Restoration Work: Responding to Everyday Challenges of HIV Outreach

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There has been a growing commitment across the fields of Computer-Supported Cooperative Work (CSCW) and Human-Computer Interaction for Development (HCI4D) towards investigating the design and deployment of technologies in the context of complex healthcare ecologies. We present a qualitative inquiry of one such context, as we examine the outreach practices and everyday challenges of workers at a community-based organization in Gujarat (India) that works with People Living with the Human Immuno-deficiency Virus (PLHIV). Drawing on Yosso’s framework of community cultural wealth—apt for such intersectional settings—and the lens of articulation work, we describe how the workers at Vikas build and strengthen varied forms of capital to restore “old normals,” or what life was like for their PLHIV clients prior to diagnoses. Finally, we propose that attention to this nature of restoration work, and the workers’ engagement with diverse forms of community cultural wealth, allows us to reflect on how technologies might (or might not) be designed to impact social and affective aspects of health.

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

Additional Key Words and Phrases: HIV; healthcare; India; qualitative; HCI4D; ICTD

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1 INTRODUCTION

According to the United Nations Program for HIV/AIDS (UNAIDS), 36.9 million people were living with the human immuno-deficiency virus (HIV) in 2017 [79]. The vast majority of them live in low- and middle-income countries, with India ranking third among them. The recent UNAIDS guidelines of 90-90-90 target the control of the global epidemic by ensuring that 90% of individuals living with HIV are aware of their status, 90% of them get anti-retroviral therapy (ART) treatment, and 90% of those under ART are virally suppressed by 2020 [40]. In India, the National AIDS Control Organization (NACO) [71] oversees efforts to meet these guidelines, and has stated that the country has a long way to go to meet the above targets [104]. Though NACO’s policies and programs have invested significant attention towards controlling and reducing the incidence of HIV, issues like discrimination, social stigma, and denial pose immense challenges, creating a climate in which...
state regulations are not likely to be followed [10]. In such socially charged landscapes, outreach workers play the critical role of bridging the gap between the state and individuals with HIV [48]. These outreach workers stand at the center of our research, as we investigate the potential for technology to assist in their day-to-day workflows.

Our paper examines the efforts of Vikas (anonymized), a non-governmental organization (NGO) that has been focusing on outreach efforts targeting HIV-positive populations across Gujarat, India, for the last 16 years. Specifically, we investigate the workflows of Vikas’ outreach workers as they interface with an HIV-positive population and its intersectional realities to address its health and other everyday needs. Intersectional feminist perspectives have previously emphasized the multiple ways in which individuals with HIV are marginalized (e.g., [14, 120]). Not only do these populations with HIV that we studied lack economic privilege, they are also marginalized in their access to public healthcare infrastructures, and subject to immense social stigma and discrimination. Our research invokes Yosso’s lens of community cultural wealth [125] to highlight, however, that there are also multiple assets present among these communities that are leveraged by outreach workers [60], in ways that technology design might further support (or not).

Many technology interventions have been designed to address the challenges faced by those with HIV, especially in regards to treatment adherence and information dissemination (e.g., [43, 73, 85, 105]). Natarajan and Parikh have recommended that research go beyond prioritization of “efficiency, standardization, and measurement” to consider the affective and relational experiences that are key determinants of the spread of HIV [69]. In similar vein, prior work calls for viewing individuals with HIV as “more than patients” in need of healthcare, referring to the stigma they are subjected to [15, 43, 98]. More recent research at CSCW has begun to look at these aspects such as the desire to maintain privacy around HIV status, and the need for care providers to build trust with patients with HIV [75, 82, 119]. We contribute to and enrich this line of work with our focus on the workflows of HIV outreach workers, and the everyday challenges they face. We also identify opportunities for technology design to support, extend, and leverage the labors of these workers.

In pursuing this research, we extend a growing body of literature in CSCW and HCI4D that investigates potential contributions of technology towards improving the lives of underserved populations (e.g., [22, 35, 45, 113]). There exist scenarios, however, where conceptualizing improved living conditions for the future may benefit from looking to the past for guidance towards “normalcy” (e.g., [30, 59]). We consider one such “life-disrupting” scenario [59] of being diagnosed with HIV, with our empirical study of outreach workers in Surat, Gujarat. We examine, in particular, the restoration work performed by these workers, or the articulation work they are involved in [100, 109] as they contend with everyday challenges to restore “old normals” for their clients with HIV. For these workers, this work involves engaging various kinds of capital [125] to mitigate the impact of such diagnosis. Here we also connect with a rich, emerging body of work on repair (e.g., [38, 95]). Finally, we reflect on how and where technology design might assist such efforts, also recognizing when it may be most ethically appropriate for technology to not intervene [7].

2 RELATED WORK

Below we situate our work in a body of related research on HIV and HCI4D, drawing attention to the social and affective aspects of HIV in particular. We then describe the intersectional and assets-based approaches that shape our analysis, before proposing restoration work as a construct through which to understand the everyday undertakings and challenges of the HIV outreach workers we study.
2.1 Augmenting HIV Research in HCI4D

Global health is a domain of critical and growing interest to HCI4D researchers and designers, as emerging scholarship in the larger CSCW and HCI communities demonstrates (e.g., [5, 18, 50, 67, 87, 88]). With regards to research on HIV, HCI4D has engaged in the design and deployment of digital health interventions to extend care to patients (e.g., [41, 75]). Studies have reported the effective use of SMS-based reminder systems for suppressive antiretroviral therapy (ART) adherence in Kenya [52, 89], Uganda [16], and South Africa [56]. Such interventions have highlighted the importance of social support and trusting relationships with healthcare providers, and personalized and bidirectional communication [25, 116]. However, using texts is challenging for low-literate users and leads to privacy concerns, hindering the uptake of interventions in contexts with high stigma, as routinely found in India [43]. Joshi et al. demonstrated the effectiveness of using Interactive Voice Response (IVR) systems instead for improving adherence to ART and information dissemination, also emphasizing the need for personalized messages in local languages [43].

Despite the growing body of research on the design of technology for managing HIV, most interventionist work has focused on testing and treatment [4, 8, 80, 112] or information dissemination [21, 29, 31, 43, 66, 105], rather than taking a holistic perspective towards the management of everyday challenges that HIV-positive individuals face in their private and social lives [41, 42, 69]. Natarajan and Parikh made an important contribution by drawing attention to this need in their research on how married women in Chennai (India) who were HIV-positive managed knowledge of this HIV status [69]. Their findings emphasized the potential for digital health interventions to go beyond information dissemination and account for the social and affective aspects that routinely impact uptake of healthcare. We build on their work to focus on these social and affective aspects, centering the activities involved in outreach work, which requires significant navigation of institutions and relationships in the face of discriminatory attitudes in society, and has thus far received little attention. These activities might be viewed as analogous to those of community health workers whose contributions are actively studied in HCI4D, and considered critical for covering the last mile in healthcare delivery (e.g., [81, 91, 124]). Here we also connect with CSCW research that has begun to investigate the collaborative community-based efforts that these workers engage in towards capacity-building, information dissemination, among other goals (e.g., [35, 36]).

2.2 Investigating Social and Affective Aspects of HIV

In focusing on the social and affective aspects of healthcare-provision, we also respond to Fitzpatrick and Ellingsen’s call for a “shift from the ‘patient’ with condition X to the ‘person’ and their extended social network and how they integrate their care needs as one part of their practical daily concerns” in CSCW research [26]. Research published in CSCW and HCI venues has begun to take this perspective—such as through the use of social media to achieve normalcy by hospitalized children [54], personal health management [57, 101], collective sense-making among patients [78], and communication of non-health information between doctors and patients [53]. These studies bring to light the need for an additional focus beyond hospital settings to the daily concerns of individuals.

For individuals with HIV, daily concerns related to burdens that are economic, physiological, and social, end up disrupting the care-seeking process, as highlighted in research from the Dominican Republic, Singapore, and Tanzania [6, 33, 62]. Recent advances in medicine have made it possible for people with HIV to maintain relationships with their partners and have children, an important part of overall wellbeing. Long-term studies have indicated that ART renders the retrovirus non-transmittable via sexual contact for those who have attained and maintain an undetectable viral load [93, 94], also minimizing the risk of mother-to-child transmission [3]. Many countries (including India) have managed to stem the increase in HIV prevalence and even reverse the numbers [111].
However, public health literature asserts that the resulting “post-AIDS” discourse is problematic and misleading as “despite significant shifts in access to ART, HIV continues to be fundamentally shaped by economic determinants and social and cultural practices” [117].

Multiple recent studies conducted across the Global South have brought to attention the pressure of keeping up appearances due to the moral implications of having HIV, along with economic pressures, among ART adherents (e.g., [6, 28, 33, 62, 102, 118]). Though disclosure is not legally mandated in India and an HIV-positive status cannot be lawfully discriminated against, stigma continues to persist and impact overall wellbeing [76]. This stigma is typically absent across other chronic ailments, and although social stigma has received a lot of attention in the medical community, with the aim to normalize HIV as any other chronic illness [64], attitude change has been historically challenging [12]. Our focus on outreach work highlights the daily labors of the workers at Vikas towards navigating and addressing this stigma.

2.3 Taking an Intersectional Lens

Working with a stigmatized population poses a unique set of challenges; an HIV-positive status overlaps with other aspects of identity leading to loss (or fear of loss) in economic capacity, familial relationships, and social status. As we contend with multiple axes of differentiation in our context of study, our research aligns with Kumar and Karusala’s recent call for Intersectional Computing [49], which entails a push for greater intersectional awareness across domains of computing, and careful examination of how emerging computing technologies may be directed towards impacting the lives of variously vulnerable populations, such as the outreach workers we studied.

Both the CSCW and HCI communities have been engaging with intersectional feminist approaches in recent years, beginning with Fox et al.’s workshop on imagining intersectional futures at CSCW 2017 [27] and Schlesinger et al.’s proposal for an Intersectional HCI [99]. Further developing this lens, Wong-Villacres et al. uncover how penalties and privileges emerging on account of varied axes of differentiation might be leveraged to reveal “pathways for technology design” [121]. This work reinforces the value of assets-based approaches to community development, attempting to shift away from a deficits-focused mindset [60]. This is also Yosso’s goal as she redefines Bourdieu’s notion of capital to include an array of cultural knowledge, skills, abilities, and contacts possessed by socially marginalized groups [13, 125]. She labels this community cultural wealth, which is comprised of various forms of capital, including familial capital, social capital, aspirational capital, cultural capital, linguistic capital, resistant capital, and navigational capital [125]. In examining the workflows of the outreach workers at Vikas, we found that they aimed to engage several of these forms of capital as assets that they could rely on and leverage, as they addressed various dimensions of marginalization present amid their communities.

2.4 Motivating Restoration Work

As we foreground the labors performed by the outreach workers we study, while they continually negotiate and defend the intersecting vulnerabilities of their target populations with HIV, we turn to the construct of articulation work. This is a construct that finds purchase in a significant body of CSCW literature (e.g., [11, 36, 82, 109]) that engages in the inspection of the many facets of work—“what tasks, who does them, how, where, the consequences, the problems involved” [100, 109]. Attending to the articulation work performed by Vikas workers demonstrates that their daily focus remains on working with and for their clients with HIV towards restoring their “old normals” through engaging community cultural wealth [125], which leads us to label these efforts as restoration work. We define restoration work as a type of articulation work that looks to the past for inspiration on the labors required. Our findings expound on the ways in which these workers...
build and strengthen social, resistant, and other capitals with the goal of identifying opportunities for technology design that might lighten the burden of intersectional, HIV-positive realities.

This type of restoration work is reminiscent of CSCW research on care and repair, such as that of Rosner and colleagues [19, 95], Jackson [38], and others. We note that, like with repair work, restoration work enables us to look to the past to determine future steps, along with the acknowledgement that it cannot ‘bring back’ the past. Just as repair restores value in the case of material artifacts, so might restoration work add value to the lives of HIV-positive individuals (in their and Vikas’ perceptions), as our findings demonstrate. In a sense, restoration work aims then to foreground human realities rather than solely material ones in pursuit of improved sociotechnical realities with the human at the center.

The point of breakage (and thus repair) in our case is a “life disruption,” which Massimi et al. have described in prior CSCW research as “life events that are unpredictable, uncontrollable, and destabilizing” [59]. The authors discuss how intimate partner violence, homelessness, and death motivate a journey towards a “new normal.” Liu et al. consider this journey in the case of children diagnosed with a chronic illness such as cancer [54]. In a context of acute social stigma, we found that the outreach workers engaged in efforts to restore the “old normal,” or the life that people with HIV had before diagnosis, with aspirations of eliminating the impact of stigma altogether.

### 3 METHODOLOGY

We now describe the process by which we undertook data collection, and how we analyzed our data. We then reflect on our positionality, which was an important consideration given the sensitive nature of our research. Our study was duly approved by the institutional review boards at the Indian Institute of Management in Ahmedabad and the Georgia Institute of Technology.

#### 3.1 Data Collection

Our interaction with our partner organization in this research, Vikas, began on Rajesh’s longstanding association with the organization. Kantaben (anonymized), who is the chief functionary at Vikas, invited us to Surat (Gujarat)¹ to investigate how the mobile technologies that Vikas’ outreach workers were routinely using could be leveraged to aid in the organization’s various workflows.

We conducted a dedicated field study of Vikas’ workflows and the articulation work [109] performed by Vikas’ employees in the process of delivering care to clients—people with HIV. We were inspired to take an ethnographic action research-based approach, which entailed following these workers in their everyday engagements to develop an in-depth understanding of the same [110].

The data we draw on for this paper includes a combination of field observations, focus group discussions, and (multiple) semi-structured interviews with 21 participants. These included five senior administrative functionaries, thirteen outreach workers, and two data managers and one counselor who worked at the ART center. Three outreach workers were male; the remaining participants were female. Participants were between 20 and 45 years of age. The senior administrative functionaries helped us understand the context within which the outreach work was situated. All participants were employed by Vikas between March 2016 and March 2017, when our data collection took place. During this period, Samyukta spent 15 days collecting data on site, but corresponded with Vikas throughout the interim period. Another author, Rajesh, was located in Surat for much of this duration, moderating communication for the team.

The 15 days on site involved various types of data collection. Samyukta and Rajesh together conducted approximately 30 hours of non-participant observations at two centers to understand the roles of different workers; these centers were located in different areas of the city of Surat.

¹Surat has the highest incidence rate of HIV in Gujarat [20].
and catered to people with HIV from different demographic backgrounds. They also conducted participant observation by shadowing two outreach workers (one experienced, and one less) to attain a deeper understanding of the nature of Vikas’ outreach activities. During the participant observation, the authors paid close attention to the articulation work performed by the outreach workers before, during, and after a visit to client’s home. This data was then leveraged to facilitate focus group discussions with outreach workers at Vikas with the goal of informing the future design of solutions that might address the needs of the workers. While it would have been considered inappropriate to ask questions around incomes of our participants, it was evident that they were from socioeconomically disadvantaged backgrounds. All research participants were HIV-positive.

The process of data collection was complex due to the sensitive nature of the work of the outreach workers. Almost all interviews were recorded and transcribed by Samyukta, who had been sensitized to the context of study through engaged mentorship by researchers with prior experience. For some ad hoc conversations however, when it seemed inappropriate or disruptive to turn on a recording device, the present author took extensive field notes during the conversation or right after. There were also occasions when we were asked to pause note-taking activity because the workers felt it might attract undue attention or generate unnecessary discomfort (during home visits). In general, we all exercised extreme care to express regard for ensuring the ease of participants, throughout the duration of our research.

### 3.2 Data Analysis

Although the analysis began at the same time as data collection, shaping the interviews and discussions that followed, a formal analysis came after. Once the data was collected, we subjected it to an in-depth, inductive analysis process, as Merriam recommends [65]. Our coding entailed a rigorous categorization of data, as we identified patterns to arrive at appropriate themes. We began with open coding, distilling relevant initial themes from the data. The first-level codes were carefully linked to the data, such as ‘outreach worker is compelled to assume a different identity’ and ‘faces challenge during ART adherence.’ In subsequent rounds of coding, we went from raw empirical data to more general explanations such as ‘fostering relationship with clients,’ ‘navigating highly sensitive topics in social settings’, and ‘building awareness among family members.’ The emergent themes of intersecting identities and roles of people with HIV as going beyond ‘patients’, and the various forms of social, resistant, navigational, and familial capital that outreach workers engaged and attempted to develop, brought us to engage with the lens of intersectionality to analyze our data [121, 125]. Subsequent data analysis entailed an iterative process of going back and forth between data and theory, identifying recurring patterns, exploring new and emergent themes, and examining relationships between the concepts. The final concepts and themes were arrived at through mutual discussion among all authors.

### 3.3 Self-Disclosure

All authors are of Indian origin, with fieldwork experience in underserved, rural and urban, public health settings in India. Samyukta, who conducted most of the fieldwork, underwent a period of rigorous training and sensitization, talking to other researchers who had worked with similarly disadvantaged HIV-affected populations in India, so that she was prepared, knew what to expect, and could act responsibly and respectfully during the study. We also note here that we were unable to interview people with HIV (also referred to as clients) during the household visits with outreach workers due to lack of appropriate access. The outreach workers had painstakingly established trust with the clients and we were outside that zone of trust. The sensitive situation and fear of disclosure also meant that outreach workers were already barely welcome to clients’ homes, and further involvement beyond observation could have adversely impacted their work and relationship.
4 FINDINGS

Prior research in global health has recognized the stigmatization that HIV brings, particularly in more conservative social and cultural contexts (e.g., [9]). Research has also highlighted the lack of support and care for HIV-affected individuals in communities and healthcare settings (e.g., [63]). Organizations such as Vikas have emerged to address this need, and we find that they face a slew of challenges as they do so. We organize our findings by first describing Vikas’ roots and why it came into being. We then detail the restoration work performed by Vikas’ outreach workers, that is, the articulation work [100, 109] they undertook to restore the lives of their clients with HIV to “old normals.” In the process, we uncover how they engaged various forms of capital (seen through Yosso’s lens of community cultural wealth [125]) amid communities of PLHIV.

4.1 Roots and Commitments of Vikas

Vikas came into being in the year 2003, when there was low awareness and considerable stigma around HIV in India [1, 10]. The lack of disclosure of an HIV-positive status was understood to significantly impact relationships and social standing, resulting in feelings of isolation. We learned from Kantaben (anonymized)², one of the co-founders of Vikas, that forming the organization at the time was an immense challenge and was met with great reluctance. However, this also meant that the need was immense and a tremendous gap needed to be filled:

“When I found other HIV-positive people, their self-stigma was so high that they were not opening up and coming out. They hadn’t told anyone in their family. They were even going through a depressive environment like if anyone finds out then their life will be over.”—Kantaben (Female, Co-founder)

The beginnings of the organization were modest; 35 members worked out of one member’s home with limited financial means. The group’s initial meetings were as much to provide support and solidarity to each other as they were to support the HIV-positive community. Public health literature has recognized that, in addition to HIV-positive patients facing discrimination in health settings [47], HIV-affected health workers are often discriminated against, frequently leading to fear of disclosure, and sometimes untimely death [74]. The first batch of outreach workers at Vikas came together to provide social and emotional support within their group. Over time, their interactions with each other and their experiences delivering care helped develop resistant and navigational capital [125], as we see below. According to Yosso, resistant capital includes “knowledges and skills fostered through oppositional behavior that challenges inequality,” while navigational capital refers to “skills of maneuvering through social institutions.” [125]. We note that these institutions were not created to accommodate HIV-affected individuals in mind. Both of these kinds of capital are laid out by Yosso as part of a community’s cultural wealth [125], and we observed dedicated attempts by Vikas to restore this wealth and knowledge such that the HIV-status was not an influence.

Kantaben felt that Vikas’ employment of HIV-positive individuals was key to the sustenance and longevity of the organization. This helped create a safe space where neither outreach workers nor any outsiders with HIV faced discrimination. Gaining social acceptability, however, has been an uphill endeavor all along. We learned that the focus and resilience of Vikas’ outreach workers in getting together to collectively pursue their organizational goals of providing support to those with HIV are what helped them face the stigma around their own HIV status. This resistance enacted collectively against a conservative and prejudiced society serve to develop resistant capital [125]. Vikas’ initial activities were focused on providing counseling sessions so as to motivate HIV-positive populations to not give up hope and continue to engage with treatment:

²All participants’ names have been changed to pseudonyms.
“We felt that why not start this organization by which the [HIV positive] community can benefit. We thought let’s start something so that whatever has happened with our lives, let that not happen with others. We are not experts—we are not psychiatrists and we do not have any degree—but we have first-hand experience—and with that we can at least motivate other people to live.”—Kantaben (Female, Co-founder)

The birth of Vikas—an exercise in solidarity for and by individuals with HIV—was thus motivated by the idea of assisting these individuals in moving towards a state that closely resembled the “old normal”—an HIV-free, ordinary societal existence. Vikas’ focus was not only on counseling to ensure treatment adherence but also on actively and daily enacting care and delivering information critical to overcome the effects of discrimination, stigma, and denial that individuals with HIV are routinely subjected to [10].

Our data highlighted the painstaking and successful efforts of Vikas towards the development of navigational capital [125] that would allow individuals with HIV to interface with health and government institutions at various levels without facing challenges on account of their HIV status. As Vikas’ work grew and its reach spread, it received official support from the state. Today, its district-level offices span the state of Gujarat and its work is formally integrated with the vision of the National AIDS Control Organization [72]. Vikas works closely with state-run ART centers as well, which is where they have their first interaction with individuals newly diagnosed with HIV. While it is the ART center’s responsibility to provide treatment, it is Vikas’ workers who connect patients to the Care and Support Centers (CSC) [70] stationed in every district. Vikas operates through CSCs to ensure that patients are aware of various social and economic welfare measures available to them, so that they can continue leading lives that seem as “normal” as possible. Further, these workers labor to ensure attendance and adherence to treatment. In cases of lack of adherence, the Vikas outreach workers trace the non-adhering patients and attempt to bring them back to treatment. Vikas is responsible for bridging the gap between CSCs and state policies; this allows room for impact. The workers at Vikas, all living with HIV themselves, are able to draw on their experience and connections across their communities to counsel, motivate, and generate awareness, generating and amplifying social capital in the process [125]. They have succeeded in bringing about gradual change at both state and community levels with their work, as Kantaben noted:

“If I talk about stigma in 2003, be it World AIDS day or be it Gujarat government’s any program, finding even one HIV positive speaker to be invited was very difficult. But during the recent International Women’s Day (2016)—our programs got published in the media in every district. Even in village meetings our members go and do awareness programs.”—Kantaben (Female, Co-founder)

Understanding the genesis and history of Vikas—its struggles and successes over the last 15 years—helped us develop a better understanding of its mission to restore various forms of capital for the people with HIV who experience multiple forms of marginalization, the challenges faced in the pursuit of this mission, and the potential for technologies to fill in the gaps. Certainly, Vikas’ impact has been visible across Gujarat, based on the numbers shared by Kantaben, and its credibility among those living with HIV also appears to be high, signaling the social capital [125] developed within the community of people with HIV. Vikas’ mission (as expressed by Kantaben) for the state of Gujarat is to assist HIV-positive individuals from the moment that they receive their diagnosis, through their coping process, and until the process of restoration is complete. This is a long and painful process all the way, and entails significant tenacity on the part of the outreach workers, as we found. Workers visit their clients with HIV regularly for following up about their treatment, tracking them down when they go missing, reminding them about upcoming tests, and ensuring that their documents remain updated. These visits gradually become regularized,
tolerated, accepted, and—in some cases—even welcomed. However, for each new individual added to their purview, the workers must contend with a host of challenges in the short and long term. The sections that follow detail the everyday challenges that Vikas’ outreach workers deal with to restore various forms of community cultural wealth for individuals coping with HIV.

4.2 Navigating the Long Road to Adherence and Improved Health

Our interviews and observations revealed that locating and motivating individuals with HIV to adhere to treatment were crucial elements of the everyday work performed by the outreach workers. These workers frequently encountered challenges while ensuring ART adherence. Reasons for this lack of adherence have been documented in past literature as including financial barriers, sociocultural barriers, attitudes and behavior towards medication, and lack of care and counseling at the treatment center [39], which our findings confirmed. The outreach workers explained that cases where the patient is irregular or absent for the treatments at the ART center are labeled Loss to Follow-Up (LTFU). When it has been over 180 days since the patient’s last visit, the ART center records the case as an LTFU [17] and shares this data with Vikas. The Vikas outreach workers then begin their follow-up process.

4.2.1 Locating People and Places. We found that every CSC of Vikas has a dedicated set of outreach workers with a pre-assigned zone. The workers are responsible for all cases in their zone. There are only 1-2 CSCs per district, so the zones covered by a worker are quite large, and completing outreach work is a logistical challenge. Once a worker is assigned an LTFU case, they must locate the address provided to establish contact with the individual. However, these addresses are shared at the ART center at the time when a person has just discovered that they are infected. In their vulnerable state, patients believe that providing accurate identities and addresses might mean that someone would come to visit them, or (perhaps accidentally) disclose their status to their family and/or neighbors. The fear of disclosure leads them to provide incomplete or inaccurate addresses to deter follow-up visits. These factors make it seriously challenging for an outreach worker to trace a LTFU individual.

“Some gave incomplete addresses or don’t update a change of address. It can take up to three hours just to find a place and even then the place may be locked down because the person is a migrant worker who has moved away.”—Suguna (Female, Outreach Worker)

We also found that other intersectional identities interacted with HIV-positive status, resulting in further marginalization with respect to healthcare access. Migrant workers, in particular, have shown high incidence of HIV infection [97] and LTFU [2], and present an additional challenge to outreach workers. When they register at the ART center, the address they provide may only temporarily be accurate, since they are constantly on the move. They might also provide addresses that are wrong or incomplete for fear of being found out. In these cases, the assigned outreach worker must go through the painstaking process of locating an address, often to find that the person does not live there anymore. The workers then rely on information provided by neighbors to understand what has happened to the individual. In some cases, they are able to find the necessary, accurate contact information, when they reach out to inform the patients of an ART center closer to their new location. However, with migrant laborers there is also the additional issue of language barriers as they typically come from different cultural and linguistic backgrounds across India and workers mentioned had trouble communicating with them. To be able to connect with them effectively, workers must cultivate linguistic capital, bridging the communication gap above.

Migrant workers, in addition, did not always inhabit the safest locales, we were told by workers who often found themselves surprised or alarmed when they ended up in a seemingly unsafe area.
“When I got there I realized that this person sleeps in the factory where he works. There were a lot of men doing the same. When I walked into the area I could see men who were barely clothed walking around. They were defecating in the open. In that situation, I had to go looking for this person. It is hard but sometimes we have to go into places like that.”—Sabha (Female, Outreach Worker)

Other workers shared such experiences as well. Since every zone is assigned to at most one worker, workers make their visits alone. Incidents such as the above are common and add additional stress to their daily lives. Operating alone in such environments and with multiply marginalized populations despite additional challenges and personal risks, points to a form of resistant capital that must be engaged by the workers themselves [125].

4.2.2 Building Trust. Outreach workers worked hard to establish social capital, strengthening ties among people with HIV [125]; upon having located the individual with HIV, they began the painstaking process of establishing trusting relationships with these individuals.

“Some of them are scared of our visits; they think we’re going to reveal their status to their family and neighbors. So they chase us out.” —Saroj (Female, Outreach Worker)

People living with HIV are entrenched in stigma, and having not disclosed their status at home, they lack familial support [15]. Their need to maintain secrecy is strong and can last a long time; disclosure among married couples can sometimes take even up to eight years [69]. As in Natarajan and Parikh’s work, we find that the fear of being faced with extreme social stigma and the overall fear of being “found out” is so high that, even in the face of deteriorating health, fear of disclosure trumps the desire for seeking care and treatment [69]. Thus, maintaining social and familial capital takes precedence over ensuring improved health. This is in line with Natarajan and Parikh’s findings, which report that the “maintenance of social relationships was frequently valued over health and longer life spans” [69]. These individuals are understandably hostile to outsiders’ assistance. It is not easy, and sometimes quite challenging, to penetrate their social safeguards. It is with cognizance of an individual’s need for privacy, and by building trust through endless efforts, that the workers are able to get through to the individual and make progress with their own goals. After an outreach worker has accomplished the already arduous task of locating an individual with HIV, the delicate work of establishing trust begins.

Navigational capital includes being able to navigate social relationships, including operating in secrecy [125]. We found, particularly through our shadowing exercise, that the outreach workers were experts at operating secretly. They were quite aware of the possibly delicate nature of the situation at patients’ homes, and cognizant of the fact that these individuals they were visiting may not have disclosed their HIV status yet. When making their first visit to a home, they always assume this to be the case. Thus, when they get closer to the address they are trying to locate, they try to call the individual they are looking for to ask if it is a good time for them to visit, as well as whether he/she has informed those at home about their HIV status. Depending on the answer, the workers may arrange to meet away from their homes. If they are not able to establish contact, they make their way to the address with extreme caution. They talk to no one but the concerned individual, and verify to ensure that they are speaking to the right person before commencing any sensitive conversations. If they meet any other members of the family, they casually evade or lie about who they are and then leave. Through all these interactions, they ensure that the individual with HIV understands that his/her privacy is respected, that the outreach workers are there only to support them and not to meddle with their personal lives in any way.

This secrecy and lying needs to be maintained not just to protect privacy at home, but also in the neighborhood. Our participants reported that in a small neighborhood or village, they needed
to exercise greater caution because the unexpected presence of a new, unfamiliar person sparks everyone’s curiosity. We were told that the workers needed to appear as incongruous as possible so as to blend in and not raise any eyebrows. Arriving with a lot of paperwork could elicit unwanted questions, as apparent from our notes.

As we neared the address, she (Suguna) took away my notes and put it in her bag. I was staring perplexed when she explained to me— if we showed up with anything out of the ordinary, the neighbors will gather around and ask numerous questions—“what is this? who are you? why are you here? A lot of our time will get wasted in trying to lie to them because we don’t want them to find out.” Just as she said it would, this happened at our next visit. The landlord of the person we were trying to trace told us he had moved away but not before asking us—“Are you here to collect money from him too? How much does he owe you?” To which Suguna replies—“I will discuss that with him.”—Field notes

In the situation above, Suguna quickly adapted to the assumption that the landlord had made, without actually saying anything insinuating. When the workers go looking for a patient, we were told, it is common for them to rely on neighbors for directions or information. In fact, in many cases, the workers reported that the neighbors’ help was key to completing the task of person-and address-finding. However, taking their help also elicits many questions and—depending on the situation—they may need to construct an appropriate lie. These efforts by outreach workers to prevent inadvertent disclosure of an individual’s HIV status helps in building a relationship of trust. However, these opportunities may not arise on their own; it remains up to the workers to identify ways of establishing trust. In some acute cases, the individual they are trying to get through to may be adamant and even violent. The workers then have no recourse beyond recording the reasons, and leaving without intervening.

4.2.3 Achieving Adherence. Even after a relationship of trust is successfully established, HIV patients may not become regular with their treatment. Trust alone is not sufficient in overcoming the issues that prevent patients from adhering to treatment. In such cases, the workers turn to counseling, and keep trying to assure the patient of the positive outcomes of adherence, cultivating here aspirational capital [125]. The workers, through incessant effort, convince the individual to be regular with his/her treatment. It is through this continuous effort that real breakthroughs in trust and adherence are achieved, as we see from Sushma’s account below.

“I sat down in their house and just refused to leave until they came with me to the treatment center. It was my third visit to their house and the couple told me they would make it to the next session. They had said the same thing the last two times too. So I decided I had to insist that they go with me to the center that day itself. Seeing I was trying so hard, they gave in and came with me.”—Sushma (Female, Outreach Worker)

When one outreach worker’s efforts are not successful in convincing individuals with HIV, they bring in other workers. If this is not enough, they seek the support of more senior Vikas employees. Social capital is helpful here. Participants shared that the patient usually becomes appreciative that so many people are vouching for his/her treatment and agrees to become regular. Although such concentrated efforts do end up being successful, Vikas—as an organization—appeared to recognize the need to iron out the number of external factors that contribute to missed visits. For example, the Gujarat state government’s project jatan provides travel assistance to those with HIV, so that they might reach the ART center [44]. While it is true that this eases the financial burden on those economically disadvantaged, the process of getting the reimbursement is so cumbersome that not everyone is able to benefit in the end. One major requirement laid down by the government was that the person must have an account with a pre-specified bank:
“It is already a challenge that they should have one bank account. Being specific about this makes it very difficult for them. They lose trust in the system and just think that money is never going to come. So we have spent a lot of time to work with the government to relax this requirement. Now an account with any bank will suffice.”—Raju (Male, Outreach Worker)

By collaborating with the state government, Vikas was able to fix certain (though not all) issues in the reimbursement process. The process of ensuring ART adherence is complex and influenced by several external factors that are not just limited to stigma and fear of disclosure. To succeed, the workers must leverage their navigational capital [125] to engage with various institutions and at multiple levels—of the individual, the society, and the state. This requires physical and social labor from the workers; it also requires persistence and commitment to work at the bottom-up and top-down levels.

4.3 Beyond Improving Health Outcomes to Strengthening Familial Ties

Disclosure of an HIV-positive status can impact familial, social, and institutional capital, making it more challenging for those affected (and/or their families) to return to “normal” life. We discuss below the work that Vikas must perform to both build and restore such forms of capital.

4.3.1 Interfacing Across Institutions. Outreach workers shared that the society is largely misinformed or under-informed about HIV, as prior work has underscored [9, 10]. This means that, from time to time, they need to get involved in discussions with several institutions that HIV-affected individuals and their families are a part of, to ensure that concessions are made to account for the physical and economic difficulties faced. This is needed, because without addressing systemic issues that are beyond the individual’s control, efforts to address social stigma and restore “normalcy” remain incomplete. Interfacing schools is just one among many responsibilities that Vikas takes on:

“There was a couple who were both HIV positive and they could not afford their child’s school fees. The school was asking them to pay the fee or withdraw the child. So we went in and spoke to the school principal, explained the situation, and they reduced the fee by half.”—Sabina (Female, Outreach Worker)

When the workers learn about social and affective concerns around HIV, they step in to do the work of sensitization that is needed. In these efforts, they frequently encounter gaps; the people with HIV may not have the right identification documents, so that they are unable to receive necessary services. The fees associated with getting the official documents might also pose a financial burden. In these cases, workers not only assist with the procurement of requisite documents but also negotiate with issuing authorities (like lawyers and notaries), explaining the situation to have the fees reduced to more affordable amounts. These acts of sensitizing are completely dependent on the situation at hand, and the workers get involved as the need arises. Their responsiveness is critical. On some occasions, the need for sensitization is more dire; when the identities of those with HIV are discovered, they may be subject to severe discrimination [10]. In such cases, the District Response Team (DRT)—a dedicated group of workers—arrive to intervene and alleviate the situation. If a solution does not seem imminent, they assist the individual(s) with HIV—and their families—by taking necessary legal action. To provide some context, discrimination based on HIV-positive status is banned in India and punishable with imprisonment and/or a fine [76].

4.3.2 Taking Care of Children. Children affected by HIV are also victims of social stigma and discrimination, as we learned during our visit to Vikas’ orphanage. This orphanage houses 52 children living with HIV; it takes care of their nutrition, education, and overall development needs. While the children are at the orphanage, they have a strict medicine regime and the greatest care is
taken in maintaining their health. Vikas provides care here to children with HIV whose parents have passed away or whose parents had HIV and were unable to take care of them. We learned that some of the children living there were legally the responsibility of the extended family, who did not wish to take full custody for fear of contraction, and only took care of them during vacations. This makes these children even more vulnerable, and the cycle continues. The outreach workers shared that caregiving families tend to neglect the child’s medical care even when they are given clear instructions and all the medicines. Seema, who was responsible for running the Vikas orphanage, shared that the greatest challenge she faced was at the end of the summer vacation when the children returned sick; it then becomes the responsibility of the Vikas workers to spend time and effort in restoring the health of the child. Thus, Vikas not only provides social and economic support when possible, it also attempts to strengthen familial capital by communicating with the extended family and providing care in the case of children discriminated against by their extended families.

“A lot of the children end up caring for themselves while they are away because the family is scared of infection. When they return, the children are so weak, they need to be admitted. And it can take months for them to gain their strength.”—Seema (Female, Outreach Worker)

It became apparent to us, gradually, that these workers were not responsible for a pre-determined set of tasks alone. They needed to be responsive to a slew of day-to-day needs that would emerge—of all those affected by HIV, and in diverse aspects of their lives. To do so, they drew on knowledge they had cultivated regarding healthcare, social, and political institutions over many years.

4.3.3 Facilitating Marriage and Childbirth. We found that restoring “normalcy” of life for HIV-affected individuals also involved helping them partake in life events such as marriage and/or bearing children. The everyday tasks involved in achieving these are more complicated for HIV-affected individuals and an additional source of anxiety. Not attending to these tasks can have severe social, emotional, and physiological repercussions.

Marriage in India is a complex affair; in the more conservative households, individuals are expected to marry within their caste, religion, region, etc. [83]. Marriages are typically arranged by the families of the bride and groom [68]. Thus, if a family is unaware of a person’s HIV status, there is likely pressure on that individual to marry healthy individuals. In contrast, knowledge of HIV status could distance the family from the individual’s need for companionship. Prior research has recognized that establishing matrimonial services for individuals with HIV would be a culturally appropriate way of improving their quality of life [46]. To address marital needs, outreach workers counsel individuals with HIV to embrace their HIV status and marry within the HIV-positive community. In order to assist them in identifying companions, Vikas runs a marriage bureau; any individual with HIV who is registered with them can find a partner through this bureau, such matrimonial services have been recognized to be culturally appropriate in prior research [46].

Vikas’ marriage bureau is based on a paper database of individuals’ profiles. The database has not been moved online because of their clients’ fear of unintended disclosure. Vikas acts as the medium that stores information securely, and disseminates information to only other interested individuals with HIV. By doing this, Vikas is able to foster participation from such individuals without worrying them on account of accidental and/or unintended revelation of their HIV status.

We learned that it remains challenging to elicit participation from women who have HIV, highlighting again the intersectional nature of this context. One major point of concern expressed by the workers, in the running of this marriage bureau, was that some women on file were harassed by other HIV-positive individuals who feigned interest to get their contact numbers. This happened on a few occasions where male clients harassed female clients over text/call after obtaining their contact information on the pretext of marriage. The workers believe that apart from sociocultural factors, fear of such harassment is possibly what results in fewer female participants. To counter this,
workers share individuals’ profile information sparingly, without revealing any identity-exposing data, until it is absolutely clear that both parties are interested and that the interest is genuine. However, working with paper files makes it challenging to share information as securely as desired.

“Sometimes when I am explaining an individual’s profile, they try to lean and peep to find the phone number. They note it down and then trouble that person through calls and texts. I am very careful...I always cover the personal details but sometimes it still happens.”—Raashid (Male, Outreach Worker)

An important life event that follows marriage, especially in conventional Indian contexts, is childbirth. An inability to have children can lead to issues of low self-esteem, frustration, and a feeling of powerlessness, among other factors [96]. Many outreach workers faced challenging situations while counseling couples with either one or both of the partners being HIV-positive. The couples ask the workers about their prospects of becoming parents, consequences for the child, among other things. This gets especially complicated for discordant couples. According to the workers, most couples are unaware of recent advances in medicine [115] that can prevent mother-to-child transfer of infection. They mostly assume that they cannot have a child, based on non-credible sources of information. In these cases, the workers make proactive efforts to refer the couple to relevant doctors at the ART center. Here we note that some workers were themselves unsure of the protocols involved in child-bearing for mothers with HIV, but most were aware of the possibility.

Our findings thus revealed that an HIV-positive status was frequently accompanied with a loss of aspirational capital—“the ability to maintain hopes and dreams for the future, even in the face of real and perceived barriers” [125]. Outreach workers play a critical role in helping nurture and fulfill aspirations for social acceptance, protecting children’s futures, finding a partner, and having additional children—to restore “normalcy.”

### 4.4 Cultivating Capital within Vikas

Apart from responding to everyday needs and challenges and helping fulfill existing aspirations, Vikas tried to motivate people living with HIV to build aspirations around leading fulfilling lives, particularly when individuals are first diagnosed with HIV and are coming to terms with their illness. This includes reclaiming/restoring expectations they may have previously held around being physiologically healthy, having social relationships, getting married, and having children. Such expectations now become aspirations to strive towards; they are no longer taken for granted due to the additional steps and complexity involved, as outlined in the previous sections. The outreach workers tried to build aspirational capital primarily through formal and informal counseling with individuals with HIV, within and outside the center, and sometimes also with their families and friends. They also worked to educate institutions and the broader society to support the quest for “normalcy.” These are typically one-on-one sessions, and the workers are on their own in these experiences.

Within the center, counseling sessions are mainly organized to create awareness around a few selected themes; these include the social and medical facets of restoring healthful living for people with HIV. These sessions tend to go smoothly as they have a relatively structured format. Workers are able to leverage materials such as picture storybooks, which assist workers by giving context to what they are saying. They find that this is “more effective than speaking with words.” However, in-center counseling sessions can be challenging due to long queues and high waiting times.

“Sometimes 15-20 people come at the same time and at those times doing quality work is hard. It’s a sensitive situation because many of those clients could be coming to us for the very first time. They’ve just found out that they are HIV positive, they are tensed, they’ve...
not received the best of care at the government centers, and now they come to us and they have to wait here too. It’s not easy and some of them get angry and leave or create a fuss.”—Saloni (Female, Outreach Worker)

Outside the center, outreach workers hold one-on-one counseling sessions with people with HIV, often at the latter’s homes. These sessions are less structured and, depending on the scenario, the worker may not be able to use visual aids to support and strengthen verbal claims. Interactions can be particularly challenging and awkward for relatively inexperienced outreach workers. Every case is unique, and the workers have to rely on past experiences to adapt.

“We need to do the counseling based on the attitudes and body language of the client. Sometimes they have lost all faith, thinking they will die soon. Even when this is the case, we need to lie to motivate them. Other times they are angry at the system and society and you have to find a way to calm them down. It takes time to learn what to say when and to whom.”—Rupesh (Male, Outreach Worker)

This expertise—even the knowledge of when to lie and how—can take a long time to build, and effective experience-sharing between the workers can accelerate the process. However, we found that many of these experiences are not shared among the workers. The main form of knowledge transfer is through formal training sessions for new workers. This means that new workers start off (largely) on a clean slate as far as actual experiences are concerned, without any prior apprenticeship. The need to preserve expertise further arises from the fact that the employee base of the organization is constantly changing because members are lost to HIV:

“Four people who were there with me at the start…their death has occurred. So I lost my good friends. Some others left. Only three people here today were also there during the time of formation.”—Kantaben (Female, Co-founder)

After having painstakingly developed different kinds of capital within the communities of outreach workers and people with HIV, there is no mechanism in place for passing on and preserving community knowledge. This highlights opportunities for design to look at how such localized and rich expertise of Vikas’ workers might be preserved from generation to generation, so that there is some semblance of a support network for the workers to draw on for each other.

5 DISCUSSION

Our findings highlight the restoration work conducted by the HIV outreach workers at Vikas, which we define as a form of articulation work [109] that aims to restore “old normals” impacted by “life disruptions,” such as that of HIV diagnosis in the case of our research [59]. We found that our workers aspire to cultivate and strengthen community cultural wealth (as per Yosso’s framework [125]) in the process. By laying out the daily labors performed by our participants towards medical adherence, maintenance of social standing, stronger family and social ties, among other goals, we foreground the time and effort expended by these workers in these regards and aim to identify ways for technology to support, extend, and/or leverage their efforts. At the same time, the sensitivity of the situations examined demands that we pay close attention to recognizing that technology may only have minimal impact and an intervention may not necessarily be advisable (along the lines of Baumer and Silberman’s recommendation [7]).

In section 5.1 below, we detail the ways in which our participants worked to build and strengthen community cultural wealth, and accordingly recommend potential means of intervention. We then highlight, in section 5.2, how the restoration work performed by Vikas outreach workers might inform future efforts in CSCW, HCI4D, and the larger HCI community.
5.1 Building and Strengthening Community Cultural Wealth

Focusing on the restoration work performed by Vikas’ outreach workers [100] drew our attention to the intersectional realities that HIV-positive individuals are subject to in our context of study. Yosso’s exposition of community cultural wealth regarding communities of color allowed us to recognize different forms of capital that might exist in intersectionally diverse settings by taking an assets-based approach [61, 125]. This is a departure from deficits-based perspectives that have commonly been used—in ways that disempower and cast the marginalized population as being passive and acted upon [125]—towards acknowledging the persistent labor that participants are engaged in to restore “normalcy” following life disruptions [59]. We now reflect on these labors to provide recommendations for how community cultural wealth might be built and strengthened in the context of HIV outreach work, connecting these with insights gleaned from our findings.

We note that forms of capital intersect and feed off each other. Also, even as we recommend possible points of intervention for technology to bring value, we note that technology is not always useful or relevant in such contexts; we outline opportunities for technology to ease the workflows of healthcare providers and those with HIV, and point out where it may be more desirable to not engage it at all. Finally, even if it can potentially bring value, it is ultimately the perceived affordances that matter and must be attended to. No matter how effective a private communication medium is, for example, fear of unintended disclosure is so high that it might dissuade uptake.

5.1.1 Aspirational and Resistant Capital. An HIV diagnosis could be accompanied with anxiety around achieving milestones considered part of “normal” life. Hence, Vikas’ workers were consistently laboring to cultivate and/or strengthen aspirational capital, or the “ability to maintain hopes and dreams for the future, even in the face of real and perceived barriers” [125]. We saw this in the case of their provision of support towards marriage and pregnancy, navigating bureaucracy to ensure the enrollment in schools of children of couples with HIV, and even in their own desires—as a group with a mission—to grow their impact across the state of Gujarat. Thus, by supporting those with HIV and by driving Vikas’ mission, workers aspired for hopes and dreams to be nurtured in the presence of—and even sidelining—an HIV-positive status.

Cultivation of aspirational capital to nurture the aspirations of clients was made possible through recurring counseling sessions. With a growing online population (as documented in recent scholarship on community health workers in New Delhi [37]), online forums and social media platforms can now be leveraged to provide such counseling in the manner of support groups. However, these would need to be closed or even secret groups (on Facebook, for example) such that complete confidentiality is maintained. If clients do not own their mobile devices, or are not in complete control of their web access, this is not a tenable solution, given the extreme stigma that must continually be navigated.

Even as workers’ fostered new aspirations among clients and helped reclaim some old aspirations, the stigma attached with HIV-positive status remained intact for the most part. Workers focused on developing resistant capital among clients to be able to face this stigma. HIV-positive, Vikas’ workers also built their own resistant capital by not only managing their condition, but going beyond to proactively and consistently provide care to others with HIV, and by building a new future for themselves by working with Vikas. Drawing on their own experiences, they could motivate others to also challenge oppressive structures. Technology design could help in sensemaking (e.g. [58]), by enabling individuals to come to terms with their HIV status and comprehend the way forward (or to “old normals”) through the sharing of experiences and acts of resistance online among HIV-positive individuals (anonymously), with workers mediating and moderating interactions.

5.1.2 Navigational and Linguistic Capital. The restoration work performed by our participants continually entailed navigating within and across institutions, building and exercising their navigational capital. In this process, they were frequently engaged in translating contexts for their clients, thus leveraging and extending linguistic capital.

On a daily basis, the outreach workers needed to carefully navigate communications with various entities—coordinate private conversations, manage one-on-one interactions with their HIV-positive clients, protect these clients’ status from family and/or neighbors, identify allies within government institutions, and more. New workers were frequently ill-equipped to perform these interactions, and the high attrition rate due to HIV-shortened lifespans of workers was an additional disadvantage. Creating repositories of learning resources that can be passed along cohorts of workers, as well as interested clients, could be valuable. This could be done by cultivating a knowledge base of how these practices are executed, by creating interactive journey maps for new workers as well as clients. These maps could also consolidate and curate questions and answers that the workers and clients had experienced as challenging. These could be offline resources made available at CSCs; they could also be provided online for those not afraid of disclosure. These resources could also be made using immersive virtual reality (VR) environments, with low-cost cardboard viewers, which are increasingly being demonstrated as being helpful for perspective-taking [114].

Though most stakeholders understood Gujarati, the language of the state, there were also groups of migrant workers that our participants found themselves engaging with who presented language barriers. Even if communication was possible in Gujarati and/or Hindi, an understanding of legal paperwork, and thus an awareness of rights, was absent. This is also a finding in prior CSCW literature [35]. Legalese was not understood by most clients, who were often low-literate, and the burden of translation fell on our participants. In such cases, it is possible for linguistic capital to be enhanced through the provision of materials that demystify documentation, and allow individuals to become aware of their options. It may also be possible to facilitate ad hoc communication between the individual and the outreach worker whenever there is documentation needing translation. Exploring potential for policy change by making this documentation easier to interpret for less educated populations is an additional avenue worth exploring.

5.1.3 Familial and Social Capital. An HIV diagnosis impacted familial capital in multiple ways, hurting kinship. Many lived in fear of disclosure of their HIV-positive status, as this could mean being ostracized by immediate and extended blood relations. These attitudes commonly extended beyond the family, impacting social capital as well.

It is unclear whether technology can change discriminatory attitudes around HIV that are deeply entrenched in society, although interventions such as TeachAIDS [105] have made a valiant attempt. Technology could, however, support, extend, and/or leverage restoration work by helping to manage existing relationships and build future ones. Outreach workers were already managing an offline, ad hoc marriage bureau to help people with HIV find partners; this could be digitized. Existing online services that do this [32, 90] appeared to be overwhelming for participants. These workers repeatedly mentioned that many people with HIV they had helped to find partners for did not want their information online. Design constraints for this marriage bureau signaled the need for a human infrastructure-driven information brokering to be put in place, so that personal information was revealed with extreme care and caution. A system that masks callers’ information but allows them to communicate regardless could offer one recourse. Giving the human more control so that all communication was moderated and managed by them could be another; this could be done by Vikas’ workers who are already engaged in the labor-intensive work of matching individuals and maintaining records. Privacy features of existing matchmaking websites could also be adapted. For instance, certain platforms allow users to hide their photos until the match gets more serious [92],
others allow women to message first [86]. Avatars and dummy phone numbers [77] could mask online identities until users felt comfortable sharing their details.

Restoration work could also help cultivate social capital between workers, between workers and clients, and for clients in targeted social contexts. Workers constantly drew solidarity from exchanging notes with each other, giving each other company, or helping each other out. Although WhatsApp has been found to be accessible and useful in recent research [37], it also presents privacy concerns due to phone numbers being visible. A private platform that could also allow workers to share knowledge with each other, potentially through photos (such as over closed Instagram groups), making their movement more tractable, could be valuable. Second, gaining trust and support of HIV-positive individuals was an arduous undertaking for our participants. Technology cannot identify correct addresses if the client willfully provides the wrong one. Nor can technology substitute for an in-person visit to the ART center. However, it can help make movement more seamless, by facilitating private communications via phone. Finally, we saw evidence of Vikas building social capital over time within political institutions, as shown by the support of their work by the Gujarat government. Various media could help publicize and strengthen this association, legitimizing Vikas in the eyes of potential clients recently diagnosed with HIV.

5.2 Towards Restored Futures

Examining the past to design for the future has received attention in HCI research in various ways. For example, Wyche et al. demonstrated how history might be integrated into early stages of design for housework technology [123]. They additionally made a case for following similar strategies in designing other aspects of the domestic environment, such as “cooking, childcare, or entertainment, as well as for other activities outside the home” [123]. Peesapati et al.’s design of the Pensieve relied on everyday reminiscence through emailing memory triggers, looking at social media content previously created, for instance [84]. More recently, Soro et al. made a case for “designing the past”, suggesting that people are continually engaging with re-designing their past, either accidentally or intentionally. In particular, they pointed out that “insofar as possible futures rest on existing past conditions, a designable past opens up further possibilities for design” [106]. Steinhardt and Jackson extended this line of thinking with their proposal of “anticipation work,” or “the practices that cultivate and channel expectations of the future, design pathways into those imaginations, and maintain those visions in the face of a dynamic world” [108]. By proposing that we attend also to restoration work, we recommend an appreciation of the everyday practices that seek to respond to life disruptions by restoring “old normals”. We discuss this further below.

5.2.1 Restoring “Old Normals”. Our research participants aimed to simulate an existence for their clients that mitigates the burdens and breakdowns resulting from an HIV-positive diagnosis, and we closely align with CSCW scholarship on breakdown and repair in this regard (e.g., [34, 38, 95]). Further, even as our participants are driven towards restoring “old normals,” restoration of aspects of the past could additionally shape the planning of futures alongside new possibilities, like with repair [34, 38, 95]. For example, a focus on strengthening social capital could lead not only to maintaining old relationships but also creating new ones with other individuals with HIV or with Vikas’ workers. We note here that restoration, like repair, does not simply ‘bring back’ the past, as growing scholarship has acknowledged. Just as repair restores and adds value in the case of material artifacts, so are restored futures aimed at adding value to the lives of HIV-positive individuals (in their and Vikas’ perceptions), beyond attempts to replicate the past. For instance, familial capital may need to be further enhanced to provide more support for the individual with HIV to draw on, particularly during harder times. Additionally, as scholarship on repair in CSCW reminds us, what is broken cannot always be brought back into existence as it once was. The “old normal” may not
be possible to restore, and workers may not succeed in their efforts. We must acknowledge that there are limits to what is possible.

Restoring “old normals” may be desirable but impracticable. We may wish to restore only fragments of the past, such as aspirations for marriage and a family or improved economic status. There may, additionally, be explicit aspects of the past that we wish to leave behind, particularly in the case of populations that may be already marginalized along multiple, intersecting dimensions such as gender, caste, and class, before the additional dimension of an HIV-positive status. Even in such contexts with histories of oppression, however, we emphasize that resistance exists alongside oppression and can illuminate ways to move forward, as visible in prior work [36, 51]. In such cases, an assets-based approach as possible by adopting Yosso’s framework [61, 125] can help us take a more targeted approach to identifying which fragments of the past we wish to restore, thereby uncovering opportunities for design.

We acknowledge that restoration work is also fraught with various tensions and contradictions. Memories are fundamentally unreliable and a sense of nostalgia surrounding memories of past happiness may make moving forward more difficult and set unrealistic expectations for the future. Navigating these tensions is part of the labor involved in restoration that the outreach workers at Vikas are engaged in. For example, people with HIV who wished to marry are now restricted to a much smaller pool of potential partners. Though this could be difficult to come to terms with for clients, Vikas’ workers work hard to facilitate the process of finding a suitable partner.

5.2.2 Development Outcomes. The development project shares design’s vision of better futures and “making those things happen” [106], a primary focus in the field of HCI4D as well. However, these better futures are conceptualized around ideas of economic growth and mobility, and ones that western nations have propagated in a post-colonial world [23]. There is an increased focus on decolonizing methodologies [103], and looking to re-construct plural histories to inform the present [24]. Our research, conducted in a canonical development context, also highlights that this development (in our case, improved global health outcomes) is greatly facilitated by the restoration work performed by outreach workers. The future they look to create or restore, however, is very much aligned with and inspired by the past, as they look to eliminate the loss in pay that prevents children from attending school on account of school fees, or the disruption in social lives on account of the stigma of the HIV-positive diagnosis, and convince patients to go for ART through persistent house visits. By examining these day-to-day challenges and the workers’ response to them, we gain a holistic understanding of how people with HIV could potentially lead better lives. These are considerations that global health researchers and practitioners must make in designing and targeting improved health outcomes.

Crafting preliminary outcomes that must be met even as adherence to treatment is prioritized could help to better align top-down development (and technology design) goals with ground realities. For example, seeing that the outreach workers took care of HIV-affected children at the Vikas orphanage, particularly where the extended families were legally responsible for taking care of them, might bring us to set the desired development outcome that more HIV-affected children be placed with their families, as was true in their past. Focusing on such paired outcomes will also help better achieve traditional goals such as ART adherence. For example, fear of disclosure resulted in poor adherence with ART therapy, and strengthening familial and social capital could assist towards overcoming this fear of disclosure, in turn impacting adherence.

5.2.3 Other “Life Disruptions”. Beyond acquiring an HIV-positive status, there are several disruptions that, we might imagine, could transform lives forever. Such contexts have long been of interest to the HCI and CSCW communities. Natural disasters such as earthquakes and floods [122], political disruptions leading to mass mobilization [107], other health conditions such as...
acquired disabilities [55]—all of these might leave individuals and/or communities in a position where the most desired change might be to turn to the past, not generate previously unimagined futures. Thinking about design in terms of reconstructing a familiar, desirable past, or sustaining status quo, may hold even more value then, even when this is largely impossible in situations such as our participants faced. This implies that our metrics for assessing attainment of development (and design) outcomes might also need to change. For example, for individuals with HIV, this might mean being able to get married, have children, and send these children to school, just as their non-HIV-positive family members and/or neighbors might. Additionally, the progress made by children with HIV in the Vikas orphanage might be measured in terms of various aspects of “normalcy,” such as the development of peer relationships or academic progress.

6 CONCLUSION

We conducted a field study of the everyday practices and challenges of HIV outreach workers employed by Vikas, a community-based organization in Surat, Gujarat (India). We investigated the intersectional realities of the contexts they operate in, as they aim to restore “old normals” or life before diagnosis for PLHIV. By focusing on the articulation work performed by these workers, we learned that they not only aspire to address health conditions, but also attempt to facilitate restoration of various forms of capital of their HIV-positive clients. We drew attention to the spaces where technology might be of assistance to them (or not), through an examination of the ways in which they engage diverse forms of community cultural wealth [125]. Finally, we reflected on how a focus on restoration work might advance CSCW, HCI, and HCI4D research.

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