

Understanding Barriers to Information Access and Disclosure for HIV+ Women

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ABSTRACT

ICTD researchers have employed several technology interventions to help combat the HIV/AIDS epidemic in developing regions. These interventions address medication compliance, decision-making support for health care workers, and awareness campaigns. A majority of these interventions focus on dissemination of information on HIV prevention, testing and treatment. Our research surfaces the situated knowledge of HIV positive women to examine how heterosexual married couples in Chennai (India) manage knowledge of an HIV-positive status, illustrating why dissemination models often fail to lead to safer health practices. Timely disclosure to sexual partners is critical for preventing transmission and ensuring effective treatment. However, voluntary disclosure between married couples can take up to eight years. Patients often valued maintenance of social connections over longer life spans and health. We describe these sites of dissonance and articulate the conflicting needs and conditions that determine concealment of HIV status. We discuss how socio-cultural factors such as gender structures in intimate relationships determine access, understanding and use of information critical to prevention of the HIV/AIDS epidemic. We ask how the ICTD prioritization of efficiency, standardization and measurement neglect the affective and relational experiences that determine the spread of the largest global health crisis. Finally, we provide a set of design considerations and provocations for ICTD researchers to begin addressing the underlying socio-cultural factors that could ensure greater use of beneficial health information by individuals at risk.

Categories and Subject Descriptors

J.4 [Social and Behavioral Sciences]: Psychology, Sociology; J.3 [Life and Medical Sciences]: Health

General Terms

Measurement, Human Factors, Standardization, Design

Keywords

HIV/AIDS, gender, disclosure, stigma, information dissemination, information access

1. INTRODUCTION

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The HIV/AIDS epidemic is currently the leading worldwide cause of mortality for women of reproductive age [36]. Although stable globally, the proportion of infected women has increased in many developing regions of the world [32]. Women aged 15-24 are twice as likely than men of the same age to contract HIV/AIDS globally and eight times more at risk in regions such as Sub-Saharan Africa [31]. Women are more vulnerable to HIV infections due to biological reasons as well as social factors including widespread gender inequities. These include the inability to make key life decisions around sexual partners, timing of marriage, and choice of spouse. In addition, lack of opportunities for education, financial independence, property ownership, restricted mobility and access to healthcare contribute to increased vulnerability to the adverse social and biological consequences of an HIV diagnosis.

Marriage can pose a risk to many women who are forced to marry at a young age without adequate sexual education, often to men much older than them, with whom they lack negotiation power [32]. In Asia-Pacific, a majority of infections contracted by women are through the spouse or long term partner who indulge in high-risk behavior including unprotected male to male sex and paid sex, and injected drug use [30].

ICTD researchers have employed several technology interventions to help combat this deadly epidemic in developing regions. These interventions are often mobile-based and address medication compliance [14][21][25], decision-making support for healthcare workers [16], confidential test result delivery [35] and awareness campaigns [9] [33]. A majority of these interventions focus on increasing access to information on HIV prevention, testing and treatment. Here, they share an important concern with many mHealth projects: the standardization and efficiency of information flow between the NGO with domain knowledge, and the patient. It is important to analyze how concerns over the efficiency of knowledge flows have come to be so central.

In their analysis of a related field, ubiquitous computing, Dourish and Mainwaring reveal the remnants of colonialism in present day technology design [7]. They mirror the sentiments of development era critics such as Arturo Escobar in describing the following legacies of colonialism that influence ubiquitous computing, and guide current ICT-enabled development projects as well. First is the idea that there is a single path to development, including scientific expertise and technical advancement that the developed world attained a long time ago; the global south is merely at an earlier stage and development interventions are meant to help them “catch up” with the west [8]. Second is the notion that there is a lack of rigorous scientific knowledge in these regions and it is the responsibility of those in power to fill this knowledge gap. Third is ‘universality’, the idea that knowledge generated and applied in one location will result in a similar effect, regardless of where else it is applied [7][8]. Finally, the colonial enterprise grasps complex social phenomenon through systematic quantitative analysis designed to enable prediction and efficient

control [7][23]. It positions itself as the central authority and access point by organizing, classifying and standardizing knowledge [7]. Similarly, a majority of ICTD for health interventions revolve around the same issues of finding, organizing and presenting information in ways that allow healthcare systems to control information flows, further standardize care and manage disease more efficiently. Godlee et al. for example, assert that a decade of past experience in public health objectives of “health information for all” or universality has reinforced the value of information pull rather than push in knowledge transfer [11]. However, they state that “there is a continuing tendency to push information rather than strengthening and responding to the pull of their information needs.”

Dourish and Mainwaring draw from James Scott in describing how in this process of universalizing information, aspects that do not easily conform to standardization are expelled or broken down into forms that can be universalized [7] [23]. HIV/AIDS is a case where the effectiveness of any intervention to prevent the spread of disease relies first and foremost on knowledge transfer between partners in an intimate relationship to enable risk assessment. This relationship is outside the institution’s purview, cannot be universalized, resists measurement, control, and standardization, and yet determines the institution’s ability to discern who needs care and the individual’s ability to seek it out.

Abjection in ICTD is the inability to find information one seeks. As an emergent field, we aspire to alleviate poverty of information through efficient and scalable systems whose impact can be easily assessed. It is important to ask, however, what kinds of information needs are most amenable to this framework? Whose need can be counted? How might this framework prevent better health outcomes while enabling performances of productivity and efficiency in health systems?

Recent work by DiSalvo highlights the productivity of differences and contestation in technology design [5]. His emphasis on differences follows traditions of feminist epistemology, a framework directed at countering inequities of power in knowledge production. At its core, feminist epistemology states that all knowledge is situated [12] and informed by the particular position of the knower in a larger institutional and cultural framework. Any act of knowledge production, including academic knowledge production, is embedded in a network of relationships that regulate what can be known. Donna Haraway suggests that it is precisely in this limited location, with its partial and situated perspective, that objectivity resides [12]. Unlike dominant epistemological frameworks that seek to erase these partial perspectives in the quest for generalizability, feminist epistemology brings these differences to the forefront to highlight what is ignored but central. This paper’s emphasis on the lives of HIV+ women and their accounts of HIV/AIDS follows this tradition in its choice of informants and its focus on what is left out of dominant discourses on health in ICTD.

Our research uses an ethnographic and grounded theory approach to examine how heterosexual married couples in Chennai (India) manage knowledge of an HIV-positive status, and the situated knowledge of HIV+ women to illustrate why information dissemination and standardization models often fail to lead to safer health practices. We investigate how gender structures in intimate relationships determine what kinds of information men and women can access and use in relation to HIV. How does gendered control of information related to sexual education, sexual activities of partners and infection status marginalize women further from the collaborative decision-making required to

ensure sexual health of communities at high risk of HIV/AIDS? We focus on directing attention to affective and social aspects of disease that are extensively researched in public health but under-researched in ICTD and mHealth projects, and suggest opportunities for supporting these underlying socio-cultural structures in ICTD interventions for health.

2. BACKGROUND & RELATED WORK

India has approximately 2.39 million people living with HIV/AIDS [17]. Heterosexual unprotected sexual encounters are the primary mode of transmission in this region, comprising 87.4% of all infections. Tamil Nadu state is one of four high prevalence states in India. This research was conducted in its capital city, Chennai, where a majority of HIV+ informants reported being the wives of either long distance truck drivers or migrant laborers in neighboring states, two main bridge populations for HIV infections [17]. Bridge populations are those that transmit HIV from high-risk groups such as sex workers to the larger population. Because bridge populations are important target groups for HIV education and stigma reduction programs, they have greater exposure to information disseminated on prevention. Disclosure is the crucial next step in preventing transmission to the general population. However, disclosure is perhaps the most controversial and perplexing issue in HIV/AIDS. A long history of research on sexual health has complicated the relationship between awareness, disclosure and safe sex practices, provoking intriguing questions about the role of human relationships for the ICTD community to consider.

2.1 HIV Serostatus Disclosure

There is a high level of variation in disclosure rates in the literature. Studies in India have found that rates of disclosure are higher for women than men. One study in Kolkata found that among men, 65% of unmarried males and 82.3% of married men disclosed their HIV status to their sexual partners, while all female participants had revealed their status to their sexual partners [28]. Studies of disclosure by HIV+ women in Sub-Saharan Africa and Thailand have found rates varying from 16.7% to 86% [15]. One survey of studies on disclosure revealed that women who tested positive during pregnancy in antenatal care settings had lower rates of disclosure than women who tested positive through voluntary testing centers [15]. The most significant obstacles to disclosure for women were fear of abandonment, discrimination, accusations of infidelity and physical abuse.

In Jamaica, research on disclosure found that 49% of males and 60% of females had disclosed to their partner. This study found that perception of family support was significantly associated with higher disclosure rates. In addition, age and perception of family support was significantly related to consistent condom usage [2]. How do expectations of family support relate to a greater desire to protect oneself and others?

In the USA, in a study of both men and women, disclosure rates were 78% for regular partners and 54% for non-regular partners and regardless of disclosure of a positive status, Kalichman et al. found that the use of protection in sexual intercourse with HIV negative partners remained constant at 68% to 77% [13]. It is unclear that disclosure results in safer sex practices [26]. In a study of HIV+ men, Crepaz & Marks found a disclosure rate of 53% to HIV negative or status unknown partners and noted that 28% of participants had engaged in unprotected sex with at risk partners [3]. Disclosure when accompanied by discussion on safe sex with a potential partner resulted in higher rates of protection than disclosure alone [3]. Another study in India on safe sex

practices found only a 46% condom usage rate among 925 couples where only one partner is HIV+ in Karnataka, a high prevalence state [24].

Although, earlier research shows that a majority of infections in Asia-Pacific are contracted by women through the spouse or long-term partner [30], there are emergent changes in gender structures affecting the spread of illness. In their recent study, Shastri et al. found that among couples older than 30, the infected partner was usually male. However, in younger couples, the infection was more often transmitted by the female, indicating a shift in the occurrence of female transmission of HIV [24] and perhaps underlying gender norms around premarital and extramarital sex. Marriage and procreation as the norm, along with high levels of stigma against homosexuality, exacerbate problems of disclosure. Homosexual men are forced to hide their orientation and sexual relationships and enter heterosexual marriages where they are pressured to have children [27]. These socio-cultural conditions make it harder to disclose an HIV+ status and any new adoption of safe sex practices in a long-term relationship with expectations of procreation can be seen as suspicious by the uninfected partner.

These research studies raise intriguing questions on how human experiences of companionship, desire, fear, and intimacy complicate the perhaps externally imposed quest for longer and healthier lives in HIV/AIDS. We might even speculate that they trouble the idea that a long healthy life is an aspiration held by all. It is important to ask what makes a longer life worth living for an individual afflicted with a fatal illness that can be slowed down but never stopped. What do HIV negative partners, fully aware of the fatal risks of unprotected intimacy, desire in these relationships? Do ICT-enabled efficiency, standardization and measurement consider these affective and relational experiences that determine the spread of the largest global health crisis?

2.2 mHealth and HIV/AIDS

Mobile technology interventions designed to enable better healthcare in developing regions are an important subfield of ICTD, commonly referred to as mHealth. mHealth leverages the increasing pervasiveness of mobile technology in the developing world to help deliver standardized and efficient care to disadvantaged communities. mHealth interventions aid data collection, training, disease surveillance, monitoring of health services, diagnosis and treatment assistance and patient education [4].

Mobile interventions have been assessed to be quite successful in increasing medication compliance among HIV/AIDS patients. In particular, in a system deployed in Kenya, healthcare workers sent weekly SMS messages to patients on their Antiretroviral therapy (ART) as reminders and encouragement to take their medication. The patients were required to respond within 2 days. This resulted in significant increase in ART compliance and had a positive influence on viral suppression [14]. Other mHealth projects have addressed health care decision support and confidential delivery of test results through PDA-based secure systems [16, 35].

Of particular interest to this paper are education and awareness interventions. Several of these use interactive mobile based campaigns that encourage individuals to pull and engage with content rather than passively consume information pushed at them. Project Masiluleke in South Africa sent free text messages to communicate HIV/AIDS information and a hotline number to call for help. Project Masiluleke saw a 350% increase in calls to the HIV/AIDS helpline [33]. Project Masiluleke is currently exploring home self-testing kits and confidential virtual

counseling over mobile phones. In Uganda, Text to Change used SMS-based HIV/AIDS quizzes to create awareness, resulting in a 40% increase in number of individuals accessing free testing [33]. Other interventions such as Freedom HIV in India use mobile games to create an engaging platform for awareness [9].

The “Learning about living” project in Nigeria enabled youth to text message, call or submit a question online and receive responses by trained volunteers. The service also sent questions for the youth to answer and provided awards for the best answer. This project received around 10000 messages in the first year [33].

These interventions address a wide range of barriers including awareness, stigma and privacy. In light of research in public health, we question whether education on prevention and treatment, and knowledge of HIV+ status will lead to disclosure and safer sex practices. We analyze these questions through the lives and situated knowledge of women who were made vulnerable to HIV infections because they were prevented from assessing risk accurately. We interrogate notions of time, values, inequities, fear and pressures to conform for both individuals and institutions.

3. METHODS

The first author undertook fieldwork over a two-month period in 2012 with an NGO run by HIV positive women. This organization’s services included promoting education and awareness on HIV/AIDS and reproductive health, reducing stigma and discrimination, providing opportunities for financial independence, crisis intervention, advocacy and counseling. Tamil Nadu state was chosen, as it is a high prevalence state for HIV/AIDS.

We used an ethnographic approach to understand the ways in which information access and disclosure in intimate relationships is culturally embedded. We employed an allied grounded theory approach to use the insights generated during fieldwork to iterate on our research directions and subsequently, our ICTD lens. We describe these iterations and our research trail below.

The original intent of this project, prior to fieldwork, was to understand how HIV+ women in Chennai, India conceived of privacy in order to inform the design of an ICTD-enabled information sharing platform. Our ethnographic approach was embedded in the traditions of HCI as a qualitative research method in service of computing and design [6]. However, in the initial phases of fieldwork, we noticed an emerging theme. The issue was not so much a lack of available information around prevention and treatment, but an inability to use that information. Secrecy in relationships constrained a woman’s ability to assess risk and adopt preventive measures. In addition, the lack of disclosure between spouses presented a significant obstacle for the NGO, as they were unable to accurately assess which women they needed to target for their informational and counseling services. The interconnection between gender structures, disclosure in marital relationships and information access is assessed in relation to these acute problems the NGO and women faced in prevention and care.

Spouses of bridge populations such as migrant laborers and truck drivers were assisted most often at the counseling centers run by the NGO. This presented a useful avenue through which to gain deeper insights into the implications of awareness programs on prevention as bridge populations are one of the primary populations targeted for HIV/AIDS awareness interventions and stigma prevention efforts.

Interviews and observations were undertaken at the network's office and counseling centers. Eight semi-structured 45-60 minute interviews of HIV+ women were conducted in Tamil after obtaining verbal informed consent, along with numerous other informal conversations. Field visits included observation of support group sessions of around 40 HIV+ women and observations of informal counseling sessions in the counseling center's recreation room over a 2-month period.

No personal identifiers were collected and only written notes were taken. The first author also assisted in the design of new information management and technology projects for the NGO, and in writing of proposals for funding. These projects included the introduction of a women's resource center and a phone-based broadcasting and crisis hotline. In addition, a daylong focus group was held with 7 health care workers and officers of the organization. Four of these women were HIV+ themselves.

The first author coded data from this fieldwork and identified themes. This was then presented in the focus group with 7 NGO staff members, including 4 HIV+ women. The group added to the analysis, and worked to refine the codes, themes and takeaways, which were further refined by the first author. In addition, we use secondary data from the NGO records on the number of counseled HIV+ individuals who voluntarily revealed their status to their spouse over a two-year period.

There were several methodological constraints we encountered in conducting this research. Access to HIV+ women is highly restricted for both NGOs as well as researchers due to the sensitive nature of the topic and the risks of disclosure that women face in participating in services and research. Once a woman registers with the NGO she instructs their staff members as to how and when she would like to be contacted, and how a call should be managed in case a family or other community member answers the call. Often, this involves the staff pretending to be friends or other roles depending on the situation of the call. Given that as a foreign-educated researcher one could not guarantee carrying out this performance with skill and possibly arousing suspicion, it was decided that all contact with members of the network would occur through the NGO staff.

The various factors that prevented women from accessing support meant that the staff had limited access to these women outside of their voluntary visits to the support groups and counseling centers. Restrictions on mobility and ability to travel to a counseling center without arousing suspicion and risking accidental disclosure meant that it was hard to follow up with women as well. As discussed above, the NGO's inability to identify HIV+ women in a community was a significant barrier to delivering services and information. Most often, the family shared cell phone ownership. As a precautionary measure, text messages and/or calls had to be handled with extreme care. Since the population that the NGO served was all female, the researcher had no access to HIV+ men. Sometimes, the NGO staff would meet with male spouses of women they assist or aid in counseling HIV+ men outside their own counseling centers. However, the researcher did not encounter these meetings during the fieldwork period and could not access other counseling centers or NGOs. The reasoning behind lack of male disclosure discussed in subsequent sections reflect the knowledge gained by HIV+ women through their experience in these marital relationships, and the perspective of NGO staff developed through their interaction with other HIV+ women and their male spouses.

Audio or video recordings were clearly inappropriate in these settings. Some HIV+ women would become nervous when the

researcher took handwritten notes in counseling sessions, interviews and support groups, even after informed consent was obtained and confidentiality assured. This was particularly the case with women who had only recently disclosed their status, even if this was only to other positive members in the support group.

We present vignettes from our observations and interviews to illustrate the dominant themes and concerns found and also discuss the measurement demands from prospective donors for ICTD projects that shaped how the NGO considered their intervention ideas. We consider the ethnographic encounter as one that provides insights that may or may not apply to other locations, but that can help mature the theoretical framework of mHealth, as applied to highly stigmatized conditions like HIV.

4. OBSERVATIONS & ANALYSIS

4.1 Negotiating Universalization and Standardization

This NGO differentiates itself in the HIV/AIDS domain as an NGO founded and run largely by HIV+ women. The founder stressed that this organization's emphasis on women was in part a response to western notions of AIDS as a disease predominantly affecting homosexual males. She pointed to the increasing feminization of the HIV/AIDS epidemic and how women are far more susceptible to HIV both biologically and socially. She explained that western funding agencies, that in fact largely fund this NGO, assume that the strategies they used to counter the epidemic with homosexual populations would also apply to heterosexual populations in India, treating the translation as a "scaling" exercise. This assumption was false. She stated that these and other notions of universality of information, generalizability and scale could backfire in the quest to counter HIV/AIDS where issues of trust and personalized engagement are paramount.

The NGO's activities involved a complex negotiation between the requirements of donor agencies and the actual needs of women. They reported that impact assessments that emphasize number of individuals tested and counseled versus quality of counseling places pressure on healthcare staff to cut short counseling time. In addition, they complained that counseling practice gets structured by standardization goals resulting in counselors collecting data on medication and treatment compliance, rather than creating a safe space for patients working through anxiety, stigma and quality of life issues.

Donors often insisted on quantitative measures of reach and information dissemination, rather than documentation of the long-term relationship building required to assist HIV+ patients without access to other counseling resources. Although the NGO was allowed to make its own qualitative assessments on quality of care delivered for various donor funded projects, the requirement of data collection on specific standard metrics constrained the allocation of staff and resources to services that were critical but not as easily measurable. In addition, donor funding is competitive and promising metrics that are easily amenable to impact assessments often trump deeper engagement and analysis. For example, an awareness campaign was assessed to be successful based on the number of women who attended with no assessment of comprehension or ability to use that information.

4.2 Time Taken for Disclosure

This lack of knowledge about the effectiveness of information disseminated and whether it was usable by women was complicated

by the high levels of stigma associated with accessing care and the dangers of community suspicion and accidental disclosure. Barriers to disclosure are investigated in relation to this acute problem the NGO faced in identifying who needs care and how it should be delivered. The most significant barrier to disclosure was fear of abandonment and rejection by the spouse. In addition, traditional gender roles and dominant narratives around making and admitting to mistakes, conflict resolution, and marriage prevented infected husbands from revealing their status to their wives for significant periods of time. Once the HIV status has been disclosed to the spouse, stigma-related risk analysis by couples such as fear of loss of social connections, social image and status, denial of services such as education, livelihood, housing, healthcare and fewer opportunities for children were paramount in the decision to disclose to family and community members.

“My husband got a letter signed by the doctor that diagnosed him that he wouldn’t reveal his HIV+ status to me. I did not find out for five years. When I got pregnant, I wasn’t told. He refused to tell me even when he saw me breastfeeding our baby. I only found out when he fell seriously ill and was hospitalized. I was tested at that point and was HIV positive. It was too late by then.”

According to the officers of the NGO, in this particular context it frequently takes from 5 to 8 years from knowledge of infection for the infected spouse to voluntarily disclose to the other. Of the 53 discordant couples (where one spouse is HIV+ and the other is negative) that the NGO assisted over a two year period at its counseling center, only 13 infected people had voluntarily disclosed to their HIV negative spouse about their infection. The duration of time taken to disclose in a marital relationship raises the risk of the HIV negative spouse not only contracting the virus, but also potentially transmitting it to children and suffering from the lack of early diagnosis and treatment.

The timeframe that it takes in these cases for an infected spouse to disclose to the other usually corresponds to the number of years it takes for the HIV infection to manifest bodily symptoms and illnesses that cannot be ignored or hidden. This becomes a significant turning point in the disclosure process and may result in the infected spouse telling the other or the spouse finding out through his hospitalization. According to NGO staff, it is very common for women to find out they are HIV+ at the time of hospitalization of their sick husbands. The weakened state in which the husband finds himself is often leveraged by the hospital staff to disclose to the spouse either through covert testing or direct disclosure.

The hospital staff tested two female informants covertly when it was discovered that the husband was in fact ill due to AIDS. Informed consent is required by law before HIV testing in India. However, in practice, medical staff often test individuals without their knowledge to overcome resistance to testing and to start earlier treatment.

4.3 Values: Maintenance of Social Connections Versus Longer Life Spans

“He was scared I would leave him if I found out. His fear drove him to hide his status from me for so many years. I wish he had talked about it with me instead of just assuming I would abandon him. I could have prevented getting infected. I could have ensured that I am here for my children longer. We have three children together. Am I really going to pack up and leave him after all that?”

HIV+ woman

It is important to note how dominant social connections were to concerns about disclosure. Maintenance of social relationships was frequently valued over health and longer life spans. Such prioritizing and underlying values are important aspects to take into account when creating interventions that focus on prevention of transmission and treatment. For example, counselors reported that HIV positive males who are fully aware about safe sex and how to prevent transmissions would often refuse to use a condom in order to not arouse suspicion in his spouse.

Anticipated stigma can even prevent individuals learning from awareness campaigns presented right in front of them.

“I would often see posters about AIDS at the bus stop but I dared not look. I was scared that if people saw me reading it, they would automatically think I was infected or that I had reasons to be scared. They might think badly of my character.”

HIV+ woman

4.4 Gender Structures and Disclosure

Women’s inability to discover information about risk and possible infection and their subsequent inability to reveal their status was often determined by how they and others perceived their role in their marriage and families. The following two accounts with fictitious names illustrate the gender structures within which HIV disclosure is situated and the anticipated stigma that prevents accessing support.

It is the last half hour of the support group and Subha walks up to the front of the forty HIV+ women, who are chatting, and drinking tea now. They seem relaxed. She has been in the back all this while, visibly nervous, fidgeting with her cell phone. This is her first time in the support group and she is required to introduce herself and tell her story. She introduces herself and states calmly that her husband died 3 months ago of AIDS. He infected her. She found out she was positive four years ago when she was tested while pregnant with her second child that she subsequently aborted. When her husband’s condition became severe they agreed between themselves to tell the relatives and friends that he died due to another illness. He died quickly and so it was easy to pull off the lie that it was a sudden heart attack. No one knew their HIV status outside of Subha and her husband. They took medicines in secret. Her child was not infected and does not know what his father really died of. She says she wasn’t allowed to come to the NGO though she had wanted to when she first met a counselor at the hospital where she got tested. Her husband decided that it would be too risky. Now she can since he is no longer there to prevent her. She is on the verge of tears and the other women tell her how she is not alone. One woman says: “what you see here, the number of people, this is just a fraction. There are lakhs and lakhs of us in this city, we know how you feel. You are not alone” They start talking about whether she should tell her family because it is good to have one source of support close by. She is adamant that she won’t and they ask why exactly, even though many of them have not revealed this secret to their own families either. She says that it is futile. They push her further to explain, hopeful that she will find one person she can confide in, and she says: “if I tell them I have AIDS, they will ask, ‘did God give you this disease so you can

give us an excuse to not do your housework?’” No one contests her reasoning.

Lakshmi is waiting for the counselor assigned to her to arrive and we start talking along with a few other counselors in the recreation room. She says, ‘this is my first visit to the counseling center because he didn’t allow me to come here. He is scared about what people will say and do if they find out. I am too.’ She says she got her mobile phone with her own money so she could communicate with the counselor and that she is pretending to be someplace else instead of the counseling center to her husband right now. The counselors interrupt and say how they have been asking her to come for 6 months and that they are happy she is finally here. I ask her who knows about her diagnosis. She says, ‘Just my husband and I. We haven’t told anyone else in the family and of course, the counselors here know. My children are negative and too young to understand what our HIV status means and too young to know how to keep this a secret. I can’t tell anyone my problems or explain issues we have. We have to come up with other reasons. My husband drinks heavily and I tell my relatives that our fights and his ill health are because of his drinking. No one in my family knows. When I first found out, I was suicidal but I have two young daughters and if I don’t look after myself there won’t be anyone to raise them.’

“Have you ever asked your husband how he got the infection?” She shakes her head and says: ‘No, you can’t ask those questions.’ “What about why he didn’t tell you?” She shakes her head again. “Why do you feel you can’t ask him?” She states: ‘you just can’t. They won’t admit to mistakes made. If he just told me he made a mistake and this is the consequence, it would be okay, it would be easier to take and work with. I feel like I have less respect than a chair (pointing to a chair). Women are just there to serve men; it doesn’t matter if we die doing so. He doesn’t even care that our children will be orphaned because he didn’t tell me soon enough about how I might be infected. There is no affection, no love or care.’

Subha’s response to why she couldn’t tell her family was striking in how it evoked traditional gender roles and how a disease that is fatal and causes immense suffering for the bearer could be framed within notions of housework and the obligation of women. The fact that none of the women in the room sought to argue against her reasoning hints at how pervasive that connection is and the perceived futility of trying to contest it. Lakshmi asserted that you cannot ask certain questions to your husband, even if those questions refer to why he put your life at risk and why you are now dying through no fault of your own, because you are only alive to serve them in the first place. These women talk about disclosure and their inability to reveal or ask for certain information related to their disease based on their position as women, and how they and those around them have come to believe what that means.

The NGO did observe instances of HIV+ women hiding their status in new intimate relationships. The staff members explain that there are various reasons for this, including economic hardship, loneliness and sometimes, fear and an inability to say no to advances made. However, the NGO has an even harder time

identifying women in these situations and initiating open discussions with them.

“We can’t say it is all just men’s fault. I know some women in our practice that are HIV+ and knowingly infect men who are not. It is rare that they will tell you straight to your face that this is what they are doing but you hear stories. I think part of the reason is that they are widowed young and miss sexual relationships and are afraid of rejection and ostracization. I confronted one woman and she said that I shouldn’t tell her how to behave when I have no experience of the suffering that she goes through. I kept quiet after that.”

Staff member

Although a rather extreme case, the coordinator recounts a recent media story of an HIV+ woman who transmitted the infection intentionally, to describe how the experience of betrayal through infection and subsequent societal ostracization may shift how an individual views existing gender structures, and how they rationalize transmitting HIV to uninfected male partners.

“He was from a rich background unlike her and they had to fight to be together and get married. But he infected her and passed away and she was enraged. She then sought out work as a domestic help in rich families like his in Bombay and proceeded to seduce and infect the boys in the house. She was finally caught and was all over the news. Women have lost their morality these days. The reasoning these women give is this: ‘I have done everything you (society) asked me to, I have been a good girl and daughter and wife and this is how you repay me? You infect me unjustly and then proceed to hurt me and ostracize me for no mistake of my own.’”

NGO coordinator

4.5 Information Crucial to Disclosure

When I counsel individuals who are struggling with disclosure, there comes a point when there is a shift in how they think about it. In my experience, this shift happens when they are told stories, realistic stories about others like them who have suffered also, but who have eventually been able to find support and live positive lives.

Counselor

In the focus group, interviews and observations of counseling sessions and support groups, the most significant information that women and NGO staff felt would motivate early and voluntary disclosure were stories of hope, and examples of others like them who have persevered and accessed support and treatment. They often cited communication of this information as a turning point in the process of help seeking for both women and men. Information about how HIV+ individuals and couples had survived and managed to find support and positive relationships were seen as critical to disclosure and on-going treatment. Hope, however, is hard to communicate without personal interaction and time with the patient. An effective strategy would be characterized by situating possibilities for hope in the specific situation and community that men and women live in. Hope, however, cannot be guaranteed and is therefore, hard to ethically convey. This tension is apparent in the ways in which healthcare workers respond to their duty to disclose to spouses at risk of infection and treat those infected.

4.6 Multiplicity of Positions

Healthcare workers and counselors live and work in the communities that they serve and are affected by the stigma and discrimination that they see of HIV/AIDS patients. The NGO reported how healthcare workers will often deny services to those with HIV/AIDS based on their belief that a sexually transmitted disease is a sign of immoral character, and out of fear that they will get accidentally infected. The NGO sees many cases of counselors backing out of facilitating the disclosure process because of their own fears of what disclosure might unleash in the clients life as a consequence of revealing their secret. The NGO gets many calls from doctors and counselors while they are with patients to ask for advice and ways in which they can protect themselves from social and legal consequences of facilitating disclosure.

5. DISCUSSION

ICTD interventions have been framed as requiring institutional support to effect change [29]. It is a best practice in ICTD to partner with local institutions that have expertise in the specific development domain and to use their social and physical infrastructure to disseminate technology interventions in service of the goals of that institution. This is in part a response to the failures of many ICTD interventions in achieving long term change due to technological deterministic approaches that disregarded various political, social and institutional factors that play into success of ICTD interventions [34]. However, this reliance on institutional support makes mHealth and other ICTD interventions vulnerable to replicating the structures and values that these institutions operate from. When the institution is under pressure to adopt certain universalized notions of health care and quantity-based metrics that expel various socio-cultural aspects in order to be amenable to impact assessments and funding frameworks, critical opportunities for ICTD interventions may also be missed.

In relation to sexual health, some socio-cultural aspects that resist standardization and management are affective processes and intimate relationships. HIV infected individuals often prioritized maintaining a sense of normalcy in their relationships and communities over treatment and longer life spans. These kinds of values inhibited help seeking behavior and prevented many from disclosing their status to partners at risk. In addition, social pressure and traditional gender roles often prevented women from accessing information and support, even when they had the ability to do so.

In the rush for the generalizability, scale and efficiency promised by the information and computing technologies, we may overlook possibilities for deepening and improving the quality of institutional and human relationships that ICTs can also afford. This study suggests the following considerations for future mHealth design and implementation. In particular, we join the NGO we observed and do not advocate for direct intervention in a marital relationship to expedite disclosure, especially when community intrusions, and externally imposed norms and expectations are already part of the problem. We suggest addressing the social structures that surround the couple and impinge on their ability to foresee hope and feel safe in their communities as openly HIV+ individuals. In addition, we suggest facilitating the process of compensating for loss of existing community support through tools to form new relationships. Finally, we suggest that the option of “doing nothing” is often the most legitimate method of enabling development.

5.1 Expedite Peer to Peer Support

An important category of information that is left out of ICTD healthcare interventions is that which reassures individuals and

couples about the possibilities for positive living and social support, if not from their immediate family or community, then from others like them. Although, HIV prevention interventions often deal with stigma and discrimination, counselors and medical staff are often conflicted in reassuring patients. Hope can be hard to convey ethically when one cannot guarantee a positive social outcome and job structures constrain one’s ability to effectively offer support to the patient. NGO staff observed that disclosure processes were expedited when a patient meets another HIV+ individual immediately after discovering their status. However, this chance encounter often does not happen often enough. Often, the shock of testing positive prevents patients from being able to process information about treatment and support that is given to them at the time of testing. As a result, the health care system loses track of these patients and they are not sufficiently informed or reassured.

Researchers in other ICTD domains have found a preference for peer sources of information [18]. Similarly, peer-to-peer communication and advice on handling the social consequences of the disease, and leading a fulfilling life is an important source of hope for current patients, and may lead to better preventive care for uninfected partners. HIV+ individuals would benefit from the appropriate design of ICT enabled patient-to-patient support services taking into account local device, infrastructure and accessibility considerations. We suggest integrating such a system with HIV testing and delivery of results so as to expedite peer to peer encounters.

In the focus group, the suggestions offered by HIV+ women to increase better health outcomes emphasized tools that could help negotiate love, desire and companionship. For example, NGO staff and HIV+ women expressed a need for a phone-based dating and marriage service that could connect them to other HIV+ individuals looking for relationships. The NGO receives frequent calls from HIV+ individuals asking whether they could help arrange marriages and they have even held marriage ceremonies in their counseling centers. Confidentiality and safety is key for this service, along with the ability for low to semi-literate individuals to parse through profiles and communicate stories. In addition to facilitating new relationships, the existence of these services may help mitigate the fear of abandonment and loneliness in disclosure processes.

5.2 Support Existing Relationships

Existing social relationships are paramount in the quest for health regardless of the nature of disease. However, in HIV/AIDS and other highly stigmatized diseases, these relationships determine prevention and access to treatment. Existing relationships can often take precedence over new ones, especially in situations of uncertainty and fear, and their underlying structures can be fatal if they are not supported or addressed. For example, interventions need to help HIV+ individuals manage the anxiety and logistics of handling a controlling spouse or family. Often the spouse or family will prevent women from accessing care due to their own fears of accidental disclosure.

Women need to be able to communicate with NGO staff without arousing suspicion. One HIV+ woman suggested using ambiguity in messaging to ensure safety.

“We need to communicate in a secret language that is our own. For example, if the NGO is organizing a women’s support group soon, you could send me a picture message of a group of women sitting together in a circle instead of actual details. We would have an understanding what these symbols mean and I would know that I need to call to find out more. We get so much MMS spam, it would just look like

everything else. It would not arouse suspicion and I don't need to be anxious about my spouse reading my messages."

Ambiguity has been proposed as a method by which deeper engagement with technology can be fostered [10]. We suggest that ambiguity in information design could also be a resource for safety in ICT enabled delivery of health care.

5.3 Support Affective Aspects of Health Care

mHealth interventions that cater to healthcare workers need to be aware of the multiple and sometimes conflicting positions that healthcare workers hold in relation to HIV disclosure, human rights and treatment. Current interventions that aid decision-making and peer-to-peer support are promising directions for mHealth in this space, if combined with spaces to provide psychological and emotional support in addition to currently delivered information about diagnosis and medical knowledge.

ICT programs for affective support and the creation of long-lasting relationships of trust and care will also require deviation from the currently prevalent scale and quantity-based metrics of program evaluation. Human care cannot easily be generalized and scaled. As such, we need metrics that can assess the depth and quality of relationships created and fostered by ICTs and other interventions.

We also need to be able to further devise and assess highly situational, and context-specific approaches to fostering such relationships. For example, Ramachandran et al. addressed resistance to healthcare delivery by using ICTs to enable greater trust and engagement between health care workers and women needing maternal care [19]. The key component of this project is the use of videos of trusted community leaders to mediate the relationship between the health system and patients, while increasing healthcare worker motivation. In their work with female sex workers in Bangalore, Sambasivan et al. also used the voices of respected members of the community to foster a sense of personal relevance and trust in their broadcasting system [22]. Also notable, are interventions that create virtual simulations of context specific situations to enable high-risk users to explore their own reflexive tendencies in sexual practices [20]. These studies point to important future directions for ICTD, in their shift from information standardization and dissemination to systems that enhance access and use through personalization, reflection, engagement, trust and usability of information.

5.4 Support a Reflective ICTD

Anokwa et al. describe the tension between experimentation critical to research practice, and delivering on development goals set by partner organizations in the field [1]. They also discuss some of the conflicting incentives that drive these tensions:

"Our field stories are also revealing in what they do not discuss. No stories dealt with the process of selecting a worthwhile problem to research or identifying the objectives of a project. Instead, our stories focused on issues that arise after the technological artifact is already under development. These issues—arguably emphasizing efficiency and technological innovation over the needs of stakeholders—seem to be a product of the exigencies of the research world. Our practical incentives as researchers, to publish papers and satisfy our funders, unavoidably dictate where we focus our activities. Since our research community emphasizes

frequent publication and a technological focus, much of our work tends to adopt those priorities."

Participants in the field question these incentive systems and our subsequent priorities as well. The following is an excerpt from the first author's field notes of an interview with an HIV+ street food vendor at the counseling center.

I thanked her for talking to me and was getting ready to leave when the counselor asked me to write in the guest book. While I was writing, the lady whispered to the counselors: "Is she going to write her paper now?" I turned around to look at the counselors and they were nodding. The lady then turned to Lakshmi and the others in the room and declared loudly: "In the end, we are just papers for these people." I was surprised, a little hurt and immediately offered a rather incoherent explanation about how my group at school develops technology for similar communities to overcome their information access issues, and I will have to write a paper but only to let everyone know what her needs are. I ended by proclaiming: 'I am only here to help!' They smiled. I quickly gathered my things and left the room.

Anokwa et al. ponder a similar confusion in the ICTD world and ask what the difference is, between "doing research" and "doing development" [1]. We would like to join them in urging the ICTD field to foster dialogue on these boundaries. What do we consider as success and as failure? What do we fear as rejection, and from whom? How does our culture regulate what we have to offer as legitimate help?

In particular, within this extremely high-risk context, we recommend that "doing nothing" is a legitimate act until we unpack how we are culturally and professionally situated in relation to the HIV+ women we seek to "serve".

6. CONCLUSION

Our research analyzed the situated knowledge of HIV positive women to examine how heterosexual married couples in Chennai (India) manage knowledge of an HIV-positive status, illustrating why dissemination models often fail to lead to safer health practices. It highlights the significant amount of time it takes for voluntary disclosure of HIV+ status to a spouse at risk, and the gender structures within which problems of disclosure are embedded. It also revealed the differing cultural values that drive disclosure and concealment of information. We offer design guidelines and provocations for ICTD to support these underlying structures that could ensure greater and safer use of existing health information, services and other resources. In general, the mHealth field must reflect on the possible impacts of our current values of standardization, efficiency, measurement, scale, universalization and proactivity on health and social outcomes. We must also consider the current limits of models of access. We offer personalization, engagement, trust and context specific usability of information as useful goals in the fight against disease.

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