Crossing Disciplinary Borders to Address Challenges of HIV Outreach

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Abstract

India ranks third among the HIV-affected populations of the world. There is an ongoing, massive, global effort that aims to provide treatment, spread awareness, and mitigate the effects of HIV/AIDS. Issues of societal stigma, discrimination, and denial complicate the effectiveness of these efforts. In our research, we focus on the work of outreach workers who act as a bridge between the state and the People Living with HIV (PLHIV). Based on data we collected, we identify key areas that align with day-to-day and long-term challenges of their outreach work. We posit, in this paper, that we need collaboration from researchers and practitioners from health, finance, design, policy, and HCI to collaboratively address the challenges described. At the symposium, we hope to learn from the perspectives of researchers from other regions and disciplines so we are better equipped to address this challenge.

Author Keywords

HIV; Health; ICTD; India.

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous; See [http://acm.org/about/class/1998/]: for full list of ACM classifiers. This section is required.

Introduction

According to the World Health Organization, there were 36.7 million People Living with HIV (PLHIV) in the world in 2014 [8]. The vast majority among these live in low- and middle-income countries, with India ranking third among them. In India, the National AIDS Control Organization (NACO) [5] oversees efforts to mitigate the disease and spread awareness. While NACO's policies and programs have invested significant attention towards controlling and reducing the incidence of HIV/AIDS, factors such as discrimination, social stigma, and denial pose immense challenges, creating a climate in which government regulations are likely to be side- stepped [1]. In such socially charged landscapes, outreach workers play the critical role of bridging the gap between the state and the PLHIV [4]. Our work thus far has closely examined the work practices of these outreach workers to understand how they interface with the PLHIV community, and the challenges they face in doing their work. In this workshop paper, we provide brief summaries of our preliminary findings and analysis from the ethnographic research we are currently in the process of conducting. We use this preliminary data to support the case that there are many different domains of expertise that must come together to ensure that the HIV outreach work our participants do is effective.

Background

For our initial study, we studied the day-to-day work practices and long-term goals of a specific NGO–Vikas (name changed)–that has been focusing on expanding outreach efforts for the PLHIV community in the state of Gujarat (India) over the last 13 years. Our findings reveal the sensitivity and rich, situated understanding with which these workers, who are PLHIV themselves, carry out their activities. For one, Vikas works closely with state-run antiretroviral therapy (ART) centers; this is where workers have their first interaction with the PLHIV. While it is the ART center's responsibility to provide treatment, it is the Vikas workers who connect with the patients to ensure that they are aware about various social and economic welfare measures available to them. Further, they ensure attendance and adherence to treatment. In cases where there is lack of adherence, the Vikas outreach workers trace the specific patient and attempt to bring him/her back to treatment. Thus, Vikas is responsible for bridging the gap between the state's policies and the PLHIV communities, which gives it potential to make considerable impact. The workers at Vikas are able to draw on their experience and connection to the community to counsel, motivate, and generate awareness.

Responding to prior research that calls for viewing PLHIV as more than patients [6, 2, 3], we emphasize the pivotal role of the outreach workers at Vikas as well as the need to examine how HCI might design *and mobilize* sociotechnical infrastructures that could support these workers.

Research Proposal

Technology interventions have been designed by global health and human-computer interaction (HCI) researchers to address the challenges faced by PLHIV, especially in regard to treatment adherence or ensuring that vulnerable populations are better informed [3, 7]. However, working around the social stigma and discrimination requires careful and discreet attention from a variety of perspectives, as we found in the field. With this in mind and based on our research findings we have identified some key areas of need. We would like to present these to an interdisciplinary audience to learn and discuss how these might be appropriately addressed:

Day-to-day challenges

The outreach workers face logistical challenges from locating PLHIV to navigating the nuances of government policy (*e.g.,* with the adherence to ART). While these challenges aren't unique to outreach work, they are more pronounced in this context as the systems in place are not designed to account for the stigma and lack of trust associated with the disease. The outreach workers recount that it takes a long time before the PLHIV learn to trust them. They are entrenched in a society of stigma and having not disclosed their status at home, lack familial support [2]. Governmental policy, outreach work, and any technology that needs to be embedded in this space needs to be cognizant of the delicate interplay between stigma associated with HIV/AIDS and the resulting lack of trust.

Life challenges

In doing the field work to reintegrate PLHIV into normal living there are life needs that arise. For example, in seeking companionship, PLHIV need to be advised to find partners amongst other PLHIV. Existing matrimonial platforms do not serve the needs of this target population and so the organization runs its own matchmaking service. It is primarily manual and benefits a small number of PLHIV at present; digitizing their system is a key need. Understanding why existing platforms don't work and how the organization acts as the intermediary is important before proceeding towards digitization.

Long-term preservation of expertise

A major part of the worker's responsibility is counseling. The outreach workers are always counseling, formally or informally. These counseling sessions are usually one-on-one and leave the workers on their own in these experiences. Thus, skill development becomes an important need for successful outreach work. Currently on-the-job learn-

ing and help from senior outreach workers are the key avenues of training. However it is a skill that is picked up over time. Thus the transience of the employee base of the organization, due to all its members being PLHIV, presents a concern. This motivates the need to look at how the organizational expertise might be preserved from generation to generation. This would provide a support network for the new workers to draw on.

Understanding the intricacies of all these challenges and how the outreach workers navigate them is key to developing technologies for this context. Borrowing from the principles of HCI and applying a user centered design approach that begins with empathy and contextual understanding before ideation would be a key step in the process. Drawing on the learning from an abundance of ICTD health projects will be useful in breaking down the complexities of the problem space. Inputs from health practitioners would also provide useful insights. Moreover, this would ensure that the lens of technology alone not drive this research and that it heavily draw from findings in health research.

At the Symposium

The overarching goal of this research is to discuss how privacy boundaries of PLHIV are negotiated and defended by Vikas' outreach workers. Understanding this will help to make design recommendations that prioritize the needs arising from the above areas of challenges. HCI Across Borders will allow us to connect with other researchers who examine and design technology in similar contexts relating to global health. A key question we grappled with in this research was how the findings would translate to the rest of India, or even the world. Collaborations with other HCIxB attendees might help answer this question. Understanding this would give more meaning to our work by making it useful for vulnerable populations across the globe.

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