other service providers like Airtel, making banks more accessible in this case.

Considering the dominance of cash in health workers’ lives, health workers also needed to adapt to the process of converting digital forms of money, once received, into cash. The ease with which workers could adapt was shaped by their income and place of residence. With respect to banks, they were relatively accessible for salaried workers but only a minority of CHVs. Similar to how this caused issues for opening bank accounts, this was due to the fact that most salaried workers lived near the town centers where banks and ATMs were located, while many (though not all) CHVs lived in more remote areas. For these CHVs, traveling to the town center had significant costs, essentially taking money out of their stipend on account of their place of residence:

“With a bank account, it’s complicated because you have to travel all the way to town. For instance, I have to use 300 shillings to and from and you deduct the bank transaction fee, that’s around 300 again. I’ll have lost 600 to go and withdraw 1000 or maybe 2000.” (CHV7)

There were workarounds in place for making banks more accessible, though still costly, such as withdrawing from local bank agents (for a fee). The MoH once again attempted to scaffold, directing CHAs and SCCs to encourage CHVs to download mobile banking apps to transfer money from the bank to M-Pesa, which was easier and cheaper to withdraw from. However, uptake was low among CHVs with lower digital literacies and as CHA5 commented, *“the fees add on from the bank payment to mobile banking, from mobile banking to M-Pesa, from M-Pesa to cash,”* demonstrating the difficulties that arise out of the way financial systems aim to keep money strictly digital and within the system [350].

Ultimately, CHVs chose to go to the bank very selectively. Some CHVs had SMS alerts from their bank to see if they had even received money to withdraw, in light of how payment delays resulted in unpredictable payment deposits anyway. Many CHVs did not register for SMS alerts as they perceived them as costly and had to register their phone with the bank—instead they relied on meeting their social network of fellow CHVs at work-related gatherings or savings group circles to gain more information: *“One of you goes to the bank and finds out whether the money is there, or somebody else has an alert, that is when you know when money is there. Otherwise, the money can be there, and if you don’t visit your bank regularly, you might not know”* (CHV2). At the same time, to some CHVs, their distance from banks actually made them more useful for long-term saving. As CHV19, mentioned, *“It’s safe there, I’ll not be tempted to use, because I have to go to [the town center] [to withdraw]”*, a perspective driven by the desire and option to save.

Many health workers saw M-Pesa as a more accessible form of payment. Especially

for CHVs in remote areas, they could walk to an M-Pesa agent and “*just incur transaction fees and not transport fees*” (CHV7). Even CHVs who had used trusted beneficiaries to receive money felt they could reliably access money through them. Many CHVs mentioned using M-Pesa to save money, as has been found in prior work [239, 383]. M-Pesa also aligned with CHVs’ other financial needs such as being able to pay school fees, make loan payments, and take loans through M-Shwari, aligning with prior work that studies M-Pesa in the context of family life [411]. Many CHVs did not receive bank services or perceive the same utility in banks. As CHV12 described, “*We are not confirmed as county workers. It’s like we are the casual laborers, and casual laborers can’t get loans from the bank.*” This, combined with the factors described above, led to the general lack of engagement with bank accounts even after access, as noted in prior work [381].

Meanwhile, salaried workers were better served by banks not just because they were physically accessible, but because there were other resources available to them through banks. Salaried workers had the added benefit of being approved for other bank services, such as loans and auto-deduction of loan payments from salaries. Meanwhile, the high accessibility of M-Pesa was actually seen as a negative factor—it made it a more immediate, tempting form of money. As SCC1 said, “*if it is in M-Pesa, I’ll use all of it.*” Similarly, one CHA even avoided mobile banking because “*once you know you have this amount in your bank, you’ll be tempted to go for it anytime*” (CHA3). Salaried workers also felt that large sums of money such as their pay should go into a bank account rather than M-Pesa for long-term saving and perceptions of greater security. Thus, we can see how different payment methods cost more or less to adapt to, leading to different perceived levels of utility among workers depending on their financial priorities.

Continuing with Unresolved Concerns

Despite bank and M-Pesa payments having been established for several years at the time of the study, we found that there were many ongoing points of misinformation

and concerns still circulating regarding digital payments, pointing to how workers with diverse literacies had adapted to these new methods with unresolved concerns, as long as they could receive a salary.

In many interviews, there was confusion around the exact fees levied on bank transactions, even though they were standard within a bank. In one interview, we learned that CHV18 and her fellow CHVs were not aware that in addition to fees for withdrawing from bank agents (KES 110), banks also levied transaction fees (KES 300-500) when salaries were disbursed, and so she was suspicious as to why their stipends had an amount greater than KES 110 deducted from them:

“We were told the banks were supposed to deduct only 110 per month. We are told our stipend is 3000 per month. As from, February, March, April, is three months now. But you will get, we will be given only 7500, or 7600, who are these 2400 going to? Hm? If the bank is only deducting 110? [...] We don’t know what is going on there.”

While the Medic Mobile staff informed her that banks charge more in addition to the agent withdrawal fees, this scenario indicated the limited avenues for CHVs to act on their concerns around using new payment methods, and notably, the willingness to continue using them regardless. While CHV18 and her coworkers were suspicious, banks payments were the only way to receive income, and resolving her suspicions would likely require labor in terms of information-seeking.

Over time, the opacity of bank accounts combined with delayed payments also resulted in CHVs being unable to tell which month a bank payment was for. In fact, many CHVs simply stopped caring since payments would just continue to arrive months apart due to payment delays. As CHV3 laughingly noted, *“they can put [pay] one month and relax. Then another until you get confused which ones are missing and which ones are paid.”* Combined with the misinformation about fees, this indicated that information

about payments was not easily discoverable, attesting to the opacity of digital payments [349, 494], especially compared to human interactions involved in cash payments.

With respect to M-Pesa payments, health workers noted that errors in payments could still be made every once in a while. When health workers attended activities, partners would collect health workers' names and mobile phone numbers to record attendance and send payments. According to both workers and partners, workers sometimes wrote illegibly or wrote down a number that was not registered with M-Pesa or Safaricom. This was more common among those with less familiarity with the inner workings of M-Pesa. Sometimes workers would not remember to sign the sheet, or they would write the number of a trusted beneficiary without realizing that meant that the money would be sent to that person's phone. To avoid these issues, partners' project managers and CHAs needed to sensitize health workers, particularly CHVs, on remembering to fill out the sheet, writing legibly, using a registered number, and understanding conceptually that the number written on the sheet is where the money would go. Partners had a hand in creating more or less resilient processes as well. Workers mentioned that some partners were slow to make the payments, sometimes because they might not have had funds readily available. However, Medic Mobile (and other partners that health workers reported interacting with) paid health workers immediately after signatures were collected, by budgeting money ahead of time and requiring that project managers process forms quickly. Immediate processing had added advantages—if the project manager noticed legibility issues or that some transactions did not go through, they could inform the health worker while they were still present for the activity.

2.3.2 Keeping on while Payments are Delayed

At the time of our study, CHVs had not been paid by the MoH for five months, and salaried workers for two months. This was because funds were delayed from the national government, as the MoH and health workers told us. When payments did arrive,

it could be the accumulation of delayed payments or just one month's worth. We describe the various ways that health workers coped with unpredictable income in their work and financial lives, acting on the resources and constraints at their disposal.

Managing Work with Payment Delays

Salaried workers and CHVs generally reported that they continued to work despite payment delays, to ensure that the community health infrastructure in the county as a whole remained resilient. Much of this resilience stemmed from the fact that health workers cared deeply about their work and their community, and that it brought them a deep sense of satisfaction. CHA1 described how he and N1 were driven by *“the passion for whatever work you are doing. Like, she’s a nurse, she has that passion, that passion to prevent diseases.”* CHVs in particular felt that their work made them useful, respected, and trustworthy to their community, with CHV2 likening themselves to teachers and supporters:

“Actually the reason as to why we love this job despite the payment and the late stipend, is that we have the burden of our community. One thing that we like is that you didn’t know how to take care of this child, we come there, we show you, we talk with you, we see the changes, you start being responsible, you start taking care, that is what makes us happy in our life. [...] we want to save the whole community, because we are carrying the community.”

At the same time, workers needed to constantly temper their expectations around payment, which was laborious in and of itself especially *because* work was a mainstay in participants' lives. N1 described how *“if you come to work for 60 days, and you’ve not seen anything, that’s where you spend most of your time. Yeah... We feel demotivated.”* Additionally, continuing work for the satisfaction did not make it easy, and could actually be an additional constraint on top of payment delays. The physical work of traveling to and

conversing with households and attending partners' activities required time and energy that was scarce due to the cascading effects of payment delays, as CHV18 described:

“We are affected because you can only go if your household, if you are in a good mood. Sometimes you don't have anything to eat as lunch, children are lacking school fees. Even your farm, you can't even achieve good products because you don't apply any fertilizers. It is hard to visit households when you're not comfortable.”

Indeed, participants often used such language to differentiate being well “in” the home versus “out” visiting households, explaining how “*you have to be fit at home to work*” (CHV13). Strong motivations existed to work, but also to, say, ensure children were properly cared for, which meant consciously prioritizing different forms of wellbeing in the process of adaptation.

The unpredictable financial costs that arose in their work also compounded payment delays, and workers did not seem to feel like they had a choice in avoiding such costs due to their moral and professional values. For example, CHA3 mentioned that some CHAs were given motorbikes to ensure they could travel to remote areas. Occasions arose “*... when it is not in order and I want to service it, so it becomes a challenge especially if there is no salary.*” In another example, the community visibility CHVs had and desired in their role could become a constraint, as CHVs were often approached by patients in emergencies, resulting in costs that CHVs felt obligated to pay:

“Two years ago, a woman comes to me at 2 or 3 [in the morning]... I rushed her to the hospital but she didn't have anything. So if I didn't have something, I would not have saved her life. We rushed her to the hospital, when reaching there, a woman doesn't even have money for clothes for the baby because she comes from a poor family. And her husband is a drunkard. So it is me who used my money to help the newborn baby.” (CHV15)

Changing Financial Practices during Payment Delays

What was particularly difficult about payment delays was not just lack of income, but the unpredictability of income. Due to both these factors, health workers turned to various resources at their disposal to maintain financial stability.

As CHVs were given a relatively small stipend that they needed to temper expectations around even receiving, they needed to have alternative ways of making money. As CHV2 said *“so you have to think, think and be creative and say yes this is just an addition. We appreciate, but think, otherwise our children could not go to school if it is only this job that we are looking after.”* As a result, unlike salaried workers, many CHVs were also maintaining jobs, or what many CHVs called “side businesses”, such as catering, selling cereals, sugar, and clothing, or maintaining small farms to sell vegetables. However, many CHVs said there were days when they intended to work on their side businesses to make enough money but instead, as mentioned above, had to attend to unexpected, pressing responsibilities such as transporting a patient in need to the hospital. CHVs reported that disruptions could come from work as well. As CHV8 explained, *“maybe you had planned tomorrow to go and do something on the farm and then you’re called at night, you’re told tomorrow we’re meeting at the facility, make sure you come on time.”*

Health workers also turned to loans, which meant taking on debt to be handled in the future. Health workers were resourceful in finding loans, turning to friends and family, shops and shopkeepers, M-Shwari, savings circles, and banks, with CHVs rarely taking loans through banks. Loans could be helpful in that they could entirely resolve some pressing expenses in the short term, for example covering school fees so that children are not at home during the day. However, unpredictability meant that some health workers struggled to keep promises about when money might be paid back, which could have further consequences. SCC1 described how *“You’re telling the landlord that you’ll give money by the end of the month. When the month ends you don’t have that salary. So some will say that you’re joking with them, you have to vacate their houses and leave for*

other people to rent.” CHV1 also explained the additional labor that arose out of unpredictability, saying how *“this one of the county government, I’ll cheat you, I’ll dodge you, because that money’s not there. I’ll probably see you but that money’s not there.”* Meanwhile, participants who could borrow from banks had the benefit of being automatically granted a grace period, as SCC2 described. Once payments did arrive, the loans and monetary needs accrued over time meant that the stipend was spent immediately. N1 described how *“when it comes, maybe you have some debts you have to pay, maybe you have a loan you have to pay. You know that insurance covers, you have to pay. So you may not get enough money to save, even for your future, your future use.”*

2.3.3 *Demanding Payments, Delayed and Missing*

Health workers also attempted to be resilient through their persistence in ensuring they received payments, both in terms of delays from the MoH or individual missing payments from banks or partners. We detail how the MoH differentiated workers, and how differences in formality then affected different workers’ ability to demand payment. We also look at how follow-ups for individual payments took place over time, and how past experience affected workers’ future desire to conduct follow-ups.

Differentiating Workers and Managing Expectations

The MoH heavily influenced the forms of recourse that each type of worker had by managing expectations and defining the formality of different workers. Salaried workers had a contract and unions, and therefore had more legitimacy in demanding payments and asking for raises. Meanwhile, the MoH had control over how exactly the label of “volunteer” applied to CHVs. CHA2 mentioned that CHVs *“used to be CHWs [community health workers], but it changed to CHVs because you know when you call them workers and you don’t pay them salaries, it’s not that ok.”* (SCC1). This sentiment was followed and reinforced by both CHVs and the salaried workers we interviewed. As N2 mentioned

regarding CHVs, *“they’re appreciated for the well work done. You have to be specific. It’s not a salary.”* Once health administration was devolved to the county level, the stipend that the county decided to give CHVs was framed as a form of appreciation—CHV2 described how a raise in the CHVs’ stipend in 2016 was yet another token offered at the will of the county governor:

“When Bill Gates heard that the governor is supporting community health volunteers, [the governor] was called to have a meeting with this man. When he came back, he said ok, I went there because of you people. Let me add something small.”

Despite this management, expectations of payment arose naturally because stipends were helpful income. CHV9 said that despite being volunteers, the payment delays still mattered to them: *“Back when we were doing it without payment, we were doing it wholeheartedly, without expecting anything. Now the county is giving us something, so we’re looking forward to that small amount.”* In addition to wanting payments on time, mirroring prior work [322], many CHVs told us that the payments should be higher, feeling that *“they [the MoH] don’t recognize us”* (CHV12). CHV1 said *“You know today, in Kenya here, even house girls [live in maids] are not paid 2500. They are paid 7000, house girls.”* CHV5 in the same focus group agreed enthusiastically: *“Which means house girls are getting better salaries than a CHV. We are doing more important work than a house girl.”* This is not to say that CHVs or any worker for that matter did not find meaning in their work. Rather, they aspired to improved working conditions as well, regardless of whether they had the formal authority to expect it.

Avenues for Demanding Payments

While making do without a consistent income was possible and workers continued to support community health, there was still a persistent desire to ensure workers were

compensated appropriately. Health workers' avenues for demanding payment were shaped by the formality of their role, with salaried workers having the ability to demand payment or organize strikes while CHVs did not.

Nurses had the strongest unions, which were nationally recognized. Their strikes were organized by their union and the year before our study, nurses in Kenya had conducted a nationwide strike that lasted seven months. CHAs and SCCs also had unions, but they were at the level of the county. SCC1 mentioned how she had a WhatsApp group where members could message about concerns they had, such as not receiving promotions or going yet another month without receiving their salary. SCC1 herself would post concerns sometimes when payments were delayed. The role of a CHA was relatively recently instituted to help manage CHVs and provide health education at the community level. According to CHA2, CHAs did not have an official union, but *"it's just kind of a welfare thing. We meet the CHAs from [the county], we maybe share our grievances."* They also had the ability to speak directly with staff in the MoH to inquire about payments, and CHAs mentioned that they did so. CHVs did not have unions and many said that the only person they could voice concerns to was their CHA, whom they relied on to relay information from the MoH. Otherwise, *"a volunteer has no voice. We're just outside"* (CHV12).

Despite these differentials in forms of resistance, all workers felt that their concerns were not given the appropriate attention. CHAs mentioned how the MoH, regardless of how many times workers asked, always informed workers that funds were delayed from the national government, and CHVs explained how the MoH *"always just encourages us to keep on waiting"* (CHV13). Many workers believed this reasoning from the MoH, but even among those who had suspicions that it was not true, they felt there was no choice but to accept the explanation. Even nurses, who had strong representation and in the past had sometimes succeeded in getting pay raises, felt that their long strikes were not immediately effective and could not ensure that any progress was achieved. N1 described how, at the time of our study, seven months after their strike ended, nurses'

salaries had not been increased:

“Whatever they promised, actually, they’ve not even given us. An allowance was supposed to be adjusted, but so far, they’ve not done. [...] We’re still waiting, we don’t know whether they’ll really do that adjustment. It was just signed, a collective bargaining agreement but, to the salaries, nothing has been done.”

Solidarity Among Workers

These differing levels of bargaining power meant that formal workers exhibited solidarity with CHVs, but it also meant that CHVs were left to deal with the shocks to the community health infrastructure that resulted from strikes.

Salaried workers displayed solidarity with CHVs in spirit and through action. Salaried workers recognized the importance and volume of the work that CHVs did and for very little pay, often voicing during interviews that they should be paid more. CHA1 sympathized with the irregular and small stipends CHVs received despite the value of their work: *“They are doing very crucial work on the community level and they have families, they have dependents, and they do quite a lot at village level. [...] And they are given 2000 every month which is just a bit. Although other counties are not paying their volunteers, ours are paid. And we are saying still 2000 is little.”* Salaried workers made efforts to understand CHVs’ perspectives over the course of their work, making sure to be understanding (to an extent) if CHVs could not come to monthly meetings or if they were sick and could not visit houses. SCC2 described how SCCs and CHAs took care to keep from *“tasking them”* (SCC2), or insisting that they do work when payments were greatly delayed.

At the same time, health workers needed to do what they could in order to improve their working conditions. When nurses went on strike for this purpose, it had mixed effects on different workers. For instance, if nurses’ strikes received productive responses from the government, that could be helpful to SCCs and CHAs in getting raises:

You know with them, they have stronger unions, the nurses. So when they talk through those unions, at least there are some, for example, they need some allowances like health service allowance, when they receive that health service allowance, it cuts across, it's given to all the employees in the ministry of health. So it has advantages and disadvantages as well.

However, CHVs, despite being volunteers, took on the greatest amount of work due to strikes. Without nurses, the community health system became paralyzed (as was the intention, in order to demonstrate the value of nurses' work) and patients could not go to hospitals. This meant that community residents turned to CHVs for healthcare needs. CHVs then did their best to handle an increased workload and administered what medicines and medical advice they could without referring residents to healthcare facilities. As CHV7 described, CHVs could only do so much in terms of formal healthcare but were inundated with requests for support anyway:

We have to do a lot more because... some things are beyond us, like we cannot do ANC [antenatal care] for women. So we only treat malaria for under five [years old], even for over five [even though policy is that they only treat children under five for malaria]. So if someone needs services other than treatment for malaria, it becomes so hard for us. And the villagers, because they know we are CHVs, they'll come to us.

Not surprisingly, when asked if they felt the strikes were beneficial, CHVs explained that “*it increases our jobs*” (CHV7) and that “*they're not important*” (CHV9). CHAs who still worked during strikes also took on some of this burden as well. When scenarios arose where CHVs could not respond appropriately, they relied on CHAs for guidance. As CHA2 described, “*we do suffer, the community, because you know, every issue you're being brought for, in case of delivery, we just go to the CHV. Now this person wants to deliver, the CHV calls me. So now we have to advise them to go to private hospitals...*”

Following Up and Resilience Over Time

Participants also reported occasional missing payments from the bank and M-Pesa payments from partners, different from delayed payments in that these were individual incidents. According to both organizations and workers, payments went missing due to errors in the banks' maintenance of payrolls or the contingencies of signing and sending money through M-Pesa. We found that workers' avenues for and desire to follow up about missing payments were tied to digital literacies and the perception of whether follow-ups were likely to be effective over time.

Salaried workers and some CHVs had detailed knowledge of how to get their bank statement, how to access M-Pesa transaction history, and that no matter what one does with the records on their phone, Safaricom maintains their own records, *"so you cannot cheat"* (CHV13). These workers were quite confident about how to follow up with payments. Other CHVs were not sure of how to look up M-Pesa transaction history and shared that they would not know what to do if they noticed any missing bank or mobile money payments. Among health workers who had done follow-ups, they had mixed experiences that affected their willingness to follow up again and again over time. Mirroring many CHVs' experience with fruitless bank and M-Pesa follow-ups, CHV5 mentioned the complexity of following up: *"At times you go, you don't even find the accountant, at times the accountant is there. She tells you please go back to your CHA, you go to the CHA, sometimes the CHA tells you to go to the account office."* Other CHVs said they had given up on follow-ups before because the MoH required them to travel to check records at the bank, which could be too far to travel. Some CHVs also recounted stories of follow-ups where they contacted staff at partner organizations on behalf of multiple other CHVs who had not been paid at an activity, leveraging the community of CHVs for more collective methods of following up.

2.4 Discussion

Digital payments were introduced to pay health workers, due to stated advantages around efficiency, safety, and speed of disbursement. To some extent, the scaffolding organized and offered by the MoH and partners also made health workers' adaptation to changing payment methods easier. However, attending to new equilibriums after the introduction of digital payments shows how many (even if not all) health workers still took on financial and temporal costs to use digital payments. We also found that the MoH's management of expectations around payment and the production of CHVs as paid volunteers contributed to the overall costs and avenues of dealing with payment delays. We unpack how attending to distributed reproduction, or the numerous factors that converge to shape health workers' circumstances, helps us understand the limits of digital payments as a technological fix, and how we might design more sustainable care infrastructures.

2.4.1 Digital Payments and the Restructuring of the Work of Getting Paid

Attending to where the logics of population and distributed reproduction are at play in the context of this study offers an understanding of how digital payments function as a technological fix. In some ways, the rational aims of using digital payments were fulfilled in that organizations felt they made transferring funds at scale faster and safer for their staff. Health workers also acknowledged that they no longer had to queue in order to get cash payments, and for some, digital payments offered an avenue to save money. M-Pesa payments in particular aligned well with workers' existing practices. However, looking at the impacts of payments beyond the moment of delivery and attending to the varied experiences of health workers, we see that there are still temporal and financial costs of digital payments, but they are redistributed differently and unevenly across time and space. Withdrawing cash, especially for health workers far from the town center, requires time and money for travel, or additional fees for withdrawal from agents.

Fees especially impact CHVs, who, due to the way they are positioned as volunteers who receive a token of appreciation, make much less than salaried health workers.

These uneven impacts compounded the significant effort of coping with delayed and missing payments amidst the affectively charged tensions between love of the work, hope for payment, and unpredictability of receiving pay, while the MoH and other workers sought to temper expectations. CHVs needed to work on side businesses, care for children at home when school fees were not paid, cover unexpected work expenses, or attend work activities on short notice. Thus the narrative of more efficient health systems and improving worker motivation does not consider the complexity of how health workers' time and mobility is structured, or the numerous other causes of demoralization, including payment delays, but also the opacity of digital payment processes and fruitless follow-up attempts.

2.4.2 Care Work and the Complexities of “Assets”

CSCW and HCI work on resilience and assets-based approaches has focused on identifying resources and forms of resistance within communities and acting upon them in technology design (e.g., [95, 620, 634]). Numerous studies have shown how care, solidarity, or mundane technology are assets and can inspire and be supported through the design of interventions [95, 234, 260, 437]. As CSCW and HCI increasingly engage with diverse communities and a wider range of stakeholders [511, 620], designing for struggles towards wellbeing requires not just the identification of resources but also explicit efforts to understand their availability to different members within a community and the potential (and especially negative) effects of leveraging them. Prioritizing this understanding also aligns with social justice-oriented design, which takes seriously the broadest potential effects of design and how it benefits or burdens diverse populations [43, 112]. Centering the specificities of care work offers a foundation for thinking about the distribution of resources and costs of resilience and resistance in design. Care work

is done in order to meet a fundamental human right to health and is often mired in moral and emotional obligations. Its historical equivalence to women's work and material devaluation of the work creates foundations for it to continue to be exploited today. Public health infrastructures in numerous countries rely on volunteer labor, mostly from women, to address the shortcomings of health systems, but without the appropriate funding and processes in place to pay them even the relatively small incentives or stipends they are promised. While our findings show that CHVs get something out of the work, it still raises the question of what the complexities of care as a resource are, and what it means for designing for struggles towards wellbeing more broadly. We draw on aspects of distributed reproduction to pose questions for how to think about assets in design.

In arguing for a shift away from the logic of population, Murphy urges us to consider that individuals and their actions are neither one-dimensional and aggregable, nor apolitical and disconnected from others. She suggests that one aspect of holding onto complexity is attending to how bodies and choices are entangled in “nests of diminishing and assisting relations”. We see this in the context of our study with the in-between nature of paid volunteer work and, in general, the context of payment delays meant that workers had to turn to side businesses and loans, forms of support that increased precarity. In responding to payment delays, health workers turned to loans, an asset available to them through local institutions like banks and savings circles. In many contexts, loans, particularly those provided through community [348], can be a way to make important purchases in light of relatively insufficient funds. However, the very concept of loans relies on creating debt for the future, and attending to their use in the specific context of payment delays changed the nature of having loans—because of inconsistent income, paying back loans became unpredictable, creating the labor of dodging moneylenders. To provide another example, on the level of sustaining the community health infrastructure as a whole, health workers' care for their community was a significant reason for its continuation. This was explicitly so with CHVs, who were

differentiated as volunteers, but care was also relied upon more implicitly in the way work-related costs were not compensated or how payment delays continue unresolved across workers. The danger of relying so much on care, a resource that is finite considering the amount of labor it requires, becomes apparent through the strikes and the way CHVs uneasily described the obligation they felt to put volunteer duties first even if it cost them time and money. Through this example, we see how these limits should become a consideration for technology design that seeks to leverage and support care as an asset, as prior work has conceptualized [260]. Thus we might ask when considering an asset in the design of interventions: what are the limits of an asset and what constraints might they be tied to?

Another aspect of distributed reproduction is to look at how even diminishing and assisting relations are uneven and come to support some forms of life in persisting and thriving while other lives are damaged or constrained. Because differentiations among groups afford different levels of legitimacy and precarity, we found that the mobilization of an asset among one group can have impacts beyond those seeking to leverage it. We saw this most clearly in how the effects of the strikes organized by nurses created more work for CHVs, which in turn affected the solidarity among workers. At the same time, nurses were attempting to improve their own working conditions as workers with the right to be paid, and strikes only created difficulties for CHVs because CHVs' labor was understood as a potential resource regardless of working conditions. This characteristic of assets might also play out in more subtle and distributed ways. For example, numerous works have described how women's mobility is intersectional, dependent on numerous factors including class, race, and environment (e.g., [18, 145, 397, 481, 606]). Looking at how this affects assets in design, we see examples from prior work in HCI—Kumar and Anderson found that leveraging a sense of social togetherness among mothers' groups fostered discussion and inquisitiveness around maternal health education videos, but also meant that daughters-in-law from more conservative households could not attend the groups [288, 284]. This characteristic of assets brings up the question of

what the broadest impacts of leveraging an assets are, as well as what the scope of community development is—does an asset in one group, such as a strong social network, count as one in another?

Distributed reproduction also points to the role of infrastructures and what sorts of power dynamics they create that affect the lives of the many. We found that a notion of “ownership” arises when identifying assets that are unique to groups at a particular intersection, such as talents, wealth, or peoplepower. For example, the MoH and partners, as institutions privileged with expertise and peoplepower, had CHAs or field managers and know-how around financial institutions, which they used to support CHVs in switching to digital payments. The MoH and partners also had the motivation to do this in the first place—they wanted to support their workers, and it was also in their self-interest as employers as well. At the same time, it is not clear if CHVs knew to leverage this asset further, as some maintained uncertainties about the use of digital payments and how to follow up with missing payments. Another example is the MoH’s ability to determine workers’ terms of employment. The MoH chose to use their budget towards recognizing CHVs for their work, but did not need to make further promises as CHVs were seen as volunteers. However, on an institutional level, their ability to provide a monthly stipend in the first place was constrained by their reliance on the national government for funding, complicating the use of their financial assets. This highlights questions that we might ask of assets—how are they distributed and is there motivation or mechanism to extend them to others?

2.4.3 Engaging with Assets for Sustainable Resilience

As prior work in HCI has noted, resilience is characterized by emergence, fluidity, and precariousness in times of change [12, 330, 240, 239], and these notions should be attended to in leveraging assets. Community health infrastructures specifically can be shaken by disease outbreaks, varied availability of financial and human resources, and

unstable presence of health organizations [477, 624, 651]. Meanwhile, prior work has shown that women care workers in community health take on a number of private and individual risks and adjustments to keep health systems running, suggesting that these concerns must not be workers' but rather a public and collective responsibility in order to avoid recreating the inequalities that community health is meant to address. Knowing that assets, and care specifically, are complex, political, and not always evenly distributed, what does this mean for designing sociotechnical systems that can respond to change while not perpetuating the idea that workers must take on the burden of resilience individually? Our discussion emphasizes two ways in which system designers might engage with assets, in order to be more cognizant of people's wellbeing and prospects for sustainable resilience.

First, we would encourage system designers to investigate the assets that health workers rely on, and explore whether more generative assets, or assets that have more positive impacts, might be made available first. In our case, health workers turned to loans because they were a quick way to obtain necessary funds, but these debts had long term consequences. In cases where health systems are paying stipends or salaries to health workers, they would do well to consider how extensively health workers rely on loans and other income generating activities. This is particularly true when health systems are considering what might constitute a "living wage" in a particular locale, and how salary changes might influence community health workers' availability for work-related activities. Where stipend or wage increases are not possible, there might be ways to establish structures that support health workers in being able to focus on their income-generating work, creating more stability where possible. This could mean the MoH and partner organizations taking initiative to be aware of CHVs' schedules and schedule activities or meetings with greater predictability, changing the amount of disruption CHVs must face. This would require further understanding of how health workers' work is structured and communicated. Another consideration might be looking at how to support the replenishment or sustainability of assets that are often overdrawn upon in pe-

riods of change, in this case, supporting the care work that health workers, including CHVs, do. There could be utilitarian ways of accomplishing this, such as compensating workers for work-related expenses, but it could also mean understanding the feelings of obligation that health workers have and providing more of an ethical framework to navigate emergency situations or escalate them to formal health workers, especially considering CHVs' volunteer status. It could also involve probing deeper into the relationship between CHVs and higher-ups. Salaried workers reported not wanting to “*task*” CHVs during payment delays, and there may be other ways burnout among CHVs could be avoided.

Another consideration would be how to share assets or support the motivation to share assets such that community members are able to leverage them when needed throughout periods of change or disruption. For example, scaffolding to the point of ensuring CHVs could use digital payments ensured one equilibrium, but that equilibrium did not equate to CHVs having thorough control of the financial tools they had at their disposal, as evidenced by continued confusion about aspects of digital payments and follow-ups. We can also see that the time frame of adaptation is an important factor in the availability of assets. For example, some partners ensured that their expertise on M-Pesa payments was available when most needed—during the activities where health workers were around to clarify any issues with their signing of the form. Similarly, extending access to and awareness of assets like workplace financial literacy initiatives or streamlined methods of following up with missing payments could ensure better long-term adaptation to digital payments. It is also essential to think about how costs to health workers, such as transaction fees or emergency spending, can be borne collectively. Digital payments were seemingly more efficient, but that efficiency came at the cost of fees, and costed relatively more for remote workers and CHVs specifically. Organizations operating in an area (and contributing to public health system strengthening) could set standards for taking on such fees.

Chapter 3

CHAT IN THE NURSING HIERARCHY AND INVISIBLE WORK

In 2019, I interned at Microsoft Research India to conduct a study of the use of chat in nurses' work. When my would-be-manager first contacted me about this internship, she proposed a study of how hospital communication is being transformed by the "*chat revolution*". Personal chat apps were, in fact, becoming an extremely popular platform for all sorts of purposes. Looking at WhatsApp, for example, there was increasing reporting, research, and even feature updates for running small businesses, supporting organizational communication, and broadcasting on a range of topics from politics to health to news. In the health domain, there was rising interest in the potential for chat to support patient-provider communication, organizational communication, and information dissemination in general. WhatsApp's popularity among workers in hospitals around the world [565] presented an interesting case, however. Why do workers choose WhatsApp despite so many communication tools being designed specifically for workplace communication? Certainly, in HCI, hospital communication has been a prime site of research and technological intervention, with a focus on communication among providers, the flow of information among paper and digital artifacts, and the introduction of new devices [40, 41, 42, 298]. In a flip of the previous study, I now had the opportunity to look at a case in which care workers themselves adopted technology in their work—might this serve the needs of care workers better?

This is not to say hospitals themselves do not have a stake in the uptake of chat among workers. Worker-driven WhatsApp adoption in hospitals, often using personal phones, has been in defiance of bans due to privacy and regulation concerns [594, 158]. The hospital we partnered with to conduct this study was also concerned about data

privacy and wanted to understand how they might formalize chat as an organizational tool to ensure patient data is secure. We wanted to understand then what made chat so useful so as to be adopted across the hospital and within nursing, whom it served, and what the implications might be of such formalization.

In this chapter, we describe the findings of an ethnographic study of nurses' work in Shraddha, a large multi-specialty hospital in South India. At the same time, we add to the emerging literature in HCI which seeks to understand how WhatsApp is becoming embedded in organisations and how it supports work practices [358, 236, 55]. Our study uncovers the unofficial, yet highly systematic way nurses and other workers leveraged WhatsApp, structured by the hierarchical organization of the hospital and the way hospital administration positioned and managed nurses at the bottom of the hierarchy. Despite only senior nurses being allowed to use their smartphones on duty, all the nurses took part in work-related WhatsApp groups. We describe the work that nurses do through WhatsApp and how chat supports both nursing practice and the hospital overall. We explicate how chat fits into the spatial and temporal rhythms of hospital work, and how the hospital hierarchy is enacted in and through it. Whereas prior research into the use of personal tools and devices at work examined adoption as an *individual* phenomenon by knowledge workers, in this paper we examine adoption as an *organizational* phenomenon by frontline workers. That is, by examining how chat is embedded in the hospital, we throw new light on the adoption of personal tools at work. Specifically, what happens when such tools are adopted and used *as though they were* organisational tools, even when not officially sanctioned. In doing so, we explicate their impact on invisible work [542] and the creep of work into personal time, and problematize the idea of worker-driven adoption. By contrasting the logics of population with how an understanding of distributed reproduction reveals more about the extent to which nurses at the bottom of the hierarchy could influence the "worker-driven" adoption of chat, we thus demonstrate the importance of looking beyond professional knowledge workers, and individual adoption, when examining the use of personal tools and devices for

work.

3.1 Related Work

Our study connects to multiple areas of HCI research. We begin by discussing communication in hospitals, focusing on nurses' work, and then discuss workplace communication, chat, and its use in healthcare.

3.1.1 Communication Needs in Hospitals

Hospitals are communication intensive [41, 314, 633, 558, 297, 298]. Bardram and Bossen highlight the mobility work needed to make hospitals function: information and people must travel across increasingly specialized departments, locations, types of work [41], schedules, and levels of urgency [40]. Thus, asynchronous communication is important, with studies showing how shared displays like whiteboards can, to an extent, support unified understandings across different schedules [633, 106]. However, the collaborative and urgent nature of hospital work also necessitates synchronous communication which can be highly interruptive [106]. Hospital communication systems have moved from overhead pagers and telephones, to personal pagers, to mobile phones and two-way, text-based systems. Checking email or messages on mobiles supports easier communication of non-urgent information [336]. However, text may be less useful for conveying complex information, and can actually increase interruptions as messages are sent more freely than paging, which is reserved for emergencies [461, 336, 309].

Most research on nurses' communication in HCI is in the Global North¹, examining the effects of digitization on nurses' work practices [558, 390, 242, 241, 657]; departmental information flows and communication, and handovers [298, 571, 558]; and

¹Global North refers to areas like the United States, Canada, Europe, and high-income parts of East Asia that disproportionately control the world's resources. Global South refers to low- and middle-income countries in Asia, Africa, Latin America, and the Caribbean. See <http://bit.ly/globalsouthanalysis> or https://en.wikipedia.org/wiki/Global_South for examples of more critical analysis.

the design and impact of devices to support nurses' communication and information needs [641, 557, 558]. Cabitza et al. note the importance of redundancy in nurses' work, where nurses' awareness of ward status allows them to substitute for other nurses during a shift [75]. Studies have also emphasized the importance of understanding whether an interruption is urgent before attending to it [151, 297]. Lee et al. found that mobile phone calls are not conducive to nurses' work in an emergency department because they do not convey urgency, nor support group awareness nor broadcasting [297]. Meanwhile in the Global South, there is a dearth of studies on nurses' work, with more focus on nurses' perceptions of technology to inform interventions in nursing work [15, 376, 485, 275, 467].

3.1.2 Workplace Communication

Past studies of workplace communication have focused on how the increasing use of ICTs affects communication, collaboration, and worker satisfaction and participation [539, 101, 147, 148, 546, 332]. Studies of non-standard forms of work, such as "nomadic" work, freelancing, and self-employment [332, 409] highlight additional communication challenges, as workers navigate multiple and sometimes unfamiliar technical infrastructures. More recently, personal tools have begun to infiltrate the workplace. Studies examining individual workers' perception and adoption of personal tools find that workers value them [246, 245, 535, 103]. For example, receiving personal email on a work account supports family connections [103]; a personal laptop allows workers to use helpful applications not permitted on work devices [245]; smartphones help clinicians reference key medical information [127]. These studies point to how workers use personal tools in creative ways, highlighting the need for greater freedom in technology use in the workplace [509]. However, there are downsides. Work-related communication on personal devices, especially mobile devices, can lead to blurring of work-life boundaries [84, 82, 83, 103, 543]. Tenorio and Bjorn argue that mobile chat technologies

can enable workplace harassment to extend beyond the workplace, but also document harassment, all of which extends employers' legal and ethical responsibilities to the online realm [561]. In healthcare, there are an increasing number of apps targeted towards providers for use on personal devices [638, 127, 379]. However, personal phones may be used for non-work purposes, resulting in worries about distractions [356] and perceptions of unprofessionalism [127]. Scholl and Goth found that the use of personal cellphones meant that doctors might accidentally call others who are not at work that day, and nurses found it difficult to handle personal versus work notifications for them during surgery [513].

3.1.3 *Chat at Work*

Messaging has evolved over time, from SMS, to computer-based instant messaging (IM), to chat apps. Early studies of IM in the workplace [196, 212, 304, 399, 233, 147], found it was used for short interactions, often for setting up phone or in-person meetings [399], or longer discussions between frequent chat partners [233]. With the emergence of mobile chat apps, there has been some discussion of how chat impacts the organisational hierarchy, with multiple studies suggesting it affords less hierarchical communication [462], including in hospital settings, with junior doctors and interns better able to access expertise from experts and ask more questions [337, 248, 400]. However, chat cannot replace the work that hierarchy accomplishes, such as filtering relevant content [358]. Mobile chat apps like WhatsApp, WeChat, and Viber have particular relevance in workplaces in the Global South, in part because they work well with low connectivity and do not cost per message [36, 100]. Meanwhile, increasing smartphone penetration and cost-effective data plans have made free apps and smartphones a dependable alternative to expensive corporate accounts and work laptops in organisations. However, the role of WhatsApp and other tools in workplace communication in the Global South remains understudied.

3.1.4 *Chat in Healthcare*

The emergence of WhatsApp has led to a flurry of studies [335, 169, 400, 92, 248, 268, 568, 602, 615, 252, 80], primarily in medical technology and communications publications. The focus has largely been on physicians and experimental trials that test the effects of introducing mobile messaging apps, mostly in Europe. Findings include that chat has value as a channel for questions and answers, consulting, and quickly exchanging information about patients [400, 248, 251, 80, 268, 602, 187, 337]. When introduced to medical teams, WhatsApp made senior physicians' expertise more accessible to junior physicians [337, 248, 400], and junior physicians felt more comfortable sending a WhatsApp message rather than a more interruptive page [248]. Kaliyadan et al.'s survey of dermatologists in India using WhatsApp found that being able to share images was a big advantage, although image quality was seen as a significant problem [251]. Finally, Kamel Boulos et al. [252] find that chat can help bridge temporal and physical distance in healthcare, drawing on studies such as Nardo et al.'s in Italy which looks at speed of response on WhatsApp or how physicians do not need to be at the hospital to answer questions on chat [400].

Even though mobile messaging apps, particularly WhatsApp, present many benefits in hospital settings, there are organisational concerns around using chat in healthcare, such as privacy of data, difficulty of auditing, and general inability to regulate the information sent [565]. This has led to a proliferation of official chat apps for clinicians' phones, offering features such as automated wiping of data or integration of chat with patient records [565]. However, most of these apps have low adoption or remain at the pilot stage [565].

There is a paucity of work on the use of mobile messaging apps by employees other than physicians. Dorwal et al. introduced WhatsApp groups into laboratory management [134]. Using a pre- and post-questionnaire to assess pros and cons of chat, they found that benefits like sending photographic evidence, critical alerts, and duty rosters

outweighed issues like the additional burden of adding information to the app. Use among nurses specifically is understudied, despite their being integral to patient care and making up a significant portion of the hospital workforce. Yan introduced WeChat groups where nursing leadership and nurses could share training modules and lessons learned. A survey showed that this motivated nurses' enthusiasm for continued learning [655]. Bautista and Lin's interview study discusses broadly how nurses in Filipino hospitals use Facebook Messenger and Viber. They communicate with doctors and each other about patients, scheduling, and staffing, and use it for socializing and de-stressing [47].

In this paper, we examine chat use in nursing in the Global South. Compared to doctors who have been more commonly studied, nurses are lower in hierarchy, with less freedom of technology choice and use, and staff nurses were not allowed phones on shift. This enabled us to study the use of chat *for* work but not *at* work, and how hierarchy and power plays out in technology use. Further, we were able to examine how the resource constraints of the Global South, along with high patient volume, impacts technology adoption and use. Compared to trials of WhatsApp use, we also uncover why chat is adopted "organically", using in-depth ethnographic methods to examine how chat fits into nurses' work practices.

3.2 Methods

3.2.1 The Fieldsite

We conducted an ethnographic study in Shraddha² Hospital, a 450-bed multi-specialty hospital. As is typical of hospitals in India, Shraddha is concerned with providing cost-effective, high quality healthcare to the maximum number of people. Shraddha serves a population with a wide range of incomes, so accessible healthcare for the largest number of people means keeping costs low.

Shraddha is divided into wards of different types, including intensive care units (ICUs),

²All names in this paper have been anonymized.

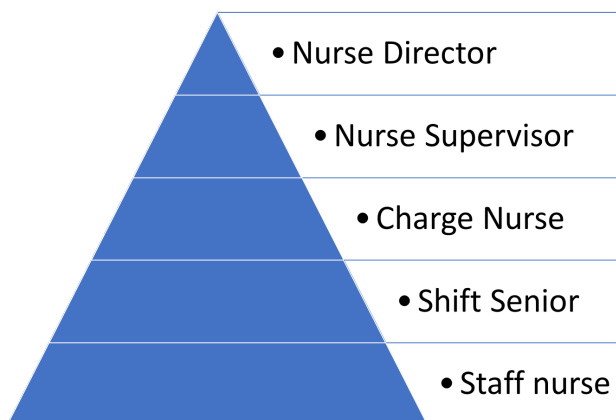


Figure 3.1: Nursing Hierarchy

the emergency ward, operation theaters, and general inpatient wards, which do not specialise by condition. Our study was conducted in these inpatient wards (known as “floors”). Patients, regardless of medical condition, are assigned beds according to the room type they desire, from open (in curtained off beds), to semi-private (two beds per room), to private. Wards with private rooms tended to serve more VIPs and patients from abroad, who are to be given particularly high-quality care. Each ward has one or two charge nurses, approximately 24 staff nurses working shifts, two doctors, a floor manager who takes care of operational issues, and a secretary. There are also other operational roles that provide services for multiple wards, such as housekeeping, transportation (who move patients), catering, IT, pharmacists, and dieticians.

The nursing hierarchy (Figure 1) consists of staff nurses and shift seniors who report to charge nurses, who in turn report to nursing supervisors, of which there are three across the hospital. Nursing supervisors report to the nursing director, who oversees the entire hospital. Staff nurses work in three shifts, with six nurses in each: 8am-2pm (morning); 2pm-8pm (evening); 8pm-8am (night). At the end of each shift, outgoing nurses handover to incoming nurses, creating a one- to two-hour period of overlap between shifts. Where there is one charge nurse on the ward, they work 8am to 4pm;

where there are two, they have overlapping shifts (8am-4pm and 12pm-8pm). Charge nurses are responsible for running their ward and managing staff nurses. Each shift has one shift senior who has additional responsibilities, including supervising staff nurses. Shifts of doctors, floor managers, pharmacists, and secretaries are from 9am to 5pm. Afterwards, the wards are served by night pharmacists, a medical emergency team, and two charge nurses supervising the hospital after hours.

3.2.2 Data Collection

Our ethnographic study consisted of five weeks of observations and in-situ interviews, primarily of nurses' work but also including admissions and two physiotherapists. These observations were supplemented by 15 interviews and three focus groups. We aimed to understand both the overall work practices of nurses and the role of chat in their work.

Observations were conducted in three visits over a five-month period. The observations were across four wards (VIP1, Semi-Private1, Semi-Private2, and General) and the admissions department. We conducted semi-structured interviews with five charge nurses (two of whom were in a fifth ward we had not observed, VIP2), one shift senior, and three floor managers. In addition to understanding the work "on the ground", to understand management's perceptions of and goals for organisational communication and nurses' work, we conducted interviews with four people in human resources (HR), the nursing director, the chief technology officer (CTO), and chief innovation officer (CIO). Finally, to probe deeper into chat use, we conducted focus groups: one group of 10 shift seniors, and two groups of five staff nurses and one shift senior. All authors made field visits, but the majority of the field work was conducted by the first author, who is fluent in both English and Telugu, the local language.

All the nurses were women and had a bachelor's degree. In general, many staff nurses hired by Shraddha were from low- or middle-class families and planned to work there for two years in order to find nursing work abroad, which could help attain higher salary

and pay off student debts; this also meant many staff nurses stayed at the hospital hostels during their time at Shraddha. Most participants had mid-range Android smartphones and data packages of 1-1.5GB per day³. They reported using popular messaging and social media apps including WhatsApp, Facebook Messenger, Facebook, Instagram, and TikTok. WhatsApp was the main app used for work. Participants typically spoke English and Telugu, or other Indian languages, such as Malayalam. Hospital documents and systems were in English (as were all messages observed).

Data collected consisted of handwritten field notes, audio recordings, and photos of work-related artifacts, including chat messages. Field notes and audio recordings of interviews were written up, translated when needed, and shared within the research team. All data collected was either anonymized during collection or shortly after, removing any personally identifiable information. We gained permission at an organisational level to conduct the field study, and asked workers for permission as we came in contact with them during data collection. The majority of time was spent at the nurses' station or the connected wings in which patients' rooms were located. In the few instances when shadowing nurses included encountering patients, nurses explained our presence and got permission from the patients for the observation, but no patient data was recorded.

3.2.3 *Data Analysis*

Our analysis takes an ethnomethodologically-informed perspective. This type of ethnography explicates the knowledgeable, artful ways in which participants organise their practice and reveals how technologies and other artifacts are used as part of the accomplishment of that practice [74, 200]. Analysis was conducted individually and together, with a close reading of field notes (recording in detail the actions and interactions observed), the photos of chat messages, computer screens, anonymized patient

³As is common in India, where data is particularly cheap; \$2 per month for 1-1.5GB per day, plus unlimited calls and SMS.

files, nurses' scratch paper, and handover notes. The aim was to understand what work a given message or note does in the unfolding situated practice. Immersion in the data through reading, writing, and discussing helped uncover gaps in understanding or new interesting phenomena that informed the next period of data collection, and resulted in the emergence of the themes around nurses' work and chat use that form our findings. Example themes include the hierarchy of work, as well as the work accomplished through chat.

3.2.4 Self-disclosure

Our positionality shapes how we collect and analyze our data. The authors are researchers in HCI and come from the United States (of Indian origin), China, and the United Kingdom. The second and third authors reside in India. All authors are experienced in qualitative research, with the second and third authors having extensive ethnographic experience.

The study was initiated through a partnership between the researchers and Shrad-dha. Shrad-dha was chosen because it offered an opportunity to understand chat use in a hospital setting, aligning with our research interests. Shrad-dha wanted to understand why WhatsApp use was so widespread despite having official organisational communication tools. We shared our findings with the hospital after analysis.

The first author Naveena is originally from the city where the hospital is located and fluent in the local language. This allowed her to build rapport. During the observations, some staff were concerned that we were working for HR. In order to ensure workers were comfortable with our presence, we frequently explained which organisation we were working for and that the intent behind data collection was to understand technology use. We further explained that the data would be anonymized and only reported outside of the research team in a way that does not identify individual workers. We also gave workers the opportunity to look at the notes or pictures we were taking.

3.3 Findings

Shraddha had two major communication needs: 1) for management to communicate to staff en-masse about organisational matters, and 2) for staff to communicate and coordinate across teams, departments, and shifts to enable coherent patient care. We explicate the role that WhatsApp played in the hospital. First we set the scene by introducing the technology ecosystem, and the characteristics of nurses' work. We then describe the work done through chat. Finally, we turn to the nuances of using a personal tool at work from the perspective of both management and staff nurses.

3.3.1 Setting the Scene

The Technological Ecosystem

As is common to hospitals in many countries in the Global South, Shraddha uses a mixture of paper and digital systems to manage patient care. Patient information is primarily kept in paper files. The electronic patient record (EPR) system is mainly used for actions related to billing such as ordering drugs and lab tests. Nurses access the EPR through shared desktop computers at nurses' stations.

In terms of communication, Shraddha is concerned with cost, confidentiality, and security, and this determines which tools are available to which workers. Only "executive level" employees (doctors, management, charge nurses, and above) have an official email account. Staff-level workers (staff nurses, shift seniors, cleaners, etc.) do not, as the license for accounts includes not just email but a suite of office tools, such as spreadsheets and presentation software, which staff workers are unlikely to use, making the license too expensive for everyone. Concerns about patient confidentiality and data security play out in Shraddha's policies on mobile phone use, applying mostly to workers lower in the hierarchy, such as staff nurses and cleaners. Staff-level workers are not allowed to use mobile phones on the floor, as management was especially concerned

about phones being a distraction or that phone cameras might be used to take photos of patient records. Shift seniors, charge nurses, and executives (such as housekeeping managers) are allowed to use mobile phones. Each ward has landline phones and internal numbers.

WhatsApp was widely used in this ecosystem. Shraddha's management was aware of this and was not against the use of *chat* per se. However, WhatsApp use raised privacy and data security concerns around sensitive information being sent over a personal app. They wished to understand how they might migrate staff to an organisational chat tool: not necessarily to regulate or formalize chat use but rather to ensure that even informal communication respected patient privacy.

Being a Nurse

Nursing work consists broadly of care work, document work, and training and learning. Their day is determined by the rhythms of the ward and the organisation, but also by patients and their changing conditions, which are inherently unpredictable. Nurses' work is both *routine* and *unpredictable*, consisting of routine tasks that happen at a set time daily (e.g., handovers; taking vitals; giving medication, accompanying doctors' rounds) and tasks which may be common but ad hoc (e.g., attending to patient calls; assisting medical staff; transferring patients; dealing with emergencies). Nurses work with constant interruption and are constantly busy, but all tasks are not of equal importance. Nurses attend to a *hierarchy of work*, prioritising medical urgency and organisational hierarchy above routine tasks. Nurses are expected to provide support to medical staff, such as doctors, surgeons, and anaesthetists, any of whom may drop by to see a patient. Nurses frequently must pause ongoing work such as documentation, which can be done later, to attend to more pressing, immediate needs. To illustrate, vitals checking and recording usually takes seven to nine minutes per patient, but during one observation it took a nurse 15 minutes per patient because of interruptions from patients' families,

a cleaner, a charge nurse, a doctor, and another nurse who urgently needed the computer she was using to record the vitals. We also observed multiple instances where the stress and high stakes resulted in breakdowns (particularly in cases where senior nurses were concerned that staff nurses had made a mistake) as well as frustrations with the thanklessness of the work.

There was a clear organisational concern with avoiding mistakes and we saw a tension between the practical work of nursing and the other work involved in being a nurse, such as documentation and learning and training. It is in this context that WhatsApp use needs to be understood.

3.3.2 *Working with Chat*

We first outline the chat groups observed before describing the work done through them. There were several *nursing groups* for management of wards and communication up and down the nursing hierarchy. Each ward had a “floor group”, made up of the charge nurse(s), shift seniors, staff nurses, and sometimes their nursing supervisor. Floor groups are the primary means of digital communication with staff nurses and their only work group, although some were members of social groups including all ward staff. As staff nurses are not permitted to bring their phones onto the floor, they must check this group when off-duty. Other nursing groups included: Shradha Nursing, which consisted of the nursing director, nursing supervisors, charge nurses, and shift seniors; and Nursing Supervisor’s Team which consisted of one nursing supervisor and her charge nurses and shift seniors. In addition, there were *cross-departmental management groups*, such as Shradha Performance (CEO, doctors, nursing director, charge nurses, department heads, HR). Finally, there were groups to manage specific projects, as well as IT and Operations groups. Altogether, these groups served to support best practice, compliance and training, as well as reporting and prioritising patient satisfaction.

Best Practice, Compliance, and Training

Mistakes can impact patients' well-being and even cost lives. A clear organisational concern with ensuring compliance with processes and procedures permeated Shradha from upper management to staff nurses. As one charge nurse shared, "*I don't want any issues in our floors, [...] even small or single issue also I don't want.*" Charge nurses consistently tried to ensure awareness of, and compliance with, best practice and procedure amongst their nurses. In person, they advise or even scold nurses on the job if they deviate from best practice. Chat is used to help ensure that a mistake is not repeated by other nurses. Charge nurses or shift seniors follow up any incident from which other nurses might learn with a post to the floor group. For instance, in Figure 2 (left), a charge nurse outlines best practice regarding labeling a lab sample, that is, not putting labels over the barcode. She illustrates the problem with an annotated image, accompanied by an explanation of how improper labeling impacts sample processing. The charge nurse expects at least some nurses to acknowledge, particularly shift seniors, who are supposed to reinforce the message in person with staff nurses. Additionally, incidents are written up in a counseling book at the nurses' station which staff nurses must sign. Chat messages instantly reach all nurses' phones, including those who are off-duty, and clearly document and detail the issue. However, they do not guarantee understanding in the same way as in-person discussion.

Chat supports *continuity of management* despite shift work. For example, one charge nurse had her shift senior send her pictures of the ward every evening after her shift had finished, to show that the ward was clean. This both serves to ensure that the ward gets adequately cleaned, even though an in-person check was not possible, and to let the charge nurse know that it is in order. Chat is also used to follow up with individual nurses, in the case of problems, even after their shift has finished. For example, as part of a new initiative in one ward, vitals needed to be entered into the EPR rather than the paper file. However, nurses were doing this late and inconsistently. The charge nurse

followed up each inconsistency with the responsible nurse via the floor group. In Figure 2 (right), the charge nurse points out that one staff nurse has not entered the 10am vitals for a patient. The nurse explains she entered it at 11am because she had to move the patient and had explained the same to another senior nurse. Chat enabled charge nurses to monitor the ward when off-shift and manage her entire team whatever their shifts. Through chat, she can question all nurses and, while she might not get an answer immediately, it enables her to get more rapid responses and better manage her own work.

Finally, chat was used to support training, distributing documentation such as updates in processes and procedures, and informing nurses of upcoming classes that they need to attend. In one example, an infection control nurse borrowed the charge nurse's phone to send study materials for the nurses to read for a test the next day.

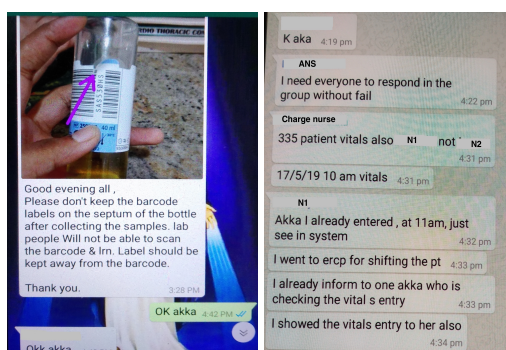


Figure 3.2: Left: Best practice on floor group; Right: Compliance on floor group

Reporting

Another way of supporting continuity between shifts was chat-based reporting. At the end of every shift, a report is created, detailing figures such as the number of patients admitted or discharged, critical patients, and any issues that arose. When the charge

nurse is not there - at the end of the evening and night shifts, or when she is on leave - this report is shared through chat. Typically, it is typed out but may be hand-written and photographed. For example, the evening report is sent by shift seniors before they leave. The shift senior asks each staff nurse in turn for the bed numbers of admitted, discharged, and critical patients. She notes this on scratch paper, collates it, and types up a WhatsApp message summarizing it (Figure 3). She mentions a patient waiting on billing, indicating an upcoming discharge, and describes in detail how an issue with cannulization played out on-shift, taking care to mention that she has informed the night supervisors so that the charge nurse knows they are accountable.

Reporting over chat enables the charge nurse to keep an eye on what is happening on the ward while not present and serves to hold the nurses and shift senior accountable for following the correct procedure when issues arise. While not on duty, the charge nurse is still in charge and ultimately responsible for what happens on her ward. Keeping abreast of ongoing work and incidents helps her when she returns to her shift, as she needs to be knowledgeable about each patient's status in morning rounds and demonstrate that she is monitoring the ward. Charge nurses similarly report to the nursing supervisor via chat if they cannot do so in person.

Despite the usefulness of reports, using chat for reporting was time consuming. Reports require a mix of numbers and letters, which meant constantly switching keyboards, and medical terms were rarely part of the keyboard word suggestions, meaning typing a report could easily take 15 minutes.

Being Patient-Focused

As well as attending to patient's medical wellbeing, nurses must also care for emotional wellbeing. If a patient has a special event such as a birthday, the team celebrates with the patient. Pictures of these celebrations are shared on the floor group for morale, and on management groups as demonstration of a good ward. As one charge nurse said "If

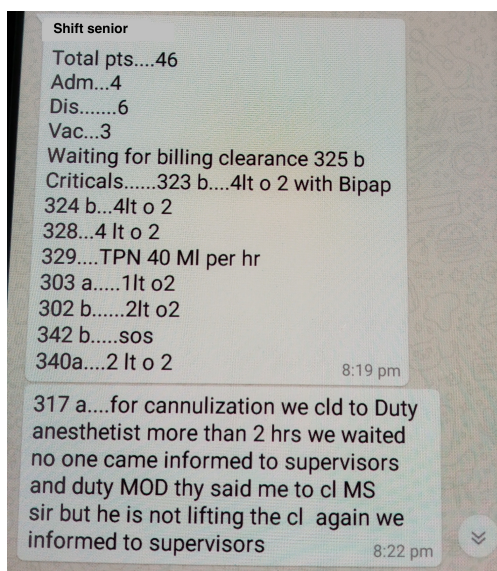


Figure 3.3: Shift report from floor group

we are having good rapport with patients, then only we'll come to know their birthdays and anniversaries and all, then only we can celebrate.”

The hospital management has a strong orientation to patient satisfaction and wards are evaluated on it. Patients can provide (formal) feedback in the form of compliments or complaints which are emailed to the nursing supervisor, who shares them through chat on Nursing Supervisor's Team. There, charge nurses and shift seniors can see feedback across wards, as well as their own. Charge nurses then forward feedback specific to their ward to their floor group, so that staff nurses can see it. Compliments that name individual nurses allow for recognition, while complaints offer a learning opportunity, reinforced offline with individual nurses. Patient satisfaction is also recorded in the Net Promoter Score (NPS), a ward-level performance metric. Scores are posted weekly on Shradha Performance, letting the management know how each ward is doing. We saw messages in different chat groups orienting all nurses to doing the right things to get good scores. Thus, chat supports both a hospital-wide awareness of ward performance,

and ward-level learning. The email-chat transition enables both group awareness and feeding back to nurses.

3.3.3 *Situating Personal Chat Tools in Organisational Matters*

In this section we examine chat use as an organisational phenomenon and the tensions its use creates.

Chat and the Nursing Hierarchy

The formality of nurses' chat use was striking. The groups created reflected the organisational hierarchy, influencing who posts, what is posted, and group formation. When new staff nurses join, they are added to their floor group almost immediately. They rarely post except with "*Ok akka [older sister]*" (see Figure 2, left) to acknowledge they have read something, to give an explanation if called on to do so, or to provide requested information, such as uniform size. The only spontaneous posts we saw were to ask for the duty roster, showing their shifts. While charge nurses are active posters in the floor group, which they use to manage their ward, they are less active in the nurse management groups, where they are lower in the hierarchy and it is usually the nursing supervisors who post on behalf of the nursing director. Even deciding what is posted is formal: as one charge nurse said, the nursing supervisors will ask the nursing director, and "***then madam will decide to please put it in the group so that everybody will be aware of the issue.***"

Information cascades down the hierarchy, through the chat groups. In one instance, the nursing director messaged the nursing supervisor about a new changing room. The nursing supervisor posted it on Shraddha Nursing, from which the shift senior forwarded it to the floor group. Similarly, one shift senior explained how her charge nurse might send messages in a group with only shift seniors: "*First she will teach us, she will keep information with us, then we have to tell to our juniors.*" The shift seniors would then

share in the floor group and follow up in-person with the staff nurses during their shift. When we asked the staff nurses how they identified which information was important in their floor groups, they laughed, *“Every information if the [charge nurse] pass it, it will be important.”* WhatsApp use reflects and reinforces the official hierarchy. While it may not be officially sanctioned, it is neither informal nor ad hoc, instead being ordered and organised by the hospital structure.

However, this does not mean there was no flexibility. Which workers are included in a given group depends on that group’s manager. For example, while the floor groups of one charge nurse only contained nursing staff and the nursing supervisor, those of another also contained floor doctors and floor managers. Similarly, some charge nurses had groups with just them and their shift seniors, while others preferred to use the floor groups for all ward-level communication.

Using Personal Chat Tools for Work

Chat’s widespread adoption testifies to its usefulness in the hospital, but it was not without problems. One problem, reported previously, is the “chat data deluge” [358] consisting of the sheer volume of messages taking up space on personal phones. When charge nurses post, staff nurses acknowledge, resulting in *“oh so many messages”* (shift senior). Participants reported that they frequently deleted messages to free up space.

Chat could also be a distraction. One charge nurse noted how it detracted from her first priority, patient care:

“I don’t like using my phone. We are spending more time in WhatsApp so we are not able to know what is going in the wards that we run. Because in this floor, 40 beds is there, so 40 patients. Criticals is there, nurse is there, she went to shifting other patient, so that wing nobody is there. If I’m not worrying about that wing, if I’m bothering about phone means [...] the patients can suffer, no? Most of the times, I’ll be [looking at] the important messages.”

Other charge nurses reported how they would mute groups, to reduce distraction from frequent notifications. Charge nurses also try to minimize the use of chat off-duty, despite their desire to stay in touch with their ward. One charge nurse mentioned “*Once I go home I’ll just keep my mobile away from me, I’ll see that when it rings only [...] apart from that I’m never using [...] I’ll just check for reporting purpose.*” In this quote, we can feel something of the intrusion of work on personal tools. One shift senior hints at attempts to separate work and home, saying “*Once the shift over, before we leave hospital, we’ll send [a report to the charge nurse].*” However, staff nurses are expected to read their messages off-shift, and they say “*We’ll make sure that we read everything.*”. Implying that the *opportunity* to separate work from life only comes as one moves up the hierarchy, but that personal tools do not easily *afford* such a separation even then.

Staff nurses did not express strong opinions about using their personal phones for work or checking messages off-shift (perhaps because they were not comfortable discussing it with us, had little choice in the first place, or had not really considered it). However, when asked if they would like a work phone, they were generally positive, as it would help them separate the “too many” work messages from personal messages. They also said that with this separation, if they were allowed a phone on-shift, they would not get distracted by personal messages nor be questioned about whether they are focused on work. They were not particularly enthusiastic about having a mobile phone on-shift in the first place, however.

The Unofficial Nature of Chat

Since staff-level workers at Shraddha do not have organisational email accounts, the use of chat leaves the organisation with something of a dilemma. Chat supplements formal channels, enabling group awareness, visual illustrations of problems, and sharing information across shifts. However, the unofficial status of chat, combined with the fact that staff are not allowed to use smartphones on the floor, mean that HR has an uneasy

relationship with it. HR employees have their own chat groups and post on management groups, but do not use chat to communicate with staff nurses. When they need to communicate with nurses to, say, advertise new benefits or instigate performance appraisals, they put up notices near the clocking-in machines, hold town-hall meetings, or phone campaigns (for remote clinics). However, these strategies are less than ideal, with one HR manager reporting that it takes a minimum of three to four weeks to reach people and even then, some will be missed. Notably, when asked, the nurses said they never read HR's notices, except when charge nurses share on the floor group! As a staff nurse explained: "*One paper notice they will keep and our in-charge, she will [...] keep a photo in the WhatsApp group.*" Similarly, HR may email management who then use chat to spread the word. For example, to get sizes for new nurses' uniforms, HR emailed the nursing director, who sent the request on chat to charge nurses, who used floor groups to collect this information. In the end, despite HR's uneasiness, most communication from HR reached workers through chat.

Making Chat an Organisational Tool

Nurses had little idea about the potential privacy issues around having work information on personal phones. While nurses did not take pictures of patient records or such data, this is still a concern for the organisation, and indeed would be a major driver for Shraddha to move to an official chat tool. However, making chat official might introduce new problems, at least for some more senior groups. Our interviewees from HR, who themselves used chat, felt that any formalization of chat would ruin a good thing. Chat was valued precisely because they saw it as informal, and they could quickly accomplish a simple task without the rules or ceremony that might be introduced otherwise. However, it is questionable whether the same holds for staff nurses who already experience chat as formal. In fact, workers lower in the hierarchy said they would be fine using an organisationally sanctioned chat app, saying "*new things we learn everyday no?*" and

tellingly, “*telling means we have to do it.*”

It is important to highlight nurse’s own notions of ownership and privacy. Less senior members, such as staff nurses in floor groups, or shift seniors and junior charge nurses in Shraddha Nursing, did not always feel they had the authority to show us the group’s content. When nurses were more senior *in a group*, they felt comfortable showing us the messages. There was also a desire to keep some chats private. In one instance, a charge nurse asked us if we were with HR before mentioning a group that she was in which coordinated with another department to handle issues with a ward initiative, suggesting that those issues may not be apparent to the wider organisation.

Finally, privacy was desired in floor groups. Staff nurses were hesitant to show us messages where charge nurses were scolding them, pointing to the internal nature of the floor groups and how they are meant to correct behavior before it affects anything else. A staff nurse in the second focus group mentioned that privacy from non-nursing staff is why she would not want to receive messages on-shift through shared computers, unless it was protected by nurses’ log-ins. This is in contrast to the management groups where we saw IT and maintenance issues being escalated in front of leadership as a way to get a resolution when traditional channels were not working. Typically, once an issue was raised in these groups, a response came within minutes.

3.4 Discussion

We examined the formal and systematic use of chat in Shraddha. Our findings contribute to the growing body of research on the organisational use of chat. In this section, we examine which features of chat have led to such widespread adoption, and explicate the tensions between the personal and organisational. In particular, we describe how *workplace expectations* of use arise, and their impact on workers’ personal choices, particularly workers lower in the organizational hierarchy. Drawing on the notions of population and distributed reproduction, we contrast the hospital’s management of staff

nurses' technology use to keep patient data private and costs low, with the way communication is actually done among nurses and how formalizing chat thus becomes not just a matter of switching to a different tool but also about recognizing the invisible work done on chat by staff nurses.

3.4.1 Making Chat at Home in the Hospital

Chat was made at home in the hospital in two ways, as a tool within the larger communication ecosystem, and as a reflection of the hospital hierarchy. While the former demonstrates the extent to which chat was useful for nurses' work, the latter shows how the use of chat was largely designed by those higher up in the nursing hierarchy.

Filling a Lacuna among Workplace Tools

Hospital work follows particular temporal and spatial rhythms, with staff on the move across the hospital or within wards and working shifts to provide round-the-clock care, while management work office hours or curtailed shifts. It is the combination of chat's features that make it such a useful tool in this setting. As noted elsewhere (e.g., [196, 358, 212, 399]), chat offers the ability to share short text messages and photos, create groups, and support both synchronous and asynchronous communication [196], and of course, chat is "to hand" *for staff who are allowed to use their phones on the floor*. We observed multiple types of communication within the groups: one-to-many announcements; many-to-one for data collection; many-to-many for social messages; and even (rather public) one-to-ones where charge nurses followed up with individual staff nurses in the group so that others could learn. Chat was used alongside a range of other communication tools and practices, such as meetings, phone calls, counseling books, posters, and email (for management). Frequently, multiple channels were used for the same message, to ensure understanding. Chat helps to reinforce messages about organisational and local work practices, detailing them with photos and enabling a rapid

spread across shift boundaries. Despite being a personal tool on personal phones it has been “*made at home*” [496] in the hospital’s communication ecosystem. It is used all the way from upper management to staff nurses, enabling management to keep communication digital by transitioning from email to chat. Indeed chat was *preferred* in that the transition happened at a high hierarchical level, rather than only occurring at the point where nurses did not have email (though this did have implications for staff nurses’ time, as discussed below). It was also used to go from physical to digital when taking photos of posters to ensure the message was conveyed. The value of photos has been noted elsewhere [251], and using them to bridge the physical and digital worlds is a core advantage of chat.

Chat was used for reporting, training and compliance, supporting best practice, and creating awareness. As in prior work [399], chat is used to set up meetings, but we also found that chat groups were created in and for continuing meetings. With multiple admins, it is possible to add the appropriate people in a decentralized way and at any time. Chat offered an easy way to rapidly spread awareness of relevant information through different strata of the hospital extending the town halls, shift meetings, in-person reporting, and process and policy reviews. In this way, chat supports the organisational concern with getting things right. It adds extra functionality to the set of resources for ensuring good practice, from photos, whether to prompt work or reveal learning opportunities (similar to [655]), to the ability for charge nurses to stay in touch through reporting when off-shift. Accountability was also practiced in various ways through chat, from calling nurses to account, to reporting, to taking photos of the clean ward.

Reinforcing the Hospital Hierarchy

Prior work on clinical teams with senior and junior doctors found that chat helps to flatten the hierarchy and ease communication [337, 462, 248]. In Shraddha, WhatsApp use *reflects* and *reinforces* the hierarchy, through group membership, who posts what, who

acknowledges what, and the hierarchy of groups. For example, staff nurses mainly post “*Ok akka*”, while Shraddha Nursing is for top-down communication from upper management. Shraddha has a formal, traditional hierarchy with staff nurses accountable to charge nurses and charge nurses to their nursing supervisor. This accountability manifested in various ways: staff nurses are directly scolded for mistakes, and the very presence of senior leadership in management groups was enough to ensure a rapid response from the relevant teams to issues raised on chat. The group visibility and membership makes chat an effective accountability device for senior nurses. Thus, communication practices such as being respectful or hesitant to interrupt a superior, do not disappear on chat but continue to manifest in various ways. It is not the communication tool *itself* (whether chat or any other tool) that determines what communication will look like, rather it is *the situated practices of using that tool*. Communication over chat can be just as hierarchical and formal as over any other means.

A particularly interesting example of hierarchy at work is in the hospitals’ information flows. While prior work has largely looked at individual conversations or groups and the coordination that happens within them [252], by examining *the network of chat* we can see how the flow of information through the various chat groups supports the organisation in using the same information in different ways towards common goals. For example, NPS scores, audit results, and policy reminders flow through multiple chat groups, gaining particular, situated meaning and purpose when they are posted in Shraddha Performance (cross-departmental management group) versus Shraddha Nursing (nursing management group) versus floor groups. The first two support organisational management functions, the third is about operations and getting the work done on the ground. This group structure contrasts with some of the issues with chat seen in prior work where a lack of filtering made it difficult for workers to tell what information was relevant to them [358]. Creating groups along a hierarchy builds in filtering, so a staff nurse will know that if a charge nurse forwards something to the floor group, it is relevant to them.

3.4.2 Using Personal Tools for Work

Because of its widespread adoption and positioning within a hierarchical structure, there were also tensions around bringing a personal chat tool into work, complicating the notion of worker-driven adoption and the separation of work and personal time.

Worker-driven Adoption

Prior work in HCI on the use of personal tools among workers has largely studied *individual* perception and adoption [246, 245, 535, 103]. They show the creative ways such tools were used, sometimes to blur the lines between work and personal (such as checking personal email) or to get around workplace restrictions (such as using applications of choice to get work done). In Shraddha, in comparison, we examined the *organisational context* of WhatsApp use. While it might seem that the adoption of WhatsApp was worker-driven, what does “worker-driven” mean here? Certainly, it was not organisationally sanctioned and is not an official communication tool. However, its use in nursing is so prevalent and formal that it is being used *as though it were* an organisational tool. That nurses have smartphones and data is taken as a given (and we found no exceptions). Critical information is communicated over chat, and they have little choice but to be part of the chat ecosystem. None of the nurses we spoke to objected to this nor really discussed it. Nonetheless, it adds a different tint to the idea of chat adoption as worker-driven, especially as nurses said that if they were told to use a different organisational chat app, they would simply have to do it. It is clear that WhatsApp, as a mobile phone-based chat app, supported the work of the hospital, but once it was endemic, *individual workers* have little choice but to use it. This collective effect, which capitalizes on widespread personal adoption and results in new expectations for use, is rather different from previous research which looked at how *individual professionals* and *knowledge workers* build and control their artifact ecologies [245, 535, 490, 544, 246, 61, 577, 62]. While the idea of worker-driven adoption might

seem equitable and democratic, it is complicated when such tools become *necessary* for that work. Further, it is worth reflecting on which workers have a say over adoption in the first place and how adoption impacts workers at different hierarchical levels, as we discuss next.

Taking Nursing Work Home

Even as chat configures time and space to reach more nurses at once and more easily collect needed information, there is the question of who this efficiency serves—for staff nurses, chat requires taking nursing work home, in their personal time and space. This has been noted in passing in other research on chat in healthcare, such as consultants responding to questions outside of work [400], but is worth examining more closely. Since staff nurses cannot use their phones on-shift, they *necessarily* have to keep up with the chat after work. Further, since messages are often about tasks that need to be done before the next shift, such as looking over training materials or showing up to a training session, nurses were obligated to check these messages not just “at some point” but sooner rather than later. This raises questions around when staff nurses are not on call in some way, or when they can be sure they do not need to check work-related messages. However, even if phones were allowed on-shift, work would still carry off-shift, in part because one of the most useful aspects of chat for charge nurses and others is bridging the temporal mismatches between shift work and management work. It is also a consequence of an *essential tension* in nurses’ work between the *doing of nursing* - a physical, hands-on job, that is busy, sometimes urgent, and frequently interrupted - and all the other work necessary to *being a nurse*. This includes training, continual learning, reporting, and being accountable, all of which are supported by chat. Reading of training documents and absorbing new material requires focus and concentration and could not easily be done on-shift because the rhythm of work does not support focus time. While there are formal structures for training, such as classes before shifts,

much of the training is more ad hoc. With chat, this ad hoc training infiltrates off-shift. Even picking up best practices, which in theory might be done on-shift, in practice could be difficult. Such work is currently largely *invisible work* [542].

Staff nurses did not particularly want to look at messages during their shift. This is in part, as noted elsewhere [127], due to concerns about being called up for doing personal tasks at work, but also because of the problems of fitting message reading in with their ongoing nursing work. They already struggle with the tension between caring for patients and documenting this care, and we have seen how charge nurses struggled to balance being present on the ward with being present in chat. As noted elsewhere [461], messaging on-shift while useful can be disruptive, but is a reasonable consequence of that to expect staff nurses to take it off-shift?

These findings contribute to understandings of work-life balance in different domains and expand on studies of using personal phones in healthcare settings [127, 356, 513, 400]. While previous studies highlighted the impact on-shift, in terms of distraction and appearing unprofessional, they do not consider the impact off-shift, although some mention in passing that work can extend past the workplace [400]. Further, these studies observe greater autonomy in whether and how *individual workers* like physicians use these tools, but in Shraddha's case, WhatsApp became an *organisationally necessary* tool. This makes the infiltration of work into personal time when personal apps and devices are used more explicit and visible. Other research examined freelance, nomadic, and knowledge workers [102, 497, 141, 84, 83, 103, 178, 543, 159]. They emphasized the ways individuals navigate work-life balance and structure their time, focusing on how they actively set, soften, or dissolve boundaries as needed (allowing work-into-life and life-into-work), or set micro-boundaries [84, 83]. However, staff nurses had much less freedom. Given WhatsApp brings work messages alongside personal messages, micro-boundaries [84, 83] are difficult. Further, while management-level nurses could put their phone aside, a less than ideal solution already, it is not clear that staff nurses even have such freedom. These power dynamics within the nursing hierarchy must be con-

textualized in the broader flows of nursing work. Staff nurses at Shraddha make up a significant portion of the hospital workforce, but have a high churn rate. Thus, their technology use is highly controlled as a way to manage privacy concerns and keep costs low. And though we did not discuss this directly with nurses, it is important to keep in mind that gaining enough work experience at Shraddha held significant stakes for staff nurses who aimed to find work abroad later. In comparison, professionals, doctors, and managers who may have different stakes and positions within organizational hierarchies may have more control over technological use and boundaries.

The Organisational Dilemma

From an organisational perspective, chat use introduces an interesting dilemma that contrasting the logics of population and distributed reproduction helps highlight. WhatsApp use poses concerns about data privacy and confidentiality [565]. However, it is widely and systematically used and is clearly organisationally useful (at least for certain organizational priorities, if not staff nurses' division of work and personal time). In particular, chat even helps fill in some of the gaps in current communication strategies that HR did not seem to be aware of, such as the inefficacy of paper notices. An obvious solution would be to introduce an organisational chat tool which takes care of data concerns. However, introducing such a tool is not quite so simple and involves intervening into a complex set of uneven relations and stakes that produces the hierarchical workplace and reconfiguration of staff nurses' time. First, given the price consciousness of the hospital, it is extremely unlikely they could buy work phones for all levels of staff. Thus, it would need to be an organisational tool on a personal device, which raises its own questions, from the data deluge, to organisational mandate. Second, the activity on chat would necessarily become sanctioned by, and visible to, the organisation. As staff nurses are not allowed to use their phones at work according to management's own policies, the hospital would be asking nurses to work off-shift. Since chat has been adopted

and is being used as though it were an organisational tool, making this invisible work [542] visible and organisationally acknowledging it would be no bad thing but it does introduce new issues. It is in the move to formalize chat that invisible work becomes visible, whereas when carried out on a personal app on a personal device, it remains largely invisible. These findings have implications beyond Shraddha, given that personal tools are likely to be increasingly used in the workplace. How can organisations understand and take into account the work done on such tools and the burdens and opportunities they bring to the workplace and workers? At the moment, chat, for example, sits in something of a gray area, as noted previously [561].

Finally, it is many of the informal features of chat that make it so useful, such as being able to create any groups you want or to be able to communicate without upper management monitoring it. Any formalization of chat through an organisational tool would need to be carefully considered. As noted in [358], the tendency for organisational tools to be implemented top-down can detract from their usefulness and uptake. This highlights another organisational tension: workers' need for informal communication versus the organisations' desire to control and monitor communication. While we recognize and, in theory, support the call for greater freedom in technology use in the workplace [509], it is also vital that we get a clearer understanding of the implications of the widespread adoption of personal tools such as chat in organisations, looking beyond professionals and knowledge workers. How can organisations and workers manage the encroachment into personal time? This is especially important to consider for those lower in the hierarchy and in, for example, caring professions where work can bleed into the personal for all sorts of reasons.

Chapter 4

PEER SUPPORT FOR YOUTH LIVING WITH HIV AND CAREFUL INFRASTRUCTURES

In 2020, I had the opportunity to analyze the use of WhatsApp for facilitated peer support for youth living with HIV in Nairobi, Kenya. While this project had been piloted in 2019, data analysis coincided with the convergence of a number of factors that were motivating looking at the potential for chat as a forum for connecting care workers and care recipients. WhatsApp in particular is one of the most widely used chat apps globally, and with the price of mobile internet data decreasing across the world, it was a way to widen reach, including to low-income and rural communities. Further, the start of the COVID-19 pandemic and quarantine measures in 2020 made online communication more necessary, not just because of quarantine measures but because stressed health systems needed ways to still offer the emotional, social, and logistical support beyond clinical diagnoses required for positive health outcomes [272, 460, 532]. This was a way to think about, then, how chat was introducing new forms of care work, taking place largely online but intended to bridge existing and new spatial boundaries that made physical and even social interactions challenging.

Prior work in HCI had mostly focused on how to improve the design of online health communities, on both existing and bespoke platforms, to meet the needs of peers (e.g., [184, 417, 492, 598, 404]). More recently work has shown that as these communities form on personal chat apps, there are new design aspects to consider, such as managing large volumes of messages [598, 417, 636, 264]. Additionally, there is room to understand how care work and community-building happens in contexts especially in the Global South characterized by phone sharing [500, 71, 9], high turnover in mobile phone and SIM

ownership [626, 628], and intermittent internet access [632, 346, 44]. These patterns of use shape engagement with chat-based interventions, impacting users' experience of them. They also complicate the use of mobile phones for addressing highly stigmatized health concerns, such as HIV, mental health, or sexual and reproductive health, since privacy can be a serious concern in these cases. These contingencies pose the question of whether and how chat-based peer support groups can be useful to members given the realities of participation.

In this paper, we present a pilot of facilitated WhatsApp-based peer support groups for youth living with HIV in an informal settlement in Nairobi, Kenya. For six months, a facilitator trained in HIV counseling posted weekly messages, facilitated group discussion, and addressed members' questions and concerns in two peer support groups differentiated by age group. The six-month period was bookended by introduction and closing meetings that offered participants the opportunity to meet in person. We describe participation in and perceptions of the peer support groups, based on a qualitative analysis of the chat records and interviews with a subset of group members and the facilitator post-intervention. We describe how participation was shaped and sometimes limited by unique social dynamics, intermittent access to the groups, and privacy concerns, all of which contributed to the work that the facilitator needed to do to support the group. Ultimately, participants overwhelmingly reported benefits from being in the group, most notably, becoming motivated by newfound aspirations and a sense of community to overcome challenges in management of HIV. We contribute to scholarship in HCI and HCI4D by describing implications for the design of chat-based peer support. We highlight what greater scale and integration into health systems could mean for interventions such as these and suggest ways that they could account for the work of the facilitator and participants' patterns of use. We also discuss privacy concerns in mobile health applications and how safety could be fostered in diverse ways. We end with takeaways for fostering social support for aspirations in health interventions.

4.1 Related Work

We draw on work in HCI and HCI4D on health messaging and technology-mediated peer support, including as it relates to HIV. We also describe work at the intersection of health, technology and internet access, and privacy.

4.1.1 Health Messaging

A whole slew of studies in both the Global South and Global North have sought to understand how messaging can be useful in healthcare, so far mostly using experimental trials to describe the effectiveness of voice messages [250, 471], patient portals [659, 551], or (most commonly) SMS (e.g., [167, 441, 442, 650, 301, 368, 274]) for communicating with patients about a wide range of chronic health concerns, including HIV (e.g., [303, 137, 93]). One-way automated SMS has been used to send patient education [301, 72, 579], tips for managing one's condition [98], reminders about personal goals and adherence [167, 195, 188, 174, 56], and brief quizzes [93, 650]. Two-way messaging additionally allows healthcare providers to directly counsel patients between visits [410, 303]. For example, Perrier et al.'s two-way, semi-automated SMS intervention in Kenya showed that automated messages prompted greater engagement and questions from pregnant women to the nurse [441]. Studies that target HIV, many of them in sub-Saharan Africa, have used SMS to send information and reminders about appointments or taking antiretroviral therapy (ART) [250, 56, 137, 174, 188], conduct large-scale campaigns to promote testing [93], and support communication with an HIV clinician [441, 303, 137]. These studies have found positive outcomes [353], such as increased ART adherence and CD4 cell count [174, 188, 353, 210], decreased viral load [303, 210], and general engagement such as asking medical and logistical questions [354, 441]. While these studies underscore the importance of periodic messaging, they have yet to address the possibilities that group-focused settings offer.

4.1.2 Chat-based Peer Support

Increasing access to smartphones and data have allowed messaging to move to mobile chat apps like WhatsApp, and chat-based peer support groups have been created organically among youth in parts of countries like Kenya and South Africa [5, 33, 420]. These apps do not cost per message, allowing for relatively more engagement if data is available. More features open up avenues for richer interactions among peers and healthcare providers while still being relatively lightweight compared to many online forums. Early studies have found that chat apps are useful for multimedia learning around health topics, patient-provider communication, and peer support [307, 278, 598, 219]. For example, Li et al. found that using WeChat to share multimedia educational material to Chinese expatriates in Niger supported malaria literacy [307]. Hay et al. interviewed mentor mothers in an HIV peer support network in the United Kingdom about their use of WhatsApp, finding that it was convenient compared to in-person meetings, but that there were challenges with the cost of data and privacy [206]. Among studies on chat-based peer support, some discuss the design of interventions that only involve peers [398, 417], such as O’Leary et al.’s design work on guided and unguided peer support chats for mental health [417]. Other studies explore facilitated groups [219, 598, 92]. Some of these studies show improved clinical measures [92, 219] but in-depth qualitative work characterizing these groups and users’ perceptions of them is scarce. Wang et al. recently shed light on the work of nurses who facilitate a WeChat group for IVF clinic patients in China and recommend ways to support the nurses in handling the extremely large volume of patient messages [598].

4.1.3 Online Health Communities and Technology-mediated Peer Support for HIV

Prior work in HCI has extensively explored group interactions in online health communities targeting a wide range of health conditions. This work has largely focused on spaces such as online forums, bulletin boards, Reddit, Facebook, and Instagram. While

our work offers a perspective of how peer support plays out on more lightweight, unstructured, and closed forms of communication like chat apps, there are a number of themes in HCI scholarship on online health communities that we draw on. Some studies have described the mechanism for how these communities support users, for example upholding experiential knowledge, or supporting a sense of community empowerment [184, 181, 434]. Studies have also analyzed content, noting tensions in whether and how users are able to meet each others' support needs [223, 522, 395, 264, 588, 329], as well as beliefs and practices that exacerbate the very problems users came to resolve [479, 306]. Prior work has looked at the rhythms of user engagement, noting how intermittent or brief engagements in these communities can be purposeful and useful to participants [6, 341, 340]. Few studies deeply describe or address the role of peer or expert moderators [221, 341, 224, 296]. Huh and colleagues explore how to semi-automate clinicians' work on forums [224] and how moderators might better support patients who ask about clinical questions [221]. A subset of this work focuses on disclosure and particularly sensitive health concerns like depression, substance abuse, and menstrual health, noting the importance of private channels, developing privacy norms, constructive moderation, and diverse levels of readiness to discuss sensitive topics [25, 640, 492, 646, 575].

HIV is a particularly stigmatized illness. Fear of stigma and associated mental health concerns can prevent people from learning about it and seeking care [402, 285, 537, 394, 135]. Long-term care itself can be daunting, requiring ART adherence, monitoring viral load and CD4 cell count, and patient education. Even with treatment, issues like negative experiences with healthcare workers can affect adherence [540]. In light of these issues, Natarajan and Parikh [402], as well as others, suggest a focus on peer support, outreach work, and digital resources for HIV that consider emotional and safety needs [190, 285, 533, 117, 311]. Lockwood et al.'s study of youth living with HIV in Kibera, an informal settlement in Nairobi, found that social support helped with a wide range of issues, including ART adherence, self-acceptance, and positive living beyond man-

agement of HIV [311]. Prior work on online peer support for HIV has largely been in medical and communications journals and chat-based interventions are rare [487]. Interventions on Facebook [173, 32, 139, 110, 312, 138], Weibo [91, 193, 600, 525, 194, 90], MXit [211], and other forums [160, 238] explore the content of these groups, network analysis of communication among members, and clinical and educational outcomes such as getting tested or improved HIV knowledge. Dulli et al. briefly note charging phones or buying airtime as barriers to participation on a Facebook group for youth living with HIV in Nigeria [139], but there is room for in-depth qualitative work on how these contingencies shape participation.

4.1.4 Stigmatized Illnesses, Technology Access, and Privacy

Prior work has noted the large range of privacy concerns for health technologies [252]. Such concerns become amplified in the context of online health communities for HIV. In general, prior work has found that anonymization, granularity and flexibility of privacy controls, and avoiding visible markers of HIV-related content are important [73, 402, 554, 285]. For example, Natarajan and Parikh and Kumar et al.'s work with people living with HIV in India note the incredibly high stakes of one's status being found out. They recommend strategies for safe communication in health interventions, such as ambiguous wording that avoids mention of HIV [402] or anonymization of online identities [285] (ambiguity is also discussed in other contexts [198, 505]). At the same time, prior work has suggested that privacy and anonymity are not absolute but rather, can be outweighed by trust and the desire for support in health management [658, 598], or satisfied through social contracts that are negotiated between people [491]. This negotiation becomes especially salient when tying sensitive health information to popular apps, as Warner et al. and Hay et al. have pointed out in their lines of work on technology use and users' HIV status [603, 605, 206].

Privacy becomes further complicated where intermittent access and phone sharing

are the norm, as has been documented in Kenya, as well as other parts of sub-Saharan Africa and South Asia [411, 608, 9, 500, 71]. Both quantitative and qualitative work in Kenya [608, 411] has found that phone sharing is gendered and more common among low-income people and rural residents. Phone sharing by youth has been documented in urban and rural parts of Ghana, Malawi, and South Africa—maintenance issues or lack of airtime can often prompt sharing family members' phones, even among youth who own their own phone [454]. Wyche and colleagues' work in rural and urban Kenya detail such maintenance issues, high risk of theft, and changing economic situations that contribute to high handset turnover and intermittent service [632, 626, 628].

Prior work has uncovered how intermittent access and sharing affect the everyday use of phones, apps, and data (e.g., [631, 363, 346, 39, 365]), highlighting the human infrastructure that makes technology work for people [503]. However, a major theme has been the implications for women's privacy. Ahmed et al.'s study in Bangladesh found instances of men monitoring wives' phones or parents monitoring daughters' [9]. Sambasivan et al.'s extensive study of the privacy practices of women in South Asia found that they used strategies like phone locks, app locks (which password-protect individual apps), and deletion of data to handle privacy breaches from monitoring or sharing, though visible protections like app locks could still garner suspicion [499]. Other work has discussed the importance of default privacy settings and the need for same-gender online spaces [4, 401]. Phone sharing also necessitates strategies for privacy in mobile health interventions for people with sensitive health concerns or jobs [441, 487, 636, 402, 505]. Sambasivan et al., in their broadcast system for outreach to urban sex workers, used multiple calls and ambiguous wording to address phone sharing and use of multiple phones [505]. Looking at SMS, Ronen et al. found that acceptability among Kenyan women of receiving HIV-related SMS messages depended on whether they had disclosed their HIV status and whether anyone else had access to their phone [487]. Similarly for chat, Yadav et al. speculate that women using a health chatbot might require features to account for sharing, such as private modes and configurable notifica-

tions [636]. Perrier et al.'s study shows that phone sharing does impact the use of an intervention—women who shared a phone with their partner found it hard to always read and respond to SMS sent to them [441].

4.2 Methods

This study aimed to understand the experiences of youth and the facilitator with WhatsApp-based peer support. We describe the formative work that informed the intervention design, the procedures used to pilot the groups, and the data collection and analysis presented in this paper. All stages of this study were approved by institutional review boards in Kenya and the United States.

4.2.1 Background on Formative Work

Formative work took place in 2017 and 2018. In the first phase (December 2017 to March 2018), we conducted semi-structured interviews with youth living with HIV who attended two clinics in Nairobi. We asked about their experience managing HIV and with peer support. We also did a content analysis of the WhatsApp-based peer support groups that youth at each clinic had created. Based on these findings, we created a prototype of a structured intervention that combines healthcare worker support with peer support to improve youth's adherence to ART. The second phase (August 2018 to September 2018) was at a third clinic in Nairobi. Youth attending this clinic did not have an online peer support group of their own. Youth and healthcare workers at this clinic, along with caregivers at all three clinics, gave feedback on multiple iterations of the structured intervention through focus group discussions. Amidst this process (December 2017 to April 2018), we also conducted a survey at all three clinics to understand youth's technology use.

These phases informed the design of the intervention described in this study. Youth in the existing groups were comfortable participating despite not knowing many members, and WhatsApp was also more pervasive compared to apps like Telegram or Signal.

Thus, we used WhatsApp as the platform for peer support due to its demonstrated feasibility. When asked about forming a facilitated group, youth wanted to establish interpersonal norms around confidentiality and wanted to meet in person, which informed the introductory meeting as a way to develop shared norms.

4.2.2 Study Design and Participants

The pilot of the intervention was conducted with youth at the third clinic (referred to as Site 3 from here on) as follows. Starting January 2019, we conducted outreach through healthcare workers at Site 3 to recruit youth; youth were eligible if they were aware of their HIV status, receiving treatment, had access to WhatsApp, and were literate. Recruited youth signed a consent form that detailed the study procedures and measures taken to anonymize and securely store data collected from the study. The form also outlined potential risks of loss of confidentiality from joining the group, namely access to sensitive information on the chat not just by group members but by other people with access to a group member's phone. The form had recommendations to password-protect their phone, use a non-identifiable WhatsApp profile picture and name, and delete sensitive messages. Participants were then added to the appropriate WhatsApp group based on their age in late March 2019. There were two groups: "Group 1" for youth between ages 14 and 17, and "Group 2" for youth between ages 18 and 24. We do note that one 18-year-old participant was erroneously assigned to Group 1. Both groups were generically titled "Youth Support Group" on WhatsApp. All titles and names of youth participants are anonymized. Participant IDs are listed with age, gender, and group number throughout the findings.

The groups were facilitated by the second author David, a researcher with background in public health and HIV testing and counselling. Once participants were added to the groups, the facilitator messaged both groups to invite all members to an optional introductory meeting held in early April 2019 at Site 3. The event was meant

to allow participants to meet, co-create group norms around privacy and communication, and determine when would be a good time for the facilitator to send the weekly message. Thirty participants attended and were reimbursed KES 400 for their time and transportation expenses. This marked the beginning of the six-month pilot period. In November 2019, participants were invited to a closing meeting, which also had 30 attendees. This event was intended to facilitate a discussion of the youth's experience with the groups and to have everyone nominate a group member and healthcare worker at the clinic to take over facilitation of the group. Attendees were again reimbursed KES 400. We provided a guide to support the new facilitators, with guidance on sample messages, suggested structure and norms of the group, and what to do in common scenarios like low activity or mediating conflict.

The facilitator followed the study's standard operating procedures, tailored to national guidelines and local practice standards. He was in charge of manually sending the pre-written weekly messages—prompts on topics such as future goals, strategies for remembering to take medication, or any troubles that were on members' minds. He was expected to respond to messages directed at him within 12 hours, respectfully clarify any misinformation posted on the chat, avoid HIV-related terms (such as ART or CD4) except in direct messages, and refer any questions about symptoms to a clinic. Any members with questions about symptoms or distress were supposed to be referred to the clinic or followed up with. In general, the study team supported the facilitator in answering any questions that he was not sure how to respond to, as well as discuss what to do about any behavior from members that was not in keeping with group norms. Finally, if the facilitator learned from members about any third-party access to their or another member's phone, he reached out to the affected member to understand if social harm had been done and corrective action was needed.

Not including the facilitator, Group 1 had 28 members (14 female, 14 male) and Group 2 had 27 members (21 female, 6 male). Participants were from low-income backgrounds. Participants 18 or younger were students and most did not know their fam-

ily income; two participants reported KES 5000 and KES 12000, respectively. Among participants older than 18 who said they were employed (50%), they made a median of KES 8000 monthly (IQR 3500-12500, 15% missing). Forty percent of participants reported sharing their phone, including 48% of participants 18 and younger and 30% of participants older than 18. Participants reported using SMS (92%), phone calls (92%), Facebook (61%), and WhatsApp (61%) to contact family and friends; some mentioned Facebook Messenger (32%), email (16%), Instagram (7%), and Snapchat (3%). Among participants who bought their own mobile data, they spent an average of about KES 153 per week. There were 13 participants, all older than 18, who had children.

4.2.3 Data Collection and Analysis

Data was collected through surveys, notes, chat records, and audio-recorded interviews. Upon enrollment, participants took a survey on demographics, phone use, and HIV knowledge and management. At the introductory and closing meetings, we took written notes on what attendees discussed. During the pilot, the facilitator downloaded and backed up all chat records weekly, for both the group and any one-on-one conversations he had with participants. He also took notes on any events that required follow-up with participants or clinic referrals. After the pilot, participants from both groups were recruited for in-person, semi-structured interviews where we asked about their experience with the group and feedback on its design. Interview participants were selected to understand various behaviors, such as high engagement, low engagement, leaving the group, or sharing distress on the group. In total, 20 members participated in interviews: seven from Group 1 (four females and three males) and 13 from Group 2 (eight females, five males). The first author Naveena, who conducted data analysis, also did a phone interview with the facilitator to understand the full scope of his work and connect it to the rest of the data. All data, including chat records, were anonymized for storage using numerical participant IDs. Chat records and interviews were in the language that

participants chose to use—Kiswahili, English, or Sheng, a slang composed of mainly Kiswahili and English that originates among urban youth in Nairobi. Interview translation and transcription were done by the interviewer, and chat translation was done by two research assistants who joined the study team for a follow-on study after the pilot was over.

We first analyzed the post-pilot interviews using thematic analysis [68]. The first author conducted open coding, creating a codebook that categorized the codes by themes, such as “factors that shape engagement: going to boarding school” and “privacy concerns: fear of stigma from group”. These themes and codes were discussed with the study team, a process through which we tweaked the codes to better represent the data. We then wanted to compare participants’ perceptions to what was observed in the chat. The first author analyzed the group and one-on-one chat records, similarly coding messages and finding recurring themes around types of interactions members had, the facilitator’s work, and rhythms of engagement over time. She also then read through the facilitator’s notes on significant events that participants were going through, matching dates to the chat group to contextualize what happened. Understanding the dynamics of the chat group and notable events, she revisited the interview transcripts. She then synthesized themes from this analysis, such as how social dynamics of the group shape engagement. These themes were discussed with the last two authors Keshet and Richard, who provided feedback on the connections between what participants said and what happened in the chat.

4.2.4 Self-disclosure

We are composed of researchers in HCI and global health and health practitioners. We are based in the United States and Kenya and have conducted research in parts of the United States, Kenya, and India. Our combined expertise is in technology design and health messaging, interventions to improve HIV care for youth, and counselling for

youth living with HIV. David, Cyrus, Brandon, Megan, Grace, Irene, and Keshet conducted the pilot and formative work. Naveena worked very closely with Keshet to gain context for the data as needed during analysis.

4.3 Findings

Our findings describe the social dynamics, forms of participation, and contingencies around privacy in the peer support groups and the resultant work that both the facilitator and youth do to support engagement in the group. We also describe how despite these contingencies, youth saw significant benefits of participating in the group, tied to developing aspirations, gaining a sense of community, and the simultaneous presence of both peers and a facilitator.

4.3.1 Social Dynamics of Facilitated Peer Support

At a high level, the two groups differed in volume of messages but were quite similar in distribution of messages among participants. Group 1 had a total of 1559 messages, with 16 out of 28 members participating in the chat, including the facilitator. Group 2 had almost three times as many messages, with a total of 4349, and 22 out of 27 members sent messages, including the facilitator. In both groups, the top contributor sent approximately 20% of messages, and the top 5 contributors sent approximately 60% of all messages (excluding the facilitator). The facilitator had one-on-one chats with 21 participants. In terms of content, other than the weekly messages, there were health-related questions and discussions, updates about youth's physical and mental health, and social messages, including greetings, life updates (ranging from returning from school for the holidays to a death in the family), motivational messages, jokes, and WhatsApp forwards. In this section, we describe how participants valued these different topics and how the facilitator worked to ensure all youth could get value out of the group.

Balancing Health and Social Topics

In each group, participants differed in what they thought was appropriate or useful content. In Group 1, members directly engaged with the facilitator's weekly messages for the first month but after that, engagement lowered and the bulk of messages were social messages. Most Group 1 interviewees still appreciated the weekly messages, however, noting that they were helpful in introducing new topics, and because they were open-ended, prompting thoughtfulness. Meanwhile, the social aspect of the group was especially helpful in sustaining connection in the face of illness. As P17 (17, F, G1) stated, *"the group taught me that we can mingle with everyone but not locking yourself inside always because of our status, we should always be jovial and even to entertain ourselves."* In comparison, Group 2 engaged much more with the weekly messages and had more health-related questions. Still, some Group 2 interviewees wanted even more of a health focus, stating that some social messages were *"irrelevant"* (P32, 22, F, G2) to the group agenda and boring to scroll through. P36 (22, M, G2) noted that he would actually feel less motivation to participate when he saw greetings:

"...you could find even in three days there is no new hot topic for discussion like people are just greeting each other, 'Hi where are you? I am here. I am just in the house,' and such like things. So that discouraged me, like when I am seeing such like messages I don't participate."

Social threads could in fact become extensive in Group 2. A recurring thread started out with greetings and would extend into discussions of what members were having for dinner and even inviting each other over to eat. However, even among members who did not prefer the social messages, there was an understanding that the group is meant for social interaction and that disallowing *"irrelevant"* messages would not have been preferable. These members generally also agreed that the intervention could be improved if the facilitator sent a topic of discussion more often than once a week, even daily.

Balancing Inclusion and Open Discussion

In both groups, participants sometimes felt excluded from conversations in the group. Participants explained how there were times when it seemed a conversation was too intense, or between a few members who were closer to each other, and so it seemed better not to engage. In Group 1, there were periodic tongue-in-cheek arguments between a few members who were friends and knew each other offline. The following conversation in Group 1 started a series of almost 400 messages over five days, which made up a significant portion of the total activity in the group:

P17: *Hey guys*

P22: *Which guys*

P17: *Don't start with me*

P22: *You too don't start*

P17: *If you are not guys why start backbiting*

P17: *Shut up*

P20: *You guys, you making me laugh*

P20: *oops!! Not guys! ;tears of joy emoji;*

The seeming exclusiveness of such conversations was in tension with the fact that there was value in sheer activity, especially in Group 1 when multiple days would often go by when there were no or few substantive messages. In fact, P22 (16, F, G1) conveyed how she felt confident playing such jokes in the group because it increased activity:

"They [other members] thought we don't get along, they thought we were strangers. They would ask why we argue but we never responded to them... There was only one admin and he wouldn't have removed us so we weren't afraid... there were many messages from us."

The facilitator in fact did not remove them, not just because they were generating activity, but because everyone was welcome in the group: *"...we agreed that we were a team."*

He did work to moderate arguments, however, and this required evaluating the impact the conversation was having on the group—whether it was a joke and entertaining to members or a dynamic that was taking away from other members' experiences. During this conversation, the facilitator would periodically interject to confirm that it is a joke, remind members to be civil (especially when the “jokes” became less lighthearted), as well as attempt to move the conversation towards the weekly topic or a health-related discussion.

There were more serious arguments in both groups, started because of contentious topics such as whether members believed in god, whether it is acceptable to consume drugs or alcohol, or a suggested display picture that a member did not like. For example, in Group 2, three members started a conversation one morning about religion and whether it was helpful or hopeless in coming to terms with living with HIV, a particularly difficult conversation given the prevalence of Christianity in Kenya. The thread ended with one member P29 (24, M, G2) messaging “*Wow, I have no words at all!*” in response to P49's (21, F, G2) explanation that “*I cut my ties with God ever since I turned out positive I blamed him for everything that's why I don't pray neither do I go to church..*” In these scenarios, the facilitator worked to reduce accusatory sentiments and reframe the situation not as a debate, but rather a sharing of opinions with mutual respect. In the evening, the facilitator sought to close the loop on this disagreement, despite members having moved onto other topics that day. The facilitator messaged asking for discussion: “*Waaatt.. why do you blame God dear?? This looks serious we need to discuss about it please.*” Other members, including everyone who discussed the topic that morning, agreed to discuss further. Reopening the discussion eventually allowed P31 (23, M, G2) to add that, though he still believes in god, he also does not attend church or listen to preachers. In response, the facilitator affirmed the common ground among group members and continued to encourage others to open up: “*Mmhh seems many are in this state. Howmdo [sic] other members feel??*”

The facilitator told us that resolving these social dynamics was one of the most chal-

lenging aspects of his work. He explained how there was a balance to be struck among various personalities and strong opinions: *“So it is a mixed group, contains a mixture of feelings and of personality and attitudes. So knowing how to balance those emotions and attitudes so that everybody doesn’t feel offended, it’s the hardest part to balance.”* The facilitator thus had to ensure that his responses were carefully crafted such that no one felt judged for their opinions or knowledge. For example, P49 (21, F, G2) asked how it would make sense to suddenly disclose to her partner that she is positive. The facilitator responded by asking members to share their experiences, but sought to alleviate any pressure that participants’ responses might create: *“There are ways we can always go about this when one wants to. I think some of us here know well how to. Any suggestions?? Remember we are just suggesting, It’s not like we are telling people to disclose when they are not ready.”*

4.3.2 Diverse Forms of Participation in Chat-based Peer Support

The full scope of participation in the intervention was best understood by looking beyond active messaging in the group, to other forms of interaction as well. We found that intermittent data and phone access shaped when participants logged on and how they sifted through messages. From the facilitator’s perspective, constant engagement with the chat was needed to manage threads.

Reading Messages, Sidechatting, and Intermittent Use

In both groups, a majority of members did not message in the groups at all or sent very few messages over six months, but there were other ways that they engaged. P15 (14, F, G1), who was using her mother’s phone, never messaged on the group, but said that she read all the messages whenever she was able to, *“...expecting that they will send something that will help me.”* P15’s statement shows how even reading messages could help participants see the group as a supportive environment. Participants also reported hav-

ing many “*sidechats*” with youth from the main group. P54 (18, M, G1), who sent only three messages, described how sidechats helped him ask for support from the right people: *“If I have an issue and someone in the group has a point, I take their number, then we sidechat.”* Even youth who sent many messages in the group had sidechats, where they could discuss conflicts or coordinate to meet up or collect medication for each other. P43 (22, F, G2) felt that sidechats also offered some members a more comfortable space to discuss sensitive topics: *“Some people fear chatting in the group so when you sidechat with them they feel free... I had a friend who had a boyfriend but had not told him [about her status]. She wanted me to advise her on how she can ask him to come and test.”*

Contingencies around accessing one’s phone and getting online also shaped participation, contributing to bursts of activity on some days and low activity on others. Throughout the intervention, multiple participants exited the chat—nine times in Group 1 and 18 times in Group 2. This was often because their SIM had changed, or their phone had been lost or damaged. The facilitator would need to follow up with them, sometimes via repeated phone calls, or wait for them to ask to be added back. These gaps in access could take anywhere between a week to multiple months to resolve, with issues like losing one’s phone taking longer in that range. Many of the participants experiencing these issues messaged least in the group chat. However, they still maintained a connection to the group—P44 (24, F, G2), who left the group for two months, said he kept reading new messages once he was added back. Other members only logged on when they were able to buy bundles, while others said they would log on for the weekly message, expecting more discussion then. Group 1 members who attended boarding school only had access to the group during holidays in April and August, while those who attended day school chatted more at night.

Intermediated use also contributed to intermittent logging on. For example, P31 (23, M, G2) and P32 (22, F, G2) were partners, both in Group 2. When P32’s phone broke, she relied on her partner to read messages, which notably still had an impact on her: *“...he told me a lot. Yes, when it reached a time for taking medication, I felt I was low, but*

after that, at least receiving the messages encouraged me.” Some participants’ parents or friends in the group encouraged them to read messages, demonstrating in-person support systems as drivers for engaging in online ones. P15’s (14, F, G1) mother would inform her that messages had arrived and if there were bundles, she would read them on weekends. P43 (22, F, G2) would meet up with another member and if she was told there were good discussions happening, she would try to buy bundles to log on and read.

How Patterns of Use Shape Engagement with the Chat

Intermittent use often meant logging on to a barrage of messages. Participants who checked messages intermittently reported trying to read as many messages as possible but would sometimes end up skipping chunks of messages. These participants also felt that, though they could read old discussions, they could not ask follow up questions or ask what someone meant by their message since those threads were long over, instead piecing together meaning from context clues. While many participants said they wanted more frequent messages from the facilitator, they also noted that it could lead to too much content to review. In fact, P15 (14, F, G1) shared how not having many messages on the group would be more manageable given how often she checked them: “...*you can’t manage two things at the same time... You know you only have Saturday, the rest of the school days you don’t have access to the phone.*”

As a result of these patterns of use, both the facilitator and group members managed participation as well as the timing of messages to maximize engagement. In both groups, there were numerous, periodic reminders from the facilitator and participants for members to engage throughout the course of the six months. Members would also often try to understand who is online at a given time, since it could not be assumed that messaging was truly instant for everyone. They would find that a few people would respond quickly, giving participants an idea of who they could converse with at that time—this also adds meaning to greetings as a way of discovering who is online. This

discovery process was also useful in Group 1 when some participants went off to boarding school—the group sent goodbyes to those who would be leaving, and then the facilitator asked who could still use their phone and would continue chatting in the group.

From the facilitator's perspective, he would check for chat messages almost hourly to ensure he was not missing messages. To respond to some threads, however, he could take time, anywhere from a few hours to a day or two. Sometimes this was intentional and signalled in the chat to encourage group members to discuss amongst themselves. In other instances, the facilitator asked for more time in order to answer questions thoroughly. Then there were times when there were simply many messages—multiple members might all be online at the same time and message constantly, while the facilitator was doing something else. In these cases, the facilitator's strategy when he checked messages again was to continue the most recent conversation, since he did not want to interrupt the flow. However, he then had to sort out old threads and carefully reply to each one or bring the discussion back up to close the loop on it. This process could take up to two hours in some cases. In one instance, after a debate about how it is possible to have discordant couples, the facilitator had to follow up with a member who had exited the group, encourage members to answer someone's question about medication side effects, and remind members to use an app lock (based on the follow up with the member who exited). After about two days and more than 200 messages, the facilitator was able to close the loop on the thread about discordant couples. However, it seems this had little impact on members, who were willing to revisit the topic. Even with multiple conversational threads, the combination of the reply feature, willingness to revisit topics, and crowdsourcing answers meant that most threads were addressed.

4.3.3 Negotiating Privacy Concerns

At the time of our study, most members had not disclosed their status to others, or only to their parent, sibling, a relative, or partner. However, they did state that they share

their phones with people outside of this circle, such as friends. As we described in the methods, the consent form recommended certain privacy measures to help reduce risk. Here, we report on how the introductory meeting allowed participants to additionally address privacy concerns as a group and how the norms they decided upon played out over time.

Addressing Privacy Concerns and Building Confidence in One Another

Participants we interviewed reported having concerns at the start of the study about who was in the group itself and what they could do with their information, such as phone numbers. P29 (24, M, G2) wanted to know if the group contained only people who had a positive status, or if it was more public. Others were worried that there could be overlap between people at “*home*” (their immediate social network) and people in the group—as P44 (24, F, G2) explained, “*I was worried that when I joined the group other people would get to know about my issues but I later discovered you can still join but not know those in the group at a personal level, so people from home will not know.*” The initial unfamiliarity with group members also made people wonder how they would discuss sensitive topics or what could happen with information like their phone number. For example, P10 (15, M, G1) was apprehensive about open discussion on the group—he did not know “*How we were going to share with each other concerning drugs, which for me I felt was something private.*” Meanwhile, P43 (22, F, G2) worried about outright stigma from members, because if there were people older than her in the group, “*they will start wondering how I got HIV at my age.*”

During the introductory meeting, participants used the opportunity to articulate concerns around privacy and agree on privacy norms as a group. There was an agreement to not share any messages outside the group, though since some of the younger members relied on their parents’ phone, this was inevitable to some extent. Many attendees were more concerned about accidental disclosure, where someone looking at

or sharing a member's phone might find out about the group. Attendees at first suggested a password for the whole phone, but because of phone sharing among some participants, the group agreed to use an app lock on WhatsApp only. P37 (24, F, G2) noted that this motivated her to open up in the group—only her mother and separated father of her child knew about her status, so everyone using the app lock helped her feel that she could open up to others without disclosing to just anyone. Attendees also generally agreed that the title of the group helped disguise it as a general youth group. Content-wise, participants agreed that explicit words like HIV, CD4, ART, VL, or medication names would not be used, to avoid disclosure of HIV status if a third party gained access to the group. Though 30 of 55 group members attended the meeting and so some did not have input into this process, these norms were shared on the groups, and were met with agreement from members.

The meeting also allowed attendees to build confidence, or *“being sure of the person you chat with,”* as P49 (21, F, G2) described. Listening to one another and seeing others make effort to attend in the first place were positive signs to participants. P37 (24, F, G2) explained how this built a foundation going forward: *“If I see you on the road, I cannot pass you, I will say, ‘Hi do you remember me?’ then you will be like, ‘I remember you.’”* Some members also opened up quite a bit at the meeting, sharing experiences, words of advice, and offering tangible support. One member shared a memory of how she confidently took medication in front of others when she was on a bus, encouraging others to be open as well. Another member shared how her partner kicked her and their baby out of their home after finding out about her status and that she was willing to house any other women forced to go through the same. Learning about each other's experiences created a basis for future conversations. P31 (23, M, G2) mentioned that he met one member who had a baby and so he knew he could reach out to her with questions about his own newborn. Not attending the meeting did not necessarily prevent people from interacting in the group. This was partly because sharing on the group itself reinforced an open environment. For example, P28 (24, F, G2) was one of the first people in

the group to post even before the meeting, sharing her struggles around breastfeeding her newborn. She noted that she did not know who messages were from but the group's openness encouraged her: *"It excited me because I saw people were free and were asking what they want."* Other members shared deeply personal experiences early on as well. In another instance before the introductory meeting, P30 (19, F, G2) posted about her feelings around losing her newborn baby and other members of the group quickly offered their condolences and emotional support.

Enacting Privacy Norms Over Time

In practice, it was not so easy to enforce privacy norms over time. Based on chat records, members in both groups liberally used HIV-related terms, including the facilitator. Slang such as *"groundnuts"* to refer to medication and *"doing the necessary"* to refer to taking medication were used very early on and just a few times by participants, but almost immediately after the introductory meeting, participants referred directly to drugs and their specific names. One to two months into the pilot, the facilitator posted informational resources about HIV using explicit terms, and as participants asked increasingly technical questions about how medication or HIV transmission works, the words were used more frequently in conversation.

Participants reported three instances where people who were not members of the group gained access to a member's phone, and we provide two examples here. Two months into the pilot, P43 (22, F, G2) exited the chat. When the facilitator reached out, the participant reported that it was because her sister had removed P43 from the group accidentally. However, the sister then claimed that P43's friend was actually the one who did it, demonstrating the difficulty of tracing any potential impacts of privacy breaches. After this incident, the facilitator sought to be transparent, explaining on the chat why P43 left, and reminding participants of the group's agreement to use an app lock. P43 was using an app lock, but the reminder was intended to ensure members in general

were not getting too lax about privacy. There was also one documented instance of harassment in a sidechat. P49 (21, F, G2), in her interview, described how she was sidechatting another member in the group when things took a downward turn because his wife had been able to access the phone:

“Let’s not take things personal, like I had an incident when chatting [group member], his wife took the phone away and started abusing me. This is just a group sharing ideas, people of the same status and nothing more. I can’t imagine someone taking my phone, going through messages to abuse people because of their status... I didn’t know things will get out of hand just because he had left his phone at home.”

She was indignant that someone could have such invasive access to their partner’s phone, noting that even if she had a boyfriend, she would not let him go through her messages. Notably, because this happened on a sidechat, it was unobserved by the facilitator, highlighting the complexity of protecting privacy in this context and how it still impacts participants’ experience of the intervention.

4.3.4 The Rewards and Limitations of Facilitated Peer Support

Even with complexities around social dynamics and privacy, participants overwhelmingly reported that the group supported them in various ways. The group offered emotional support that reduced a sense of isolation and informational support, which contributed to the development of aspirations and the motivation to do difficult tasks such as taking medication. Both peers and the facilitator were integral to this experience, though supporting peers through serious challenges could somewhat temper participants’ view of the future.

Exchanging Emotional and Informational Support

Emotional support offered acceptance and a sense of normalcy that reduced isolation and supported youth's self-esteem. Some youth had difficult social lives, stemming from not having people around them who shared the same status. P22 (16, F, G1) described how *"...initially my interaction with those at home had been difficult because they isolated me saying I would infect them with HIV."* She also explained how physical symptoms such as significant weight loss furthered feelings of abnormality and isolation. The group on the other hand was a separate, and sometimes the only, social space where participants could be open about living with HIV. P22's (16, F, G1) sentiment that she now had *"others walking with me"* was shared among many participants. Having the space allowed youth to face and become more comfortable with aspects of living with HIV, such as the need to take medication. P54 (18, M, G1) shared how he did not like discussing medications before joining the group, but group members made him feel that it is normal to take them. The group's support became integrated into participants' daily lives. The group was both a constant companion which reminded participants that they had a support system, as well as a resource that could reach people in the right moment. P17 (17, F, G1), the top contributor in her group, described its steady presence in her life: *"This group helped me to know that I have someone who cares about me and nothing will disappoint because you know someone else somewhere is concern[ed] about your life."* Meanwhile, P15 (14, F, G1), who never messaged, alluded to how the messages sometimes reached him when needed most: *"Maybe I come from school and am not feeling well and someone sends me an encouraging message, I feel am okay."*

The group also offered informational support. Members said they valued having access to both experiential and medical knowledge, such as how to manage the side effects of drugs, about preventive medication such as PrEP and PEP, and what makes up a balanced diet. Experiential knowledge in particular could be a way for members to realize that what they are going through is normal, connect over shared circumstances, such

as having a newborn, and in some cases, gain perspective on one's own situation. For example, P22 (16, F, G1) mentioned how she learned that she was *"better placed"* than boarding school students who needed to hide their medication, while she could just take hers at home and then go to day school. Members were also introduced to new resources, such as partner notification services, which promote testing in partners of people living with HIV. Myths or misconceptions, such as whether blood type can protect against infection, or whether PrEP can be taken as a one-time event before intercourse, were also cleared up in the chat. In general, sharing advice made youth feel helpful, knowledgeable, and as if they had reliable mutual support. P41 (23, M, G2) noted how thinking through other group members' problems prepared him for concerns he might face in the future, also highlighting the shared struggles members went through: *"It is like I am still helping myself in another way since if a person had a problem today it might be the same problem which I will have tomorrow."*

Rediscovering Aspirations and Ways to Achieve Them

Participants said the group supported them by motivating them to do challenging things, especially adhering to medication. A major source of this motivation was realizing that they can aspire to life goals they had given up on. Toyama defines aspirations as a "desire that is persistent and aiming for something higher," providing empirical examples such as buying a house, starting a business, or growing one's family [573]. Participants told us about aims such as studying further, getting married, having children who are not positive, being responsible for their children, and living a long life. Being in the group and meeting peers of the same status expanded participants' conceptions of the future. P49 (21, F, G2), who had found out she was positive only a year before the study, shared how those who had been living with HIV much longer were sources of encouragement and helped her imagine a future with her child:

"...I always thought I will die now. When other people said how long they've

lived like 20 years, 10 years positively, then I felt there's hope... I am just 22 years. If I add another 20 years, I will see my child grow to be of the same age just as I am now, and that will be a blessing."

Members would also try to convince one another to expand their aspirations. For example, some members were convinced no one would marry them because of their status, or that they could only marry someone who was also positive, but others would explain why that did not have to be the case. P36 (22, M, G2), who said he sometimes felt discouraged about dating, felt more optimistic about the future knowing that there were members who were part of discordant couples: *"...that encouraged me that I can live a healthy life... And I can have a partner, we can have children, and we can live. So that changed my view."*

Drawing from Kumar's notion of avenues as ways of reaching aspirations [283], the group helped youth see the connection between their aspirations and taking avenues towards realizing them—tasks like adhering to medication and using appropriate contraception or medication like PrEP with partners. Even if youth theoretically knew the importance of these tasks previously, the connection was made more concrete in part by seeing evidence of how managing one's health could make a difference in one's life. P10 (15, M, G1) shared how he used to have to be pushed to take medications and would often miss them, but he became more proactive about taking medication after the group showed him that wellbeing was a real possibility: *"It helped me a lot because there are people in the group who are doing well and it motivated me to work hard to be like them."* Experiential knowledge was especially helpful in ensuring that members sustained their efforts towards healthy living. As P37 (24, F, G2) shared, members now had a place to ask for advice in managing their health, rather than giving up on these tasks. For example, members asked the group about experiencing side effects from medication, having trouble getting their partner to use protection, or finding it difficult to disclose to their partner.

Formulating aspirations, learning how to work towards them, and having a support system built on each other. Younger participants told us they could more independently manage their health. P16 (14, F, G1) described how knowing she was not alone made it easier to collect drugs from the facility on her own instead of relying on her mother. P17 (17, F, G1) explained that learning the importance of taking medication improved her life in a number of ways: *“For now, I am well, I don’t complain of my problems because I no longer contract malaria, cold, and flu every other time. I am strong, I can even help my mother in some activities at home... I even did well in my studies.”* Some participants felt they were now the same or even healthier than people who were negative, because they cared for their health more. However, the realization that people living with HIV could achieve the same goals as anyone else was not necessarily a tool for combating stigma as much as it was for conforming to societal standards of normalcy. As P37 (24, F, G2), a hairdresser, explained, one of her learnings was being able to cope with stigmatizing comments, to the point where she could go along with them:

“I think we even learned more on how to live with people. You know, you know your status and maybe other people around you don’t know theirs, so somebody could start a topic like maybe somebody who has HIV cannot do my hair and you could get hurt thinking that they are talking about you. But now you also go with the flow and say that you also can’t get your hair done by such a person. You will just encourage them in what they are saying because after all she doesn’t know your status...”

The benefits of the group were tied to the fact that there were both peers and a facilitator. As P48 (22, F, G2) described, peers were different from others supporters: *“...not everyone will have that courage to encourage you like them... the one that doesn’t have the experience will just tell you things are just okay, but they don’t want to tell you in which way.”* This attests to the importance of experiential knowledge, and how members took time to understand each other’s struggles. A facilitator who was seen as an expert but

approached conversation like a peer was also valuable. Many participants saw him as someone who brought important topics to the chat and could offer expertise if members did not know the answer to something. This contrasted with experiences with health-care workers who were more authoritative. P17 (17, F, G2) shared that before she joined the group, she was more stressed about managing her health, explaining that she *“had been quarreled so much.”* When asked by who, P17 explained, *“Certain doctor. She was asking me why I am not taking my drugs well and I could tell her that I forgot but she could not believe.”* The group also allowed members to resolve questions that hospitals were not helpful with. For example, P31 was distressed about how the hospital was not helping him with medications for his newborn, and sidechatted the facilitator for support in obtaining them. Overall, when asked to reflect on the intervention, most participants told us they wanted both a higher frequency of messages from the facilitator, and more members to make the groups active.

Feeling the Limitations of Peer Support

Despite the rewards, there were limits on the extent to which youth felt like they could support one another or even stay optimistic about their own future. The group offered a place to share challenges, but some participants felt helpless when members shared more serious ones. P41 (23, M, G2) explained how the group could only offer so much when a member posted about suicidal thoughts: *“I was now a bit discouraged because I wondered if we are in the group helping each other. How comes that it has come to a place that she can say that. And yet we were still going on well.”* Members sharing negative experiences could also temper the encouragement that participants got from the group. For example, P36 (22, M, G2) described his feelings when members who had been on treatment for a much longer time than he had were struggling with side effects: *“...you see someone saying that he is in a bad state, and he is on medication, and period he has been taking the medication, and the complications that the person has, so that created*

fear in me... Like it seems like even me I will just be this way; with time I will be just this way.” However, he also described how as a result he became more thankful and convinced that his own medication regimen was supporting his health. These findings further demonstrate how meeting peers of the same status affected participants’ views of the future—hopefulness was mixed with the realities of managing one’s health over the long term.

4.4 Discussion

Our findings describe the emerging use of WhatsApp for facilitated peer support, outlining the social dynamics, patterns of use, and negotiation of privacy that shaped participants’ experiences, as well as how they felt the group supported them and their goals for the future. Below, we describe takeaways for the design of future chat-based peer support interventions, discussing potential models of deployment, and ways to support the work of the facilitator and participants’ engagement. We also discuss privacy in mobile health applications in the Global South, and the ways safety could be supported through building trust as well as by design. We end by gleaning lessons for understanding and supporting aspirations in health interventions, drawing on our participants’ experiences with reclaiming aspirations in the context of peer support.

4.4.1 Considerations for the Design of Chat-based Peer Support

Participants overwhelmingly indicated that they would want more messages from the facilitator and more group members in future iterations. This brings up the question of how chat-based interventions can scale to more members or groups. Prior work shows how healthcare providers’ work increases with the addition of patient-provider channels, even with a small number of users, let alone many [598, 551]. In our study, scaling would entail sifting through a higher volume of messages in more groups, moderating more frequent conversations, and following up with more one-on-one chats and par-

ticipants who need support. The most challenging work for the facilitator was practicing forms of constructive moderation, which has been proposed as a productive way to handle conflicts in already sensitive contexts [492, 648, 595]. Difficult questions to consider in this style of moderation on chat groups are what type of conversation is truly excluding members or making them uncomfortable and how long to allow such conversations to keep going before intervening. Because this was a peer support group and free discussion was encouraged, moderation thus involved a constant evaluation of how conversations were unfolding, in addition to answering specific clinical questions or checking on distressed members—this is additional or more constant work compared to what has been noted in prior studies (e.g., [224, 598, 294]).

Challenges in the facilitator's work are compounded by the affordances of chat. Unlike on a forum with threads, a chat group can easily be taken over by a small number of participants, making their conversation the sole focus. Channels or nested conversations could help alleviate problems with the single thread and organize conversations in general, but WhatsApp and most lightweight, personal chat apps do not support this. A single channel also helps ensure that all onlookers see threads being constructively moderated or questions being answered. Knowing when to intervene in threads is also made challenging by the invisibility of how onlookers feel about a conversation on chat—compared to WhatsApp, forums or other chat apps allow members to at least engage through more lightweight means like upvotes or reactions. However, there may also be benefits to reducing judgments about messages in such a sensitive context.

These challenges have implications for supporting facilitators of chat-based peer support groups. Whether healthcare workers are solely working as facilitators of such groups or are facilitating on top of other responsibilities (as in Wang et al.'s study [598]), their burden would increase with scale. One possibility for supporting facilitators in keeping track of threads is to encourage use of existing chat features and social dynamics. For example, starring messages on WhatsApp [610] could help keep a queue of messages that need replies, and the reply feature [609] can be used to let members know

which thread is being revisited, even many messages later. Youth members could also take on certain facilitation tasks, such as encouraging engagement, especially given the sense of satisfaction they derived from supporting one another in the group. Further augments to chat apps could also be useful. Periodic, scripted messages such as the facilitator's weekly message could be automated. Sentiment analysis has been proposed in prior work for determining which patients need follow up [598], and these tools could be adapted to understand the state of a conversation and whether it might need close attention as it unfolds.

On the participants' side, understanding the full scope of their engagement required looking beyond the chat, at participant perceptions and technology access, one-on-one conversations, and offline interactions. This is a theme that work in HCI4D has explored extensively by looking at the human infrastructure [503] of and offline interactions around health dissemination interventions [284, 377, 505]. Sambasivan and Smythe demonstrate that attending to human infrastructures allows us to design for social and cultural processes [503]. One insight through this approach is the value of interactions outside the chat, such as in-person meetings or phone calls, which could be supported more purposefully by the intervention for participants who feel they would benefit from it. Another insight is that WhatsApp was used intermittently, more like a social media feed than the combination of synchronous and asynchronous use that prior work often discusses. Participants were encouraged by parents or even friends in the group to check their messages or buy bundles in order to log on. This is not to say that participants did not find the group beneficial, evidenced by how a sense of community persisted for many interviewees, even those who would log on weekly or even monthly. However, getting online may be more infrequent and purposeful, as studies have found for other online health communities [341, 340, 6]. Prior work has proposed features that track and save mobile data when people get online [632, 346, 502], but we also find that curation of content can also be important to ensure that participants get the full value of the community whenever they can get online—this could also be useful

for situations where there are simply many messages to check due to bursts of engagement from members. Here, further augments may be useful to provide structure to the chat for individuals accessing it after a while. For example, an interface that allows users to jump between weekly messages so they can navigate a week's worth of discussion at a time matches the structure of the intervention itself while structuring the chat. Prior work has also designed summaries of chat conversations, which highlight certain types of discourse such as questions or resources [654]. Manually tagging or automatically detecting such messages and aggregating them could allow participants to easily view and jump to interesting questions, advice, or stories from past conversations.

4.4.2 Privacy in Mobile Health Interventions

Our findings around privacy show the value of an online health community articulating and developing privacy norms together, something that has been proposed in prior work in similarly sensitive contexts [492]. The meeting gave attendees a chance to voice the particularities of their situation, such as phone sharing, in order to ensure that privacy norms worked for them—in our case, using an app lock rather than a password on the whole phone. Beyond these notions of privacy, the meeting also allowed participants to become familiar with each other and ensure that they were confident discussing sensitive topics going forward, contributing to a sense of community in the groups. The fact that norms like using ambiguous wording in chat messages did not last long points to how participants' increased comfort over time and desire to ask more specific health-related questions may have changed their level of concern about privacy, even though risk had not changed. However, we also saw how some expectations remained. P49, for example, explained how she would never share her messages with her partner and had expected the same of the person she was sidechatting with. This complicates findings from prior work that suggest anonymity could be viewed as a social contract between members [491]—even when perceived this way, different privacy

concerns may wane while others remain very salient. It might be useful then for groups, even if they are comfortable spaces, to periodically revisit privacy norms to reinforce or update them.

Relying on social contracts among participants did have its privacy risks, bringing up the question of whether platforms intentionally designed for anonymity and privacy would be useful. For our participants, WhatsApp was convenient, and meeting in person was also important for their ability to trust in other members. Prior work has in fact suggested that using existing, widely used apps for communication around HIV helps make it “ordinary” communication, as opposed to “unordinary”, and reduces the barrier to uptake [206, 603]. However, there can always be non-users of such platforms with good reason, and scholarship in HCI4D, such as studies by Natarajan and Parikh [402], Sambasivan et al. [505, 499], and Kumar et al. [285], describes the high-stakes privacy needs of populations like women whose phones are monitored, urban sex workers, and people living with HIV in India and other South Asian countries. Taken together, these studies’ findings suggest that online interactive peer interventions may not always be feasible, or may require more concerted outreach about the benefits of participation. Further, such interventions would likely need to emphasize privacy by design in order to foster a sense of safety.

In discussing the generalizability of our findings, we highlight considerations for supporting safety and interaction, depending on the goal of the intervention. Naseem et al. propose an interactive voice forum as an anonymous and private way for low-income, low-literate women in Pakistan to share experiences around mental health [401]. However, if more facilitation and interaction is desired, there may be distinct benefits to using chat, such as synchronous group discussion (with text or voice), multimedia, and relative ease of navigating messages. For these interventions, masking phone numbers and names or enabling untraceable private modes may be necessary, as suggested by prior work [499, 636, 285]. This is particularly important since app locks, visible or invisible, may not be feasible for people who share apps (such as younger participants in

our study) or could otherwise draw suspicion for using privacy measures [499]. Tiered privacy models like Ahmed et al.'s Nirapod [10], which offers both secret and shared versions of a photo gallery app, could be another way to hide traces of the intervention while integrating with existing apps—using this model with chat apps could be explored, for example by allowing certain groups to be marked as part of a separate tier. Speaking to the design of the groups, the group size, mix of genders, and ability to sidechat in our study may not make sense in all contexts—if mistrust is high, too many connections and private interactions may be concerning, and multiple studies have noted the importance of safe spaces for women, especially from men who are strangers [401, 4]. Finally, in terms of interactions in the chat, enforced ambiguous wording (perhaps even through automated replacement of certain words with ambiguous wording) may be needed. Understanding interrelated values around privacy, safety, and sense of community, and how they might change over time, is important for future work on modalities of peer interventions for sensitive health concerns.

4.4.3 Aspirations in Health and Development

Our findings allow us to contribute to a growing body of HCI4D scholarship on aspirations and their role in design. Early work in this space looked at perceptions and use of technology as an avenue for reaching personal aspirations [428, 430, 431, 427, 283, 478]. Toyama later made an explicit call to shift from understanding needs to aspirations in HCI4D [572, 573, 574]. The premise is that needs are often rooted in negativity, easily projected onto by researchers, and fall into a neoliberal framework of “solving” problems through individualized and quick solutions [573, 572]. Toyama argues that aspirations are rooted in more positive feelings, intrinsically motivated, and focus design on nurturing abilities and shifting attitudes, while highlighting the social forces involved in a problem [573, 572]. As more scholarship in HCI4D focuses on aspirations (e.g. [273, 78, 289, 438]), an open question is how to operationalize aspirations for research

and design. Kumar et al. elaborate that aspirations are embedded in and even motivated by power structures, change over time, and have a timeframe that is relevant to design [289]. In the health domain, Pendse et al. discuss how these qualities of aspirations are intermeshed with mental health [273, 78, 289, 438]. We describe below how horizontal peer relationships contributed to fostering and sustaining aspirations, offering takeaways for health interventions that seek to support and leverage aspirations.

Our work shows that youth developed aspirations that they previously thought were not achievable on account of their status. A major reason for being able to do this was exposure to new information and lived experiences, not through just anyone but through peers, helping youth realize that people just like them can and are living well. Peer support differs in the way it engages with the temporality and embeddedness of aspirations compared to other health-related peer interventions in HCI4D. Prior work on community-led video education, for example, shows how relatability can inspire viewers to use the information they learned when needed [288, 583]. Prior work also shows how focusing on futures inspired by the past is an important strategy for supporting wellbeing of people living with HIV [285]. In our study, we see that peer support *sustains* a view to the future through its consistent presence in participants' lives. In addition to showing youth that aspirations are still achievable, participants were able to work through the everyday struggles of adherence, emotional lows, and other uncertainties. The ability to do this was strongly tied to the context of peer support. Kumar et al. have suggested that role models and mentors can offer support for aspirations [289], and while we did see youth being inspired by others who were doing well in terms of their health, youth had largely horizontal relationships with each other. In fact, youth's hopefulness was also affected by those who were having greater challenges with side effects or mental health. The groups thus encouraged mutual support, as even those who were doing well recognized that they needed to continue managing their health and might need support in the future too. As one participant said, not everyone has "*that courage to encourage*" (P48) unless they have the same experiences too. Peer support

also highlights the importance of “*others walking with me*” (P22), as opposed to following someone’s lead. These dual values may be important considerations for technology intended to foster social support for aspirations, especially in the context of health concerns that must be supported over the long term.

We found that aspirations, along with a sense of community, could motivate participants to try to stick with difficult tasks. Prior work shows that people can hold aspirations without a roadmap for how to achieve them, listing this as a limitation of the potential of aspirations [478]. However, in our study, aspirations themselves were a motivating factor that made taking medication a more meaningful act. Looking at why such tasks were not personalized previously reveals some of the larger issues with existing models of health services for HIV—health workers, for example, pushed participants to take medication with an emphasis on broader goals of adherence, but not necessarily on personal journeys towards adherence. In contrast, through peer support, youth developed reasons to take medication and also saw that they were going to be understood if they struggled. Understanding these relationships confirms the importance of certain design decisions for supporting aspirations, for example, asking about personal goals or having a facilitator who is more like a peer rather than an authority figure. The importance of this type of support adds to prior work that shows the potential usefulness of invoking authority in supporting adherence [598]—depending on participants’ prior experiences with healthcare, authority may also stem from commitment to overcoming shared struggles and experiential knowledge. Overall, examining existing social forces and how they do or do not foster aspirations around health can inform how health interventions can create environments that make tasks like adherence more meaningful. We do recognize, however, that we are discussing youth’s experiences and messaging behavior, not HIV treatment outcomes or validated measures of mental health. As Pendse et al. suggest with respect to mental health, such measures could further uncover the relationship between interventions and aspirations [438].

Aspirations in the context of a stigmatized illness like HIV were strongly tied to the

desire to live a “normal” life. Though we did not ask about aspirations explicitly in this study, the aspirations that youth did describe were limited to personal goals, rather than visions for society. Youth were concerned with how they could “*live with people*” who are not positive, as opposed to how stigma could be ended, as P37’s example of going along with stigmatizing comments shows most strongly. Prior work has also noted how healthy living does not necessarily entail an end to stigma [285], and we find that though personal aspirations were certainly important, considering how youth said they were motivating, they may not entail visions for society. This limitation brings into question whether simply focusing on aspirations instead of needs can help design divest from a neoliberal framework of individualistic solutions [572]. To provide a systemic example, aspirations have been co-opted as a policy tool for furthering individualized notions of social mobility and reducing public resources [538]. Prior work on aspirations largely discusses individuals’ aspirations for themselves [572, 573, 574], but Kumar et al. and Pendse et al. show that aspirations are embedded in larger sociotechnical assemblages and ways of conceptualizing the future. It is possible that going beyond what individuals aspire to for themselves can support reflection on this embeddedness, especially in group settings. For example, we might also encourage discussion of youth’s aspirations around health for the communities they are a part of, whether that is their family, peers, school, or neighborhood. This could be a path towards understanding how individuals see their communities playing a role in visions for the future, as well as uncovering differences in those aspirations, aligning with prior work on online health communities as sites for building community capacity for change [434].

4.4.4 *Thinking Carefully about Scale and Integration*

I now return to the question of scale and the futures of chat-based interventions as they integrate into health systems. It is certainly important for actual chat interfaces to be able to support more interaction, particularly when participants noted the desire for

more messages and members. However, it is also important to think about the future of such community-focused interventions and their integration into health systems. Here, logics of population and distributed reproduction are helpful in teasing out the limits of scale and the complex relations and regimes of care that characterized this pilot.

Prior work has noted that scale-thinking is pervasive and not always questioned [197]. Scale-thinking ends up creating systems that in many ways align with the logic of population, where units of work, such as workers, are abstract; users are of the same kind; and users must be made legible, often through datafication [197]. In a health system constrained in terms of workforce, it is likely that overburdened and underpaid health workers will need to take on the work of facilitating such groups (if not peers, as mentioned above). If we look at how care in this intervention was produced, the facilitator was able to offer the kind of encouragement and moderation needed to support relationships and aspirations among youth, and also had the support of the research team if needed. It was clear that this emotional labor was essential to the benefits of the intervention. In comparison, one participant shared an example of how previous experiences with health workers did not take the same relational approach to behavior change. This suggests that when interventions are integrated into different contexts, they may fall under diverse regimes of care. Thus, ensuring that care workers can offer this type of support is important, and brings attention to how they might be provided with the resources to do so—this is perhaps even more important than the design of the chat interface.

Another aspect of centering distributed reproduction is the importance of locality and community. To what extent can chat-based peer support be implemented such that it is still possible for youth to meet in person, collect medication for another, or reference commonly known locations or experiences? Centering the interrelations here might avoid justifying continuous growth of groups and encourage thinking about the integration of online and offline community.

Chapter 5

CHATBOTS FOR MATERNAL AND CHILD HEALTH AND REVALUING CARE WORK

Over the course of the COVID-19 pandemic, the view that chat could be highly impactful in health and development more broadly had cemented into infrastructure and communities. Turn.io is a WhatsApp business solution provider [1] that was incubated by Praekelt, a mobile health non-profit headquartered in South Africa—it grew out of the need to scale and reduce costs for MomConnect, a highly publicized and celebrated intervention for information dissemination around maternal and child health in South Africa [301]. Turn.io, in partnership with WhatsApp, has hosted “Chat for Impact” summits that have led to accelerators offering funding and mentorship for NGOs seeking to build out WhatsApp messaging services [3]. The potential of such services was in their ability to support semi-automated chatbots that could cost effectively send automated messages with information or data collection questions, while also allowing healthcare workers (or other workers) to send personalized messages in service of information-seeking, behavior change, or other purposes. These services, especially when deployed at scale, have become opportunities for sustained employment—for example, MomConnect has dedicated nursing staff who answer incoming questions from mothers. They are also becoming opportunities for those who register to receive, seek, or otherwise engage with diverse types of information. A year into the COVID-19 pandemic, which had accelerated the set up of these services, I reached out to an NGO building out a WhatsApp chatbot for post-visitation information dissemination in maternal and child health (MCH), operating across six states in India. It was a chance to understand how chatbots were intervening into the gendered space of healthcare work and women’s

health in India, centering futures of paid and unpaid care work as “chat for impact” was gaining traction.

Maternal and child mortality rates are highest among marginalized communities across the Global South and North and have been a significant focus within the global development project. There are a number of structural and individual factors that shape mortality rates. Factors include remoteness from health facilities, lack of quality and culturally-relevant health services, and reliance on traditional caregiving practices that contribute to complications. In particular, international donors and Global South countries have put significant resources towards information dissemination for supporting caregiving practices that help avoid complications or recognize them early on. Alongside human infrastructures such as community health workers and patient education via clinics, technology has been viewed as a way to share information directly to women and families. A number of studies have examined the feasibility and usability of delivery through interactive voice response systems [385, 85], SMS [441], chat [636, 635], and video [288]. Recently, with increasing uptake of mobile phones and the platformization of personal chat apps, we see similar services at scale. For example, MomConnect, mentioned above, and mMitra and Kilkari, voice-based information dissemination systems in India, have scaled across multiple regions within each country.

Such platforms are hiring trained health workers, integrating into public health systems, and intervening into families’ information-seeking and caregiving dynamics, but we know little about the political economy of these platforms. CSCW and HCI increasingly recognize the need for support from trained care workers outside of clinical settings, studying platforms such as “Ask the Doctor” services [317], chat apps [635, 128], telehealth platforms [51], and helplines [439, 438]. These studies draw attention to the positionality of care workers and care recipients within these systems, as well as the work they do in navigating them. In addition, recent work in CSCW and HCI has shown it is essential to also consider how interventions are situated within larger flows of labor and the politics of healthcare infrastructures in order to design equitable sociotechnical

systems [258, 237, 185]. Following this line of work, we consider how the patient education program and chatbot intervenes in paid and unpaid care work in India, characterized by underinvestment in labor and patriarchal power structures. We thus contribute to a small but growing body of work on the role of technology in futures of gendered work and wellbeing in the Global South.

The NGO supports patient education sessions conducted by nurses at district hospitals, and the WhatsApp-based question-answer service is introduced as a follow-up to receive more information and ask questions. Nurses employed by the NGO, whom we refer to as Medical Support Executives (MSEs), answer families' questions. We draw on interviews with MSEs, other NGO staff, and parents who use the service, observations of MSEs work and a patient education session, and analysis of chat records. We describe workers' motivation to serve this program, the work of building trust in the service and answering families, and how the service shapes families' relationships with the larger healthcare infrastructure.

In contrasting logics of population and distributed reproduction, we draw attention to the affectively charged realm of health and care work to consider what everyday feelings, motivations, and perceptions in the context of the service indicate about the political economy of the service. We find that the positive feelings associated with supporting caregivers and the potential of behavior change interventions to reduce the burden on health systems draws labor and funding flows towards the domain of MCH, behavior change, and men's involvement in caregiving. However, we also find that a significant draw for nurses and MSEs is the revaluation of care work and better working conditions. Further, the actual caregiving work that families do involves navigating more structural issues than centered in theories of behavior change. We describe what this work reveals about the role of technology interventions in both paid and unpaid care work, discussing how integration into public health systems means engaging with the uneven valuation of care work and the complexity of caregiving. We also discuss implications for the design of similar sociotechnical systems, such as health chatbots and helpdesks,

arguing for a shift beyond concerns like anthropomorphism and handling “unexpected” interactions, to consider situatedness of the chatbot within healthcare infrastructures, and the inevitability of encountering structural issues, even and especially as interventions scale.

5.1 Related Work

We situate our study in prior work on maternal and child health and healthcare infrastructures, centering perspectives from HCI and the social sciences. We also describe related work on the politics of care.

5.1.1 Healthcare Infrastructures

CSCW, HCI, and related fields are increasingly going beyond interactions between individual care recipients and providers to understand navigation of fragmented health infrastructures, and the rise of additional infrastructures that integrate with health systems. A set of work looks at the challenges of navigating existing infrastructures, particularly when they are fragmented, under-resourced, and misaligned with people’s care needs. Gui and colleagues discuss the work of new or expecting parents in the United States to coordinate across fragmented medical and financial components for themselves or their newborn [185]. They highlight how it is essential to look at non-bodily work in health, ask questions of political economy, and look at the “success” of infrastructures based on positionality of the individuals who must navigate them. They also discuss how design might combat the individualized navigation of healthcare by supporting sharing and discovery of tacit knowledge, interdependencies between infrastructures, and raising awareness of possible disconnects that people might encounter. Studies have also focused on infrastructural challenges and fragmentation within hospital settings. Carlo et al. look at how infrastructural issues in Ecuador like understaffing, travel distances, language barriers, and lack of support for women caring for children

during hospital visits contribute to negative experiences at hospitals [79]. Other work in the US looks at patients' transition to the home after hospital discharge, finding that information needs to be tailored, retrievable, and transition needs to be gradual in order to support knowledge and self-efficacy [451]. Discharge must also recognize the wear of illness during discharge, the role of intimate relationships, and reflection [450].

There have been studies of changing or complementary infrastructures across the world. Studies in the Global North largely focus on technologies such as telemedicine and remote monitoring to support management of chronic health conditions. For example, prior work discusses the challenges of health management over text and video modalities, care providers' need for feedback, and the work of switching modalities [560, 483]. Prior work has also looked at how caregivers, not just patients, might want to be involved in care via telehealth [163]. Overall, these studies address social themes of trust, remote relationship-building, privacy, and establishing credibility and competence, while also noting technical challenges related to usability, connectivity, and image quality. In the Global South, prior work has looked at the work required to make telehealth work across remote areas and in rapidly changing contexts such as the COVID-19 pandemic. Bhat and Kumar discuss how telehealth platforms and online pharmacies are changing long-established relationships between patients and doctors, pharmacists, and support staff, including aspects like trust, payment norms, frequency of communication, and process of diagnosis [51]. Chandwani and Kumar look at telemedicine in India and identified the importance of looking at the work of not just doctors and patients but also peripheral nodes, such as local hospitals who connect patients to faraway multispecialty hospitals [88].

Prior work has looked at the rise of shorter, more informal touchpoints with health-care professionals, such as Ask the Doctor platforms, patient-provider communication via personal chat apps, and helplines. Ma et al. describe how Ask the Doctor platforms perform multiple functions that complement clinical care, such as navigation of complex health infrastructures and information which allows them to better prepare for in-

person consultations and getting advice on health as it intersects with culture, lifestyle, public policy, etc. [317]. Prior work has also described the accessibility and strengthening of patient-provider relationships over personal chat apps, but also issues with work-life balance, maintaining boundaries, and privacy [598, 128]. A body of work also looks at helplines and the experiences of volunteers and callers. Pendse and colleagues have discussed how the identity of mental health helpline volunteers in India matters in engaging callers and the risks they experience when taking calls [438]. In other work, they also describe challenges in accessing appropriate and sensitive care via mental health helplines and how they could better serve callers' identity-based needs [439]. In the realm of MCH, studies have looked at helplines for breastfeeding, noting the characteristics of a good call, including the importance of mutual trust, sharing of troubles and emotions, affirmation, offering personalized advice, and assessing how callers feel at the end [567, 566, 58].

In the Indian context, healthcare infrastructures, especially for women's health, have a fraught history. The rapid privatization of Indian healthcare can be traced back to US-based structural adjustment programs in the 1990s. Since, the healthcare system has been characterized as a choice between an underfunded, overburdened public health system that may not always offer quality care, and a private health sector that can often be costly and predatory [463]. In terms of women's health, privatization coincided with national policies that narrowly equate women's health to global development priorities of reproductive and child health, motivated by the economic contributions of women's reproduction [531]. Within this narrow focus, Indian reproductive and child health policy has emphasized choice, community input, and quality in designing reproductive health services. This has included partnering with NGOs in order to increase choice. However, in reality, services such as pre-counselling and follow-ups are not consistently provided and women, particularly from marginalized communities, are still treated poorly within the health system [531]. This dynamic points to the importance of accounting for technical interventions and their impact on public health and women's

health.

CSCW and HCI have explicitly looked at the political economy of technology, and how/why it is deployed by state or private actors versus experienced by care workers and care recipients. Technology-mediated work can offer opportunities. For example, app-based work offers safer and respectable work for beauty workers in urban India [475] or electronic patient records prompt recognition of the skills of nursing work [592]. However, often these changes are complicated or hindered by the long-standing incentive to devalue, invisibilize, and control care work. In many cases, technology aligns well with a neoliberal ethos of individualistic and efficient solutions, while justifying underinvestment in addressing the root causes of social problems [265]. A body of work addresses the misalignment between the incentives and priorities of AI developers compared to the actual needs, aspirations, and safety of people like community health workers, the sick poor, and in general, anyone exposed to AI tools in high-stakes contexts like health-care [237, 463, 501]. Technology-mediated care more generally has been critiqued for issues such as attempting to invisibilize racialized and feminized labor [295] or imposing universalized and neoliberal notions of care on care recipients [265].

5.1.2 Maternal and Child Health and Mobile Interventions

Maternal and infant mortality rates are highest in the geographic Global South. In India, communities marginalized on account of income, caste, religion, and rurality are affected the most [507]. Global health ideals such as proper nutrition, utilizing antenatal care services, addressing complications like anemia, delivering with a skilled birth attendant, and healthy caregiving practices such as exclusive breastfeeding can support maternal and child health. However, barriers to these behaviors include poverty, lack of quality and culturally-relevant health services, lack of information, and competing knowledges that encourage alternative care practices. Interpretive work in HCI and other fields has sought to understand how design can support pregnant women and new

mothers' actual lived realities. Studies in South Asian contexts have shown how religious and cultural beliefs and the significant influence of family members like mothers-in-law shape care practices, sometimes contributing to restricted diets for mothers, discouraging use of health services, or unsafe practices like feeding newborns foods other than breast milk [34, 393, 288]. Studies also show how lack of husbands' involvement in MCH can be detrimental, and that their engagement can support uptake of maternal health services and postpartum mental health [279]. Prior work has also emphasized women's own agency, including how they leverage the authority of different knowledges to care for themselves in desired ways [254], and how they might be supported in their own efforts towards habit formation and sensemaking [34]. A set of studies also bring attention to the contingencies of caregiving, such as the challenges of breastfeeding and concerns around confidence and isolation [175, 636].

Other studies describe how the navigation of healthcare infrastructures can make getting care and learning key information difficult. In the Indian context, women interface with fragmented public and private institutions, resulting in disconnects in understandings of patient history and care advice. In other contexts such as South Africa and Ecuador, studies show how communication in hospital settings is also challenging, with parents having little time with providers to make sense of complicated language and wanting more discharge information [355, 79]. It can also be challenging to discuss intimate health issues, feel confident to ask questions, or balance childcare with the navigation of healthcare facilities [79].

Technological interventions in the space of MCH have largely focused on disseminating health information with the goal of behavior change, targeting women and family members. Prior work in HCI has looked at how to design and deliver content in ways that are applicable to the local context. For example, studies show how video could support community health workers in sharing information about MCH and the value of locally-produced content in engaging mothers [288, 284]. Prior work also looks at how information can reach and influence family members. Kumar and Anderson note

the importance of involving mothers-in-law in video screening [284], while Batool et al. note that SMS interventions associated with respected healthcare providers can increase women's standing in the home and allow them to care for themselves in key ways (such as resting more) [45]. Perrier et al.'s study engaged both mothers and their partners in an SMS intervention to support family planning conversations with nurses, noting the importance of maintaining options for private discussion [441].

Despite the recognition of multiple stakeholders and appropriate delivery of a pre-determined curriculum, there has been less engagement with other aspects of maternal and child health, such as the ongoing, situated practice of caregiving and navigation of infrastructural challenges. Thus, there have been calls to go beyond health literacy and information dissemination in MCH and women's health in general. This includes Bagalkot et al.'s work on supporting agency and sensemaking [34] and Ismail et al.'s work on how supporting patient-provider interaction must account for disconnected knowledges [235]. Kumar et al. also discuss how a shift must be made from simple information exchange to the complex process of learning, which brings attention to more stakeholders and women's lived realities and constraints [286]. A few interventions look more at supporting women's agency and ongoing caregiving work. Feedpal is a question-and-answer chatbot that supports breastfeeding women and community health workers in urban India [636], and Feed Finder is a mobile app that supports mothers in the UK in finding areas where they can comfortably breastfeed [35].

The service we study falls into this latter category of interventions that aim to go beyond health literacy to engage with the situated practice of caregiving by mothers and other family members. The scale of the service prompts us to explore how this care infrastructure is sustained and positioned within the larger public health system in India. This perspective is timely, as one-way and two-way information dissemination systems for MCH are shaping opportunities for care and information at scale. MomConnect, for example, is a mobile service in South Africa that registers pregnant women, shares health information, and provides channels for asking questions and giving feed-

back on healthcare facilities. It has been lauded as a model that “generates demand for health services while also collecting data to strengthen supply” and offers a template for other countries [445]. However, Schneidermann’s study of mothers’, nurses’, and researchers’ perspectives on MomConnect [512] shows that such clean narratives belie the un-ordered gendered labor supplied to make the system work. They also gloss over the disconnect between messages that push respectable motherhood and the complex realities of unhappy or unwanted motherhood. Thus it is essential to understand the complexities of how such interventions are situated within health infrastructures.

5.2 Methods

The goal of our study was to understand motives behind the design of the program, the work of MSEs, and the nature of the WhatsApp service’s engagement with families. Below, we describe an overview of the implementation of the WhatsApp service, data collection and analysis, and our positionality.

5.2.1 Setting

The NGO partners with state governments across five states in India to conduct in-person patient education sessions on ANC and PNC. The sessions are conducted mainly at district hospitals, which provide tertiary care within a three-tier public health system. The NGO recruits nurses at district hospitals to champion the training program, trains them to conduct the sessions and teach other nurses, and provides educational materials to be used during the sessions. Nurses are instructed to tell families at the end of each session about the WhatsApp-based information service and that they can register by placing a missed call to a number (which varies based on ANC or PNC content and language). The NGO places posters with the appropriate number in MCH wards for reference. The NGO also provides handouts for families to keep with them, containing a summary of the information covered in the session and the phone number to register

for the service.

Approximately 2500 families have registered for the WhatsApp service til date. When families register for the WhatsApp service, they receive automated messages regarding ANC or PNC, approximately every other day, for approximately two months. The messages contain a combination of text and emojis, and may sometimes link to animated or live action YouTube videos demonstrating caregiving practices or dramatizing family interactions around caregiving (also developed by the NGO). Families can also send questions to the service. The service receives approximately 30 to 40 questions a day. Questions will be answered by an MSE in the same language that the question was asked. In the process of answering questions, MSEs collaborate with translators and doctors. Doctors approve or help write responses to families. At the time of the study, the NGO employed two MSEs and two doctors. MSEs answer questions between 8am and 8pm, with one shift at 8am - 5pm and another at 2pm - 8pm, with three hours of overlap between MSEs. The NGO also maintains a similar WhatsApp service for COVID-19 information, and the MSEs spend parts of their shift working on this service as well.

5.2.2 Data Collection

Data collection occurred over the course of a year starting from March 2021. We began data collection by analyzing a log of all questions received from families since 2019. Since each question was categorized based on its topic, we calculated basic statistics to gain a high-level overview of what families asked. We also qualitatively analyzed a random sample of 150 questions. We noted down interesting characteristics such as affect, level of detail provided, and whether it was possible to tell if it was sent by a mother, father, or other caregiver. Then, in order to get a sense of the range of interactions a given family might have with the service, we analyzed chat records from three time periods: September - December 2019, February - April 2020, and March - May 2021. These time periods cover when the service first launched, the beginning of lockdown measures due

to the COVID-19 pandemic, and before and during the second wave of the COVID-19 pandemic in India. We noted interesting characteristics of the conversations, such as frequency of engagement, affect, how families' questions were clarified, and responses to automated messages.

We then conducted observations of MSEs' work over video to understand their situated work practices. We conducted approximately eight hours of observations, covering both morning and evening shifts, transitions between shifts, and shift overlaps. We also conducted semi-structured interviews with six MSEs and one doctor, in order to understand their perceptions of their work and their motivations for doing this work compared to alternatives. In order to understand how patient education sessions are conducted, we observed a session in a district hospital in northern Karnataka over video. For an understanding of organizational priorities and experience with implementation of the program, we also interviewed two members of the NGO's design team, one member of the research team, two members of the implementation team, and a member of the development team which works on fundraising for the NGO. Finally, we conducted nine phone interviews with registered users of the chatbot in Karnataka, including four fathers and five mothers.

All data was collected and analyzed by the first author Naveena. Data included audio recordings of observations and interviews, handwritten notes, and photos of MSEs' work during observations. Almost all interviews and observations with the NGO were conducted in English as participants were used to speaking English in work settings. One exception was the patient education session, in which the nurse conducted the session in Kannada and the video recording was translated and transcribed using a translation service. Another was the interviews with chatbot users, who spoke Kannada; a translator translated between English and Kannada in real time. All notes and recordings were written up or transcribed and shared within the research team.

Naveena analyzed the data using the inductive process described by Merriam [366]. She first coded the data, producing codes such as "traditional nursing work is taxing",

“some families expect fast responses”, and “unexpected requests for navigational support”. She then considered the relationship between codes, creating themes that describe how the service was shaping experiences of care and care work. Examples include “revaluing care work”, “constituting perceptions of the service”, and “supporting navigation of health system”. It was in formulating these themes that we noticed the centrality of affect in understanding how and why experiences of care and care work differed in the context of the service versus the health system.

5.2.3 Positionality

Our positionality shaped our approach to data collection and analysis. Naveena is a woman of Indian origin who grew up largely in the United States. She has prior experience conducting research in health in India and Kenya. This work and other personal experiences have sensitized her to care and care work as sites for understanding power dynamics around gender and capital. Through the research project, she wanted to explore how the service was shaping gendered divisions of labor in caregiving, MSEs’ work and how it could be better supported, as well as what futures of work and wellbeing the system was supporting. The NGO wanted to understand how MSEs’ work could be better supported and were interested in an external researcher’s perspective on MSEs’ experiences and workflows. Naveena gained access to participants through the NGO itself, which may have shaped what participants such as MSEs were willing to share about their experiences, co-workers, etc.

5.3 Findings

Our findings center on the affective economies at play in sustaining the WhatsApp service. We first describe how the labor that supports the service and program as a whole is garnered via the revaluation of care work, negating its wear and underinvestment and emphasizing its meaningfulness and status. We then describe what constitutes percep-

tions of the service, and how much of the success of the service relies on feelings of trust and reliability that is created by MSEs. Finally, we discuss how mothers and other caregivers turn to the service when navigating illegible and unjust care infrastructures.

5.3.1 *Revaluing Care Work*

We first describe how the labor flows that support the NGO's work are garnered through specific meanings and affect related to caregiving, the valuation of nursing work, and perceptions of the futures of work.

Caring about Caregiving

The vision of the NGO centered around the idea that family caregivers play a significant role in maternal and child health and reducing complications that result in further hospitalizations, but are currently not well supported in caregiving work due to no or low quality patient education. They sought to address this by supporting the provision of patient education in hospitals and continued information- and care-seeking within the home. Myra, a designer at the NGO, described how she thought that the NGO's focus on caregiving evoked a feeling in NGO staff that motivated them and also allowed them to relate to families who use their services:

"...it connects to somewhere in something inside of them, everyone has been a caregiver to someone at some point in their lives... every person, especially in an Indian context, would have taken care of somebody. And that's why this concept relates to people they understand. They are able to dig deep and understand and connect to probable insecurities, to probable questions, to the state of mind of these different people."

She alludes to the meaning of caregiving in India, where in many contexts, it is often intergenerational and involves numerous family members. In terms of approach

to supporting caregiving, the NGO focuses on behavior change, or teaching caregivers specific behaviors for caring for mothers and children and encouraging families to seek formal healthcare when needed. Anita, a researcher, framed this as “*low-hanging fruit*”, or an approach where “*...if you just work on this one thing, it can create, you know, a fair amount of change for not a lot of costs and a lot of resources.*” For many NGO staff we interviewed, seeing this discrete change was a key motivator for working there. Shilpa, a doctor at the NGO, shared one such experience during fieldwork: “*...there was a visible difference that we were having on these families... even like mothers who’ve got two children, how the first child was brought up and the second child, because they’ve now got a new piece of information, to be able to see that immediate change of behavior.*”

The concept of caregiving did work beyond the NGO as well. Anita described how the idea of caregiving being so central to the NGO’s model has in part made it possible for the NGO to gain traction and do behavior change–focused work relatively easily, because caregiving is understandable and relatable. In comparison, she felt that areas like policy change around caregiving require more complex data and proof. Peter, who was on the development team and managed fundraising, confirmed how funders could easily relate to the idea of supporting caregiving, and often wondered why this work was not being done in the Global North as well. Thus, we see the circulation of the emotions related to caregiving, both complicated and inspiring, a seemingly universal anchor that brings together people in very different contexts, from families in rural India to international donors. In the rest of this paper, we explore how caregiving is situated in multiple sites—district hospitals, the WhatsApp service backend, and in navigating public health infrastructures—and how it interacts with the material realities of healthcare in India.

Valuing Nursing Work

In the MCH ward of a district hospital in northern Karnataka, a trainer employed by the NGO to conduct patient education sessions is about to start speaking. Mothers are lay-

ing down on beds with their newborns, while their mothers, mothers-in-law, or other women relatives are sitting on the floor. For the next 20 minutes, the trainer goes over how to recognize signs of health complications, and reinforces the importance of a nutritious diet, skin-to-skin contact with their newborn, exclusive breastfeeding, hand-washing, and umbilical cord care. These are the five behaviors that the NGO's research has determined are most strongly linked to health complications. The skills involved in this training are notable. She seamlessly integrates materials provided by the NGO, such as a flipbook and a baby doll, as well as items around her like empty liter water bottles, to demonstrate each point. She addresses the contingencies of caregiving in the home and how it might go differently from their stay in the hospital. She asks quick, pointed questions to gauge women's understanding or challenge beliefs, for example, asking if one should apply turmeric and oil to an infected umbilical chord. In the process, the trainer refutes gender norms, for example ensuring that caregivers know the importance of mothers getting medical attention when needed or that fathers and other caregivers can provide skin-to-skin contact with the newborn. She says, *"These are for your good. Don't forget these tips."* At the end, she points to the NGO's poster on the wall behind her and says, *"Note down this WhatsApp number. Every one of you have phone in your home, right? You can type a message or give a missed call."*

Normally, nurses employed by district hospitals, not a dedicated trainer, are recruited by the NGO to do these trainings, and so the work of setting up materials, gathering families, and conducting the trainings are theirs on top of their usual responsibilities as nurses. Also, as part of the NGO's monitoring of the program, nurses must share the attendee count and pictures of the session with the NGO's implementation team via WhatsApp, and submit a monthly collated report of trainings signed by hospital administration. Notably, the trainings are also a *"key point of discoverability"* (Anita) for the WhatsApp service, contributing to its increasing adoption. Families immediately signing up for the service in the presence of the implementation team (when they observe sessions) also helps detect any technical issues with signing up and communicate them

to the NGO's design team.

MCH education for mothers and families has been shown to be desired and to benefit health outcomes [547], but families often do not receive this training in hospitals at all, often due to uneven availability of healthcare workers. To support patient education, the NGO's theory of change centers on supporting the skills required to make information accessible to families in a constrained environment. According to Anita, this entails providing trainings and educational materials to nurses that help them communicate with families effectively. Eventually, the NGO aims to shift standards of care towards more effective patient education. For example, they would like to have aspects of the program, such as the trainings for nurses, written into state budgets, and ultimately reduce readmission rates within an already strained system. Talking to the implementation team, which is in charge of support hospitals in implementing the training program, we did find that the trainings and materials are important to nurses, as is the impact of patient education in general. However, we also found that the role of affect was significant in the implementation team's efforts to motivate nurses—namely, by making nurses feel respected and a sense of ownership over the program, creating a contrast with how nurses and nursing work are ill-treated in many hospital environments (an association that has much to do with gender and caste relations and the stigma of nursing work). The training offered to nurses to learn how to conduct the patient education sessions is itself a special event that nurses are invited to. When the implementation team visits hospitals to check if nurses need support, nurses are treated especially well:

We'll call them 'madam', we'll take them to lunch or soft drinks, we'll offer them tea or coffee... in hospitals what happens, the administrators don't treat them like this, they treat them like other staff. They used to scold them. They used to blame them. [With the NGO] they don't see like that. Every time, even if they are not conducting sessions, then also we will call them as madam and sister. We will go in requesting mode. We are not ordering them [to do] any-

thing... Whenever we visit, we sit with them, we listen to them first what they are doing, how their family is doing, how their duty is going on. Whether she is having any challenges in the hospital, if you need any help, we'll help. - Pavan, Implementation team member

The “*help*” that Pavan refers to can be extremely impactful. He provided the example of a nurse who was having trouble transferring to another hospital, and the implementation team was able to help her given the strong ties they build with state and hospital administration. The NGO’s program was not implemented in the hospital she transferred to but the nurse was now especially motivated to encourage nurses at other hospitals working with the NGO to conduct trainings. In another example, the implementation team sought to support feelings of ownership among nurses while increasing the program’s status. Near the start of the COVID-19 pandemic, the NGO provided N95 masks to partner hospitals and had the nurses do the handover to hospital administration, instructing them, “...tell them that this is because of you. And that because of [the training] program only, the masks have come to your hospital.”

Notably, despite the elevation of care work, the biggest challenge to actually getting nurses to conduct the sessions was staffing shortages that were common to the public health system, especially due to COVID-19. Often, nurses were reassigned to different wards, such as the emergency ward, when needed, which made it impossible for them to be in the maternal wards to conduct the sessions at all. So we see that while affect (combined with material benefits) is an essential part of how the NGO strengthens health systems, affect also has its material limits.

Futures of Technology-Mediated Care Work

The same wear and hierarchy of nursing work that made working with the NGO more desirable, is also what brought MSEs to their current work. All MSEs had a Bachelors in Nursing or similar, which was a requirement of the position. While a common path

after this degree is to work as a staff nurse, MSEs either sought to leave staff nursing or find alternatives right after graduation. For some, as women who were married or were caring for their parents or siblings, they said that the shift schedule of nursing work interfered with family responsibilities, presenting a tension between paid work and unpaid care work. For others, nursing work was physically and emotionally taxing, with an extremely hierarchical and sometimes abusive work culture. Mala shared how being a nurse could be very stigmatizing, for example, noting how she had observed attitudes that nurses are “*overexposed*” and thus not marriagable.

If nursing work was hierarchical and physically and emotionally taxing, working as an MSE allowed for flexibility such as working from home (even before the pandemic), work-life balance, and less emotional labor. While specialized nursing or nursing education might have paid more, the relative flexibility, satisfaction of the work, and the fact that MSEs had the financial and social support of their families or partners made it a desirable position. Deepika described how even her experience as a nursing student led her to seek the satisfaction of a mix of office work and care work instead after graduation:

“So it’s very hard, we have to be very cautious, and always be ready to do first aid in the emergency ward... and there’s, you know, like accidents, and working with the families. And if somebody passes away, then the feelings of the families, all those things I have seen for four years, and it was hard to see all those things only. So I thought, let it be nursing, but kind of an office setup... [Now] if some emergency conditions are there, I can work from home and also, office timing will be like fixed... And then after that, we don’t need to worry about the work and all... we are not like completely close with the families, but still like from a far distance we are supporting the families.”

Even for those who moved onto nursing education, the medical field as a whole was still extremely hierarchical in comparison to the culture instilled at the NGO. When

asked about relationships with co-workers, MSEs explained how they are able to talk to the designers and medical team whenever needed and they can also share about one another's personal lives. If MSEs made errors in workflows, they would be corrected in a more gentle and encouraging way. Based on observations, MSEs are also encouraged to actively provide input into the work of the design team, as staff who engage with families most directly.

Working as an MSE was also unique because of its technical components, such as answering families through the chat software, logging questions and summarizing families' daily and monthly engagement in spreadsheets, and setting up the logic for the automated replies. This appealed to MSEs for a few reasons. One is that learning about new platforms and software was exciting and appealed to interests in technology from earlier in their education. The NGO was also still growing and had a number of new projects related to building out the WhatsApp service and other condition areas, adding a lot of variety to MSEs' technical work and areas for growth. Second, there was also a feeling that experience with new technologies would be useful in the future. Navya explained how she was now starting a project related to Google Data Studio, and saw technology as the future of healthcare and technical skills could help her navigate those changes:

“Because in future nowadays, many things are online... If I want to consult a doctor, if I want to get any test done, then I'm going online only. So all these things, computers, they will help me in future... So yeah, that's why I'm going there [in that direction].”

These thought processes and motivations were not limited to the MSEs. Shilpa, a doctor on the medical team, also mentioned how, *“I really feel like hospitals and being a doctor in a hospital in India can be a little toxic. And here [the NGO] that really wasn't there.”* Compared to the bureaucracy of her medical college, she described the NGO as a flat organization that encouraged employees to take initiative. Further, the work of

developing content for the NGO's projects and the WhatsApp service aligned with her excitement about the digital health space: *"I mean, it is a growing space, right, especially with COVID, we're seeing a lot of people take to the digital healthcare space. And I think it was just interesting to see how these families that do not have access to private care... how would they find this particular service useful?"*

5.3.2 Creating a Companion

"Welcome to your health service! Congratulations on your pregnancy! The time of pregnancy is not easy and we understand that. By sending messages about pregnant women's health, we will help you clear your doubts." This is the first message that a caregiver gets when they sign up for the WhatsApp service. It indicates how the messages are meant to support the caregiver's confidence, and that this is what can make pregnancy easier. The PNC version is similar, instead acknowledging that caring for a newborn is not easy. A few days into the message series, families are told the a nurse is also available to answer any questions they have. When the service is not online between 8pm and 8am and on holidays, and a caregiver asks a question, an automated message is sent explaining when the service will be back online and that in case of an emergency, families should contact a doctor. An additional line says, *"Do not worry, we are here to support you!"*

Compared to the paper takeaways that the NGO used to solely rely on, which could be lost or thrown away, the WhatsApp service was created as a more interactive avenue for engaging families after they left the hospital, reinforcing new information and offering the opportunity to ask more questions. The NGO wanted to position the service as supportive, reliable, and responsive. We describe how MSEs worked towards *producing* these feelings, how it affects them, and cases when it was clear the production of these feelings were disrupted.

How to Respond Quickly and Why

The NGO operated on the idea that fast response time increased trust in the service, but MSEs faced challenges in doing so. The MSEs' workflows for answering families largely consist of tagging families' questions via the chat software (e.g., as ANC or PNC and by language), writing responses, getting responses approved/edited by the medical team via Slack, and logging each question-response pair and metadata. If questions are not clear, for example, if the family does not provide the mother's month of pregnancy or specify where symptoms are, MSEs may call families directly. This process is highly dependent on translators and the medical team because the WhatsApp service engages families across multiple states who might not speak the same languages as MSEs, and there are Indian legal requirements for a medical doctor to supervise telehealth [529]. Wait times on translators and sometimes the medical team can be hours, especially since the translators are not full-time employees of the NGO. In one observation session, it was the start of Deepika's shift and she was following up with an unresolved question from Navya's shift. It turns out this question was from Deepika's previous shift even earlier. Deepika had written a suggested response for the medical team to approve. It was approved during Navya's shift, but Navya does not speak Kannada and despite submitting the response for translation, could not get a translation during her shift. Deepika translated and transliterated the response to Kannada herself and replied to the family, about 21 hours after their question.

While handling wait times, MSEs were at the frontlines of managing families' expectations. Navya shared how one of the biggest challenges of being an MSE was the pressure from families, which she found understandable but which she could not do anything about:

“Families, sometimes they are angry also. So that part is very difficult, how to reply them, they are asking again and again and again... I don't know how to react because one or two times you can say please wait, we've sent your query

to medical team, but you can't say thrice or four times... That's a difficult part for me and they are also not wrong. I mean they have some expectations also, that's why they are asking."

Even without this direct pressure, the emotional labor cascaded to the medical team. Shilpa expressed discomfort knowing that there were people waiting on her approval for answers, and that she was partially responsible for delays. She explained how she wished MSEs were empowered to peer-review and send responses themselves, alluding to MSEs' role in the WhatsApp service as a connection between physicians and the chat backend.

Interestingly, the COVID-19 line that the organization started in response to information needs during the pandemic is designed such that families are meant to view the line as more automated, without humans being easily available. This means that some phrasings in messages are different, such as prefacing even responses sent by the MSEs with a note that the message is from an automated system. MSEs' view is that *"...if a machine is delayed, that's fine, but if a human is delayed, they'll be angry."* Families whom we interviewed said they felt that nurses or doctors were answering the MCH line, and MSEs also reported hearing from families that they were not asking questions because they thought there were no humans behind the MCH line, indicating greater engagement when a human connection is perceived. The design team's rationale for different presentations of the lines is that the intent of the MCH line is to be interactive and offer personalized responses, while the COVID line is simply meant to make sure that people have access to the content that the NGO has developed. Further, COVID-19 is a much more dynamic condition area and there are many answers that the NGO does not have, so users are referred back to a menu of existing content, rather than prompting more questions. While we did not speak to families about their perception, this points to how the temporality of answering questions is constructed.

Building Trust and Having to Set Limits

Other than calling families to clarify the particular question or situation they are facing, part of MSEs' work is also making follow-up calls and random calls to families. As an example of the former, if a family reports that their baby is having a fever, MSEs will advise them to go to the doctor, continue breastfeeding, and not to give medications without consultation; they will follow up with the family after two days to ask if they went to the doctor and ask how the baby is doing. Random calls on the other hand, are a way to check in on families, ask after the mother or newborn, and generally ask questions about their experience with the service. In both scenarios, MSEs establish rapport by speaking in a *"bold voice,"* mentioning that they are calling from the *"WhatsApp service,"* and mentioning the question the family might have asked (Deepika). From MSEs' perspective, calling serves to uniquely visibilize support from the NGO:

"If we call them only, we ask them everything, how they do, if they have any questions. If we ask them back, how's your health? How's your baby? If you go to the doctor, if you're taking care, if you're having medicines, all these things kind of create a trust. I also, if someone asked me if I'm ill, today and tomorrow, it's like a kind of bond has created for me. So yeah I think they [calls] increase the trust that yeah, there is someone if we need anything, so they are someone we can talk to them." - Navya, MSE

Importantly, these calls also serve to create *"user stories"* that MSEs share within the organization. For example, calls might reveal unique ways the families learned about the service, such as hearing about the number from a relative, rather than through a training at a hospital. Call might also reveal positive impact on mothers' or babies' health. In these cases, the stories serve as motivation and conviction that the service is helping people: "Just to inform everyone that, just to motivate them that we are doing a good thing and we are helping someone," (Navya).

Despite MSEs' efforts, many factors shape perceptions of the WhatsApp service and what kind of support families expect. Since the service could be introduced via trainings, posters, and (as the service became more widely used) word of mouth, families could gain different perceptions of what they could ask. Families sometimes ask for prescriptions or request items such as powdered milk, for example in the case of the mother not producing enough milk to breastfeed. MSEs, unable to prescribe anything, suggest actions they can take, such as maintaining a nutritious diet, or feeding the baby more often. However, families can be insistent, which requires a phone call to clarify that the WhatsApp service cannot prescribe medications without a physical exam and that the family needs to see a doctor for prescriptions. Some families associate the service with the particular hospital they received the training in, and send questions about their experience at the hospital, such as long wait times. The association of the service with negative experiences at hospitals can tie into further frustration with the WhatsApp service. Shilpa described one scenario where a father was not happy with the service he got from the hospital. He asked the WhatsApp service to prescribe the medicines he needed instead, but the NGO had no choice but to explain they cannot prescribe medicines without a physical examination. Shilpa felt that if families associate the WhatsApp service number with the specific hospital they were at, it can make engaging with families a more challenging experience.

5.3.3 Engaging with Complex Caregiving Relations

Often, health interventions integrating with the public health system is viewed as a way to support the public health infrastructure itself. Chaya, a designer at the NGO, noted that being able to work with district hospitals allows the NGO to serve populations across income levels, and also helps improve perceptions of public hospitals because of the quality trainings. Further, the WhatsApp service's automated messages and responses often center around the importance of seeing a care provider for various ser-

vices or symptoms. This was done very intentionally—families are told to visit a government hospital, a nearby doctor, or a community health worker, depending on the level of urgency and topic of concern. Families are also regularly told about government benefits available at public hospitals, and are told to bring items like lab reports and ration cards to hospital visits.

Within the family sphere, the messages encourage certain behavior among certain family members, similar to how the trainer explained that some practices can be done by any family members, not just mothers. For example, some practices which need buy-in from family, such as family planning, start with “*Today’s message for the family is...*” Other messages that center the mother’s experiences, such as being attentive to certain symptoms, start with “*Today’s message for the pregnant mother is...*”

Interviews and the bulk of engagement over the WhatsApp service do indicate that parents were interested in the information provided, and had questions around how to evaluate and care for symptoms. However, the work of caregiving also involved more complex familial and gender relations, as well as power dynamics related to the health system. This shaped the ways users appropriated the service and the impact that the service had on caregiving work. Below, we visibilize these impacts and how the WhatsApp service was able to respond to these needs.

Information with Complex Gender and Familial Relations

Parents indicated that fathers were generally involved as much as they expected in the mother’s and newborn’s care. For example, fathers attended ANC appointments including when mothers were at their natal home, helped with transportation to hospital visits, and purchased the appropriate food and medications required for mothers. However, the barriers to being more involved were largely to do with structural factors such as long work hours, as they were the sole earners for the family. Thus, most fathers were involved in baby care for a period of time in the evenings (if the mother was not at her

natal home, that is). Also, though husbands accompanied their wives to the hospital, they were not allowed to be present during ANC visits since government hospitals prohibited it. Many participants wished her husband could attend, largely because this would ease communication of what the doctor said during the visit, making it easier to follow up on instructions or referrals. One participant Srinivas suggested that this way, he could also advocate more for his wife, for example if the doctor was being unreasonably slow in attending to her.

Parents generally signed up for the service because they heard about it in the hospital through a nurse or a poster. They often had specific topics they were interested in learning about, and the fact that they could ask questions also appealed. Participants noted that being able to ask medical questions and get “*proper information*” was impactful. They did not have to make time to go to the doctor to determine if an issue was serious, which was especially helpful for fathers in certain occupations such as driving or construction who could not afford to take too much time off or might be too far to make emergency visits. Most participants reported that ASHA workers visited periodically or not at all, with some participants noting they had phone interactions with ASHAs to ask them to visit or for vaccination reminders. In contrast, the chatbot offered a way to ask questions more quickly. Finally, information also was not just a path to behavior change per se, but rather greater ability to advocate for good care. For example, Basavaraja, a father of three kids, including a three-month old, noted that even though he had previously known to vaccinate his children, with the immunization schedule shared via the chatbot, he now knew what his baby should be receiving at what age, and ask for it if the healthcare provider is not offering the vaccine.

Participants generally reported sharing the information they received over the chatbot with their partners, parents, or in-laws, especially if they had asked a question and wanted family members to know what the advice was. However, if mothers were in their natal home, fathers would generally visit once a week if they were close enough, to spend time with the baby or help care for the baby if they were sick. In these cases,

mothers could not always consistently share what they were learning, and one participant expressed that they would want their husband to know more of this information when they went back home.

Offering Navigational Support

In the context of what is often seen as a choice between underfunded public hospitals and predatory private ones [464], we saw that the WhatsApp service served to fill the gaps in in-person care-seeking. For example, families sent pictures of lab reports, doctors' notes, or medications they were ordered to take, asking for interpretation or how to follow the doctor's instructions, indicating miscommunication or lack of support within the in-person experience. In these cases, MSEs would generally take a look and reinforce or augment doctors' instructions for care. In the case of lab reports, the medical team would interpret the report but regardless of whether there was anything of concern, would tell families to have it seen by their doctor since they would know more about the patient's history. As Shilpa explained, "*...we still don't kind of take that you know, upper hand and kind of tell them that, oh, yeah, everything's okay. You don't have to visit a doctor anymore.*" Families, including those we interviewed, also mentioned that despite being promised government incentives, such as that received for uptake of family planning methods, they did not receive them. Some families would ask about this through the chatbot, and MSEs would generally respond by suggesting they check with the hospital.

Another category of questions covered the provision of care during hospital visits and why certain care was being provided. For example, families asked why their baby was taken to the ICU, where their baby is, or where the doctor was after waiting for a long time. MSEs sometimes went as far as sharing the names and titles of people the family could contact, though this did not always help resolve the situation—in one case, a family continued to express frustration at the lack of communication from the doctor

and lack of immediate response from the WhatsApp service. In another example of the impact that navigational support could have, a family whose baby was moved to the ICU messaged the service saying the doctor was now asking for money. Shilpa and the MSEs responded by explaining that services should be free at district hospitals, and to speak to authorities at the hospital and utilize ration cards to apply insurance. In many of these scenarios, the WhatsApp service can offer information that potentially enables patients to protect their time and resources and ask for the updates they deserve.

Sometimes scenarios requiring navigational support could become complex and a call is needed to clarify what families are facing. Approximately one to two times a month, MSEs ended up calling families experiencing issues at government hospitals. One MSE described a scenario where a pregnant woman was told by a government hospital that she could delay a scan that is typically done in the third month to the fifth month. Upon doing the scan, the family found out that the baby's kidneys were not developed. However, they ended up waiting for the whole day to see a doctor for further advice and were not given their reports unless they were admitted to the hospital. They headed to a private hospital instead, where the doctor advised that terminating the pregnancy may be the safest option for the mother. After hearing about this journey, Deepika counseled the mother over the phone, explaining what she can expect next, and felt that the mother felt supported after the call, especially in comparison to her experience with the government hospital:

“The mother felt very happy because we spoke to her, because in government hospitals, they even doesn't care, and especially in this time [with COVID-19]. So she felt very happy and she thanked us for calling her and speaking to her and just you know, counseling her, saying her that nothing will happen, so she was very thankful to us, so in such cases we suggest them what is the next process, what will happen.”

Deepika described another case where a woman was in labor and experiencing bleed-

ing but at night, the doctor at the primary health center was unavailable and the nurse was unable to guide the delivery. They were told to try to get in contact with another doctor or go to the faraway district hospital. The husband recorded their conversation with the doctor and sent it to the service, as a way to demonstrate the situation and the doctor's inattention. In this case, Deepika explained how there was little she could do given this was an issue with the hospital, other than providing emotional support. She felt that *"they [the doctors] are not at all taking the responsibility,"* in direct contrast to the WhatsApp service.

Many state governments do have a helpline number managed by care providers for accessing health information and also submitting complaints about public health services, which are then followed up on. Nithin, an implementation team member, explained how when the Karnataka state government started budgeting for printing the materials for the patient education program, they wanted the 104 helpline number printed, rather than the WhatsApp service number. The trainers wrote in the WhatsApp service number before handing them out. In interviews, most parents said that they had never heard of 104, suggesting that navigational support may be difficult to access without greater efforts to raise awareness (and that the WhatsApp service is where families turn instead). Notably, as the service scales, design team members have suggested that they may not be able or willing to reply to some messages, such as complaints about hospitals or missing incentives, anymore or in as much detail. The reasoning is that the service would need to focus in on the behavior change mission and there is not much that the service can do when political change is needed to address the root of these issues.

Confronting Power Dynamics in Women's Health

Providing a safe space compared to other care infrastructures, the WhatsApp service also intervened in power dynamics around women's health. In a more common example, women often asked questions about sex, for example if it is okay to have sex during

pregnancy or how long after delivery should one wait. In Shilpa's experience, this was a topic that many women have difficulty asking about in in-person settings and to her, it indicated a level of comfort with the service.

Comfort with the service is also what may have allowed women to approach it with serious issues of reproductive justice as well. Shilpa shared how there had been cases of women coming to the service with questions about intrauterine devices (IUDs), known as Copper Ts, being inserted without their knowledge. Family planning in India has a long and contested history related to quotas and financial incentives that result in poorer women being forced into sterilization and contraceptives. These cases demonstrate the concerns that arise for the populations that the WhatsApp service seeks to serve. Shilpa's approach in counselling the mother in these cases demonstrates how the nature of the WhatsApp service allows for triaging, while the emotions that must be held back indicate the limits of the intervention:

"I feel like we've at least been able to calm her down by letting her know what it is essentially, without her having to travel maybe 30, 40 minutes... We don't dwell into finding out whether consent was taken from the husband or the mother or anybody who was present with the patient. We just focus on providing her with the information that she needs at that point of time, which in this case would be 'Hey, this is a contraceptive device. This is what a contraceptive device does. You will probably face excessive bleeding for the next few months. But you should be okay and these are the warning signs that you need to look out for.' [...] You still want to give them information without triggering them and not having to create a mess out of things without fully understanding the situation."

The service also played a role in family dynamics. On top of addressing gender norms in the training, the automated messages for the WhatsApp service start with *"Today's message to the family:"* or *"expectant mothers"*, indicating how some advice, such as

ensuring exclusive breastfeeding or making sure the mother is well-taken care of, are for the whole family to learn, while advice such as taking iron pills or avoiding alcohol and drugs is especially for the mother. This is an effort to address power dynamics within families that may result in restricted diet or other practices that do not prioritize the mother's health. However, two-way interaction allowed the service to be used as a form of advocacy for a mother. Shilpa described how a woman told the service that her family had been restricting her diet and asked that the service talk to them. MSEs and the medical team made calls to the family, and Shilpa explained how, again, the approach to counseling is not really to intervene in family dynamics, but rather explain a healthy behavior, leveraging authority as healthcare workers: *“So I would introduce myself as a doctor that’s representing this service. There’s automatically that, okay, I’ve got to listen to her... Then it’s just about the problem that she’s facing. If I was to tie up the two pieces, which is a mother’s not having enough milk and you are not feeding her enough. Explain to them about how these two are correlated, they were able to understand that... Then it’s really not about navigating the family dynamics.”*

5.4 Discussion

Our findings described how flows of capital and labor and the struggles of families towards getting and providing good care converge in a chatbot for information about MCH. The intervention itself garnered labor by revaluing and reconfiguring care work, both within hospitals and the NGO itself. We see tensions between logics of population and distributed reproduction play out in the contrast between the focus on individualized behavior change and the uneven relations that shape the complexity of caregiving. Even as families desired information about caring for mothers and newborns, they also wanted navigational support in light of an underresourced and overburdened health system. We also see the labor of the medical team in producing a service that is responsive to these varied concerns, limited by the challenges of working across linguistic

and spatial boundaries and information asymmetry. Below, we discuss how this understanding of the WhatsApp service can inform conversations on the future of care work, the design of health chatbots, and patient empowerment.

5.4.1 Do Health Interventions Care?

Our findings show that part of the reason that the WhatsApp service has drawn the labor that it has is by revaluing nursing work. Nursing work in India is largely done by those marginalized on account of gender, class, and caste. It is stigmatized, as participants noted, and receives relatively low wages, despite being physically and emotionally taxing work. It is possible that as more telehealth and similar infrastructures form, they will offer opportunities for more decent care work, though possibly at the cost of the health workforce in formal clinical settings. The issue of NGOs offering higher pay or other benefits that draw health workers away from public health systems is well known [69]. In our study, the intervention does augment public health settings in some ways, but the trainings and adoption of the WhatsApp service rely on additional work from nurses, and though the training and printed materials help, we must also consider that the intervention would not be as successful without the respectful treatment that nurses get as trainers. Similarly, MSEs take up the work because of the more sustainable work culture within the NGO. Prior work has posed the question of “do platforms care?” as a way to bring attention to the ways that gig work platforms are not indifferent but actually perform biopolitical care as forms of managing workers [475]. In our context, we consider how the revaluation of nursing work, or how NGOs care, brings into question what strengthening health systems really means for health interventions. Theories of change, especially as presented to funders or state governments, might emphasize the rational aims of the technologies involved (whether that is a standard of care, paper training materials, or WhatsApp). But in a context where underinvestment in care is part of the reason that NGOs intervene at all, how might we visibilize the investment in care

that makes an intervention possible? This iterates on critiques that CSCW and HCI have offered around visibilizing the labor that makes technology work (e.g., [179, 549])—in our case, that labor is available partly because of the privatized and uneven revaluation of care work.

These dynamics have implications for the sustainability of health interventions. If the aim is to handover implementation to government bodies, how might the work of maintaining not just material aspects of an intervention but also the social relations be centered? Alternatively, if public funding is being used on specific aspects of an intervention, such as the material resources needed, implementation may still center the relational work that makes an intervention successful—but there is the question of which health workers are provided with the benefits and if they can be more evenly distributed. We were not able to interview nurses working at district hospitals, but it is worth exploring how differing practices among multiple NGOs operating in an area interact with the relationships among workers.

5.4.2 The Design of ChatBots

Prior work on chatbots, in health and beyond, has studied how factors such as anthropomorphism, response time, tone, and self-disclosure shape perceptions of the chatbot (e.g., [299, 243, 244, 364, 271, 300]). Many of these studies consider these traits as stemming from the way the messages are constructed or sent. However, there is also increasing work on perceptions of gender that has brought attention to how perceptions are not necessarily inherent to the bot but rooted in historical and cultural meanings [519, 226]. Other work on affective computing has discussed how technologies might make assertions about emotions but their social consequences are based on further interaction with the ways societies make sense of emotions [621]. Similarly, our findings show that by looking at the circulation of emotions and the situatedness of the WhatsApp service within care infrastructures, there is much more to consider in how peo-

ple perceive chatbots, such as where it was introduced, what it does in comparison to another service, and where/if humans are in the loop. We also bring attention to the human labor required to present a chatbot in a particular way.

This shift from chatbots as people-like to infrastructure has a few implications for the design of chatbots. One is how to position the service amongst other infrastructures. For example, if families perceived the service to be related to the hospital they were at, that seemed to greatly affect the trust and perceived scope of the service, regardless of what, say, posters or welcome messages indicated. Also, in a semi-automated chatbot, expectations of humans versus automated responses and whether they are discernable may differ, as MSEs' experiences indicated. The work that MSEs do to localize engagement, such as sharing contact information at local hospitals, is also important in creating a relevant experience for users. In the case of a semi-automated chatbot specifically, a shift from thinking about human-like qualities to considering the labor of producing a certain type of service would center workers' efforts.

5.4.3 Information and Patient Empowerment

In prior work, health information has been seen as a way to increase patient participation in decisions that affect their health [146] and, especially in contexts where there may be disconnects, to reconcile patients' and doctors' perspectives [235]. In other studies, more information was not empowering at all [52]. In addition, our study showed that information could be a matter of patient rights. We found that information may not necessarily lead to new behavior but it could reorient care towards greater awareness of what healthcare providers should be offering, such as in the case of vaccines. This has a slightly different tint compared to traditional definitions of patient empowerment, where there is often assumed to be a collaborative decision-making process to begin with, rather than a demand for care. We also saw that information channels could be a (limited) way to make sense of and receive comfort during highly stressful and un-

just scenarios such as in the case of emergency deliveries or IUD insertions. Thus, information was not just about improving one's own behavior, which has been critiqued as a neoliberalization of health [265]. It was also a way to receive navigational support, which prior work has shown is just as crucial to wellbeing as health practices and access to clinical care [186, 185]. We view this appropriation of the WhatsApp service as a form of caregivers voicing their own definitions of empowerment. This is especially important to highlight in light of critiques that vertical health initiatives have come to equate women's empowerment with maternal and child health and their ability to become better mothers [531], without recognizing the complex relations and movements that characterize the work of caregiving.

When building digital care infrastructures for vulnerable populations who may turn to them for “unexpected” concerns, prior work has noted it is important to explain the scope of the intervention upfront [636]. However, despite the WhatsApp service having multiple channels to explain scope (e.g., messages, posters, trainers), there were still a wider range of concerns that users communicated. Thus, it is especially important to have meaningful and trauma-informed responses that can connect people to the appropriate channels. At the time of this study, the NGO was able to respond to navigational questions with suggestions to talk to the hospital helpdesk, even sending names and phone numbers as appropriate. MSEs were also able to offer personalized counseling and in some cases, even sought out the NGO's affiliated trainers at the hospital to have someone check in with patients. However, there is the question of whether and how these responses will be sustained with scale, and how to best route users to the appropriate, existing channels, such as 104. Pointing to the challenging space that digital care infrastructures operate in, even this may not necessarily resolve power dynamics. In the case of MomConnect, the system formalized the feedback loop by accepting feedback about hospitals and sending them to the appropriate groups to ensure it is taken into account. However, Mukinda et al. have demonstrated how this adds to multiple existing accountability channels [388], creating conditions for bureaucratic compliance

and demotivation of workers rather than an enabling framework that supports workers' intrinsic motivation to provide good care [406].

We found that among the participants we interviewed, there was not much awareness of the 104 helpline, and the Karnataka state government preferring to print it on the NGO's handout to patients indicates the need for channels to raise awareness. This suggests that it is important that NGOs consider how to avoid competition with public health infrastructures, and potentially think about ways to repurpose practices and technologies to support this.

Chapter 6

CONCLUSION

In the last four chapters, I described how and why emerging technologies are being used in healthcare work in multiple contexts in the Global South. I started with the use of digital payments in community health and then described sites of the growing use of chat in healthcare communication and provision. These interventions range from organizationally mandated and worker-driven adoption, to small-scale pilots, to scaled services integrated with public health systems. Throughout, I described the stated and potential rational economic aims of technology, such as increasing efficiency or scale, and how they interact with distributed reproduction, or the uneven relations and infrastructures that shape the wellbeing of different groups. Through these contrasts, I find that these technological fixes, even when having some benefits for care workers, also often rely on additional care work. This extra work is variously unrecognized, invisible, or valued only under certain regimes of care, with NGOs, researchers, and designers having hand in these decisions. In this conclusion, I summarize how these findings contribute to conversations on care work, health systems, and marginality in HCI, CSCW, and ICTD.

6.1 Contributions

6.1.1 Women's Work in Global South Contexts

My work offers a rich description of women's care work in contexts within the Global South. Prior work has noted that women's work in the Global South in general has been understudied, but offers important provocations for understanding worker motivations and managerial priorities that shape the future of work [475, 563]. By focusing on feminized care work in resource-constrained environments in the Global South, I draw at-

tention to specific political, organizational, and cultural power dynamics that women navigate in their work and that shape technology interventions. For example, in terms of political power dynamics, Chapter 2 shows how CHVs as public health workers are positioned between paid and unpaid work—this dynamic of taking on essential work despite lack of payment has been seen in community health in other contexts as well [235]. Thus, CHVs contended with no or low pay and struggles to balance community health work, other income-generating activities, and unpaid care work. Chapter 5 also takes seriously unpaid care work, unsettling individual behavior change to highlight the work of navigating power dynamics and resource constraints within health systems. We see examples of organizational power dynamics in Chapter 3, in the control and monitoring of nurses' communication (particularly staff nurses and other workers lower in the hospital hierarchy) due to concerns of data leaks, and the particularly hierarchical work culture within the hospital. In Chapter 5, we also see cultural power dynamics, for example in the stigma and lack of respect for nursing work that could affect nurses' quality of life even beyond the workplace. Throughout, I have described how these dynamics are integral to understanding the impacts of technological fixes—how much say care workers have over technology adoption, to whom work gets displaced, how visible and valued this burden is, and workers' motivation for seeking more decent work.

My work also describes new forms of digital labor and infrastructures that offer alternatives, demonstrating how the labor that supports technology interventions is garnered through the revaluation of care in a context where care work is greatly devalued. In Chapter 5, we saw how MSEs who had the opportunity and means to leave nursing work preferred the less hierarchical organizational cultures and more flexible work offered by the NGO. We also saw how implementation of patient education sessions at district hospitals was successful due to the revaluation of nursing work, and not only the materials and training that nurses received to conduct the sessions. Going beyond recognizing that human labor is what makes technology work, these findings present questions around visibilizing how good working conditions are what garners labor in

the first place, so as to support struggles for better working conditions overall.

6.1.2 *Technological Fixes and Care Work*

With the increasing focus on the care crisis and varied strategies towards addressing it, my work also offers an understanding of some of the possibilities and inevitable limitations of technological fixes in care work. I uncover how even technologies that meet real and urgent care needs will need to grapple with underlying crisis tendencies. In Chapter 2, we saw how digital payments did ease payment logistics, including reducing queuing times for health workers, but also resulted in the work of withdrawing cash, burdening the lowest paid and most remote workers. In Chapter 3, the use of chat to help senior nurses communicate and meet important priorities such as ensuring best practice also created off-shift work for staff nurses. Finally, Chapters 4 and 5 show that even scalable technologies run up against structural issues, such as the integration of chat-based interventions into the workflows of overburdened and underpaid health workers, and the inevitable appropriation of information-seeking services for navigational support. These studies strengthen calls for holistic and in-depth understandings of health systems and a wide range of stakeholders when evaluating technological interventions. While technologies might be deployed with particular rational aims and even meet those aims, Murphy suggests that it is also important to unsettle the positive valence of care in order to grapple with the fraught histories and structures that shape care [391]. In the context of understanding technological fixes, my work points to the value of attending to the experiences of workers lower in the healthcare hierarchy, work beyond the confines of the workplace and the home, and the appropriation of technologies as indication of care needs.

6.1.3 *HCI and the Future of Work*

As noted in related work in previous chapters, scholarship in HCI and CSCW is increasingly emphasizing the importance of an ecological perspective and participatory methods to better align technology with the situated practice and challenges of care work from workers' perspectives (e.g., [237, 463, 438, 453]). Conversations around the future of care work, then, often refer to the design of technology itself (or the design process) as contributing to futures. Largely aligned with this body of work, there have been more meta conversations around researchers and practitioners' approach to understanding the future of work. Prior work has suggested we attend to the non-economic, in efforts to more fully understand the relations between workers, technology, and social relations beyond waged labor [475, 292]. Meanwhile, there have also been critiques of funding priorities in future of work research in HCI, looking at actors such as the National Science Foundation and their endorsement of ever greater surveillance, control, and productivity of workers [8]. My findings further these conversations by centering how researchers and practitioners are not just designing technologies for journeys towards better futures of care work. We are also making decisions about money, labor, relationships, and discourse, which do not happen in a vacuum but rather within fragmented regimes of care and hierarchy, amidst struggles for better working conditions. In Chapter 2, we saw that NGOs working with community health workers in the area made decisions around taking on transaction fees, how much to pay workers, or when to schedule activities. Chapters 4 and 5 indicate the valuation of care that happens in the implementation of technology interventions and how this shapes flows of labor and working conditions for some but not all care workers. If it is important to acknowledge the work that workers do to make technology work, it is also important to talk about the work that we as researchers and practitioners do and how it interacts with struggles for the material support of care that has been lacking under the care crisis.

6.2 Future Research Directions

My work suggests a number of research directions that might further uncover the limits and alternatives to technological fixes in care work. Having worked with health organizations in the space of global health, automation, and AI, scaling health technologies presents unique and often unforeseen challenges, and the transition process often increases work burden for care workers. Scale may change workflows, relationships between workers, and the nature of the caregiver-care recipient relationship, and most importantly, may not even be an appropriate path towards supporting care workers' goals. As the NGO implementing the chatbot seeks to scale operations, my follow-up work will use speculative design methods to understand what a worker-centered process of scaling looks like from the perspective of MSEs, or if scale is desirable at all. As health organizations increasingly move beyond "pilot-itis" to scale technologies, this work will offer lessons for attending to worker experiences and conceptualizing care accordingly in the process.

With the rise of care infrastructures that support online information-seeking and communication with health workers, these systems generate data streams that present opportunities for data-driven tools. However, there are significant ethical implications of using this data, as recent events such as the monetization of data from Crisis Text Line has shown [493], bringing up questions of data ownership and recognition of the labor that produced the data. Amidst greater conversation around how data stewardship and cooperatives might be appropriately implemented [370], if at all, in more diverse contexts, understanding care workers' and care recipients' perspectives on data use in sensitive healthcare contexts presents a highly relevant case study. This research direction could contribute an understanding of the realities of data stewardship and relevant policy, centering how care workers and recipients actually think about and prioritize (or not) the use and privacy of their data.

Finally, a recurring theme in my work has been the benefits of articulating and shar-

ing knowledge around how technology is impacting care workers within a given workplace. I aim to understand how care workers create knowledge around and act on experiences with technology or other changes in the workplace, particularly when they have negative effects on workers. This may entail an exploration of how care workers have successfully organized around and achieved change in their workplace. I aim to understand if and how design might support efforts to co-construct and act on experiential knowledge, considering factors salient to forms of healthcare work in the Global South, such as a distributed work environment and strong worker hierarchies.

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