Designing Information for HIV-AIDS Affected Persons
Professor. Anirudha Joshi
Open Design School
Indian Institute of Technology, Bombay
Lecture No. 63

In this section, Professor Anirudha Joshi presents some of his work in which he has used ethnography approach to design products and services for a varied set of contexts.

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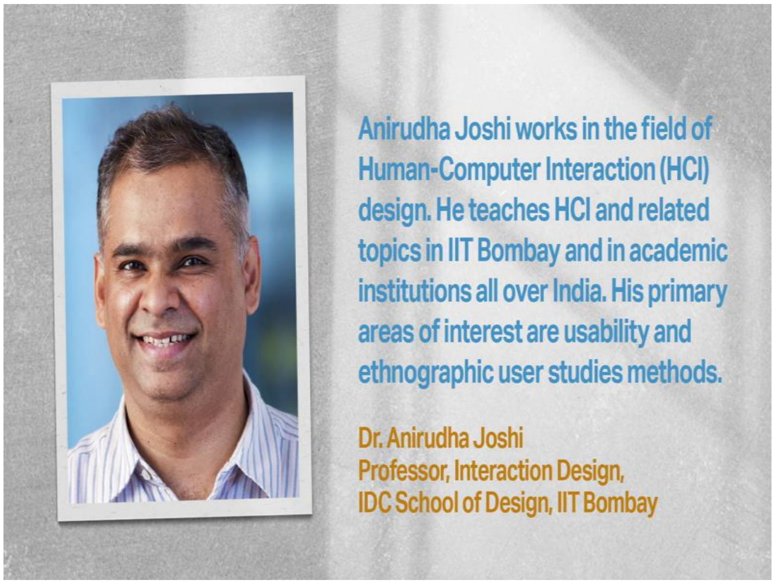

Anirudha Joshi works in the field of Human-Computer Interaction (HCI) design. He teaches HCI and related topics in IIT Bombay and in academic institutions all over India. His primary areas of interest are usability and ethnographic user studies methods.

Dr. Anirudha Joshi
Professor, Interaction Design,
IDC School of Design, IIT Bombay

Professor Joshi teaches interaction design at the IDC School of Design, IIT Bombay. He has been involved in designing interactive products for emergent users in developing economies with a particular focus on Indian users.

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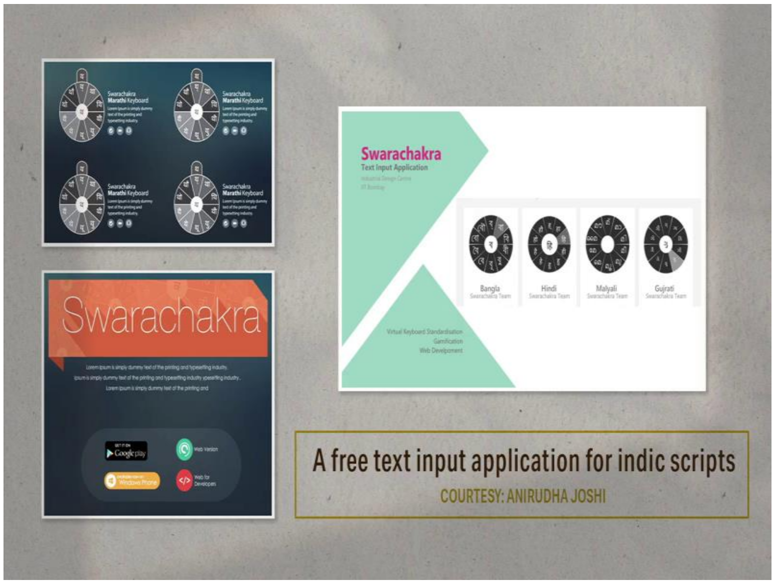

A free text input application for indic scripts

COURTESY: ANIRUDHA JOSHI

Among his many projects is Swarachakra a free soft keyboard for Indic scripts on Android devices. Some of his recent research looks at the acceptance of information and communication technology amongst pregnant women and new mothers in urban slums. Let us hear from him.

Hi, I must first say that I am not an ethnographer I am a designer, so I make things. But in order to make things, I need to understand people.

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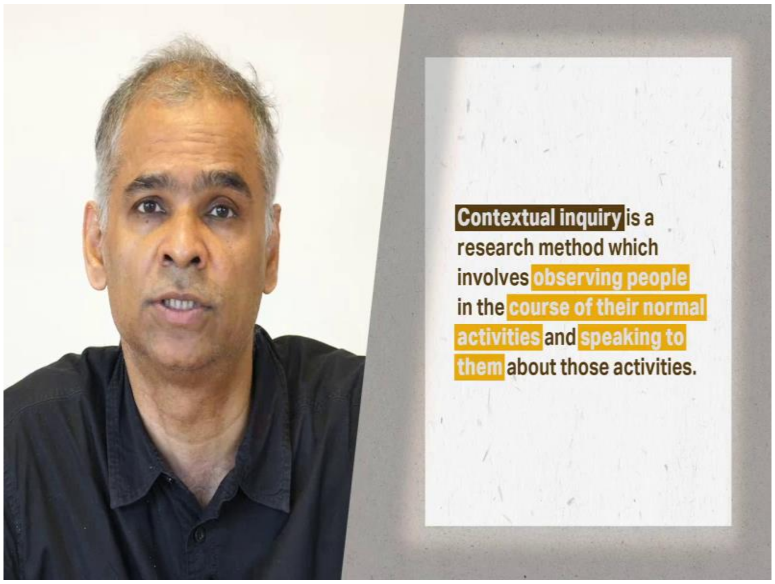

Contextual inquiry is a research method which involves observing people in the course of their normal activities and speaking to them about those activities.

And I use contextual inquiry as my main method to understand people. And contextual inquiry, as it happens, borrows a lot from ethnography. It uses an ethnographic approach. But ethnographic approach is not ethnography, per say.

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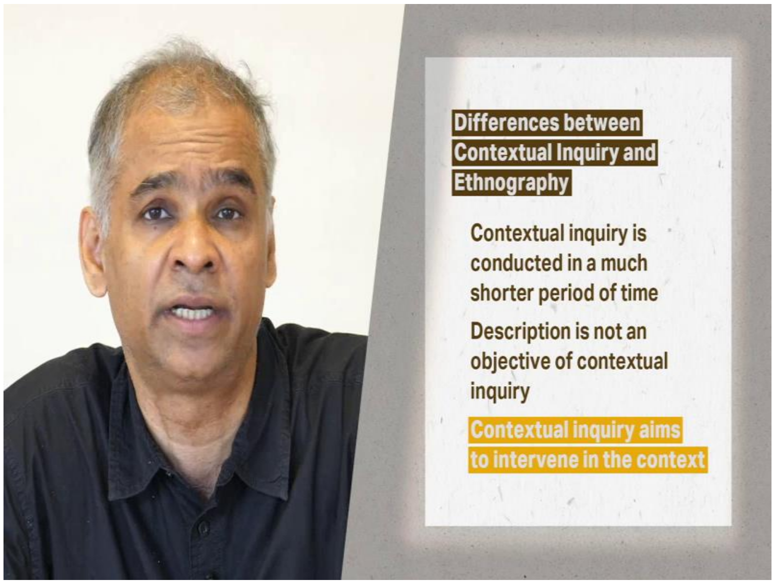
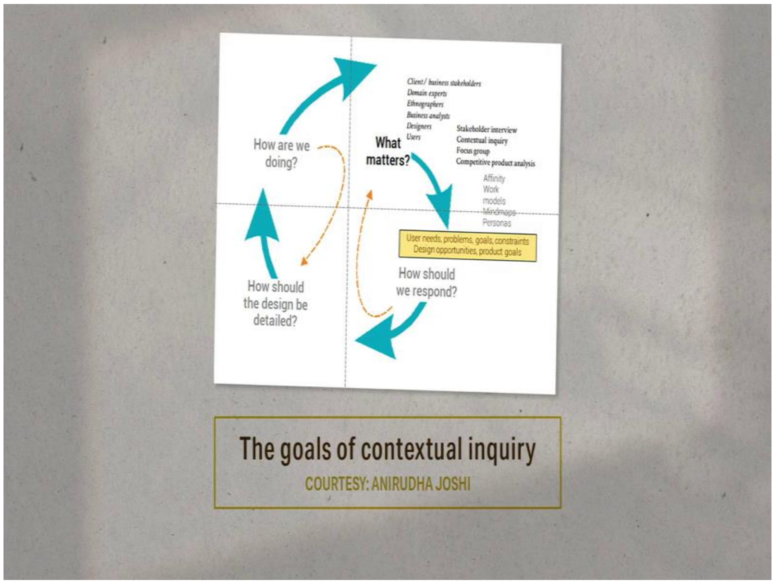


Differences between Contextual Inquiry and Ethnography

Contextual inquiry is conducted in a much shorter period of time

Description is not an objective of contextual inquiry

Contextual inquiry aims to intervene in the context



The goals of contextual inquiry

COURTESY: ANIRUDHA JOSHI

Contextual inquiry shorter in time ethnography is typically has long involvement with users. Contextuall inquiry, usually maybe 30 minutes, 40 minutes. That kind of short involvement produces. Ethnography has goals of description, contextual inquiry derives methods from ethnography but not the goals. Ethnographers are very, very careful, in fact, not to change things that they are observing. They are very, very careful.

They do not want to disturb anything, what they are trying to understand. In contrast, designers are constantly trying to change things.

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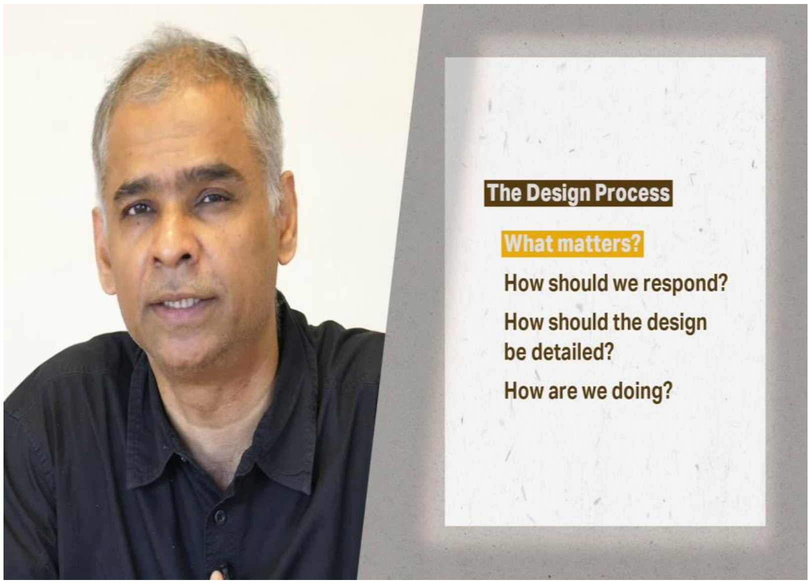

The Design Process

What matters?

How should we respond?

How should the design be detailed?

How are we doing?

So, this overall scope of things, contextual inquiry and ethnography broadly is trying to answer the question what matters, what matters in society? The case study that I wanted to talk about was a project that I worked with a large number of people.

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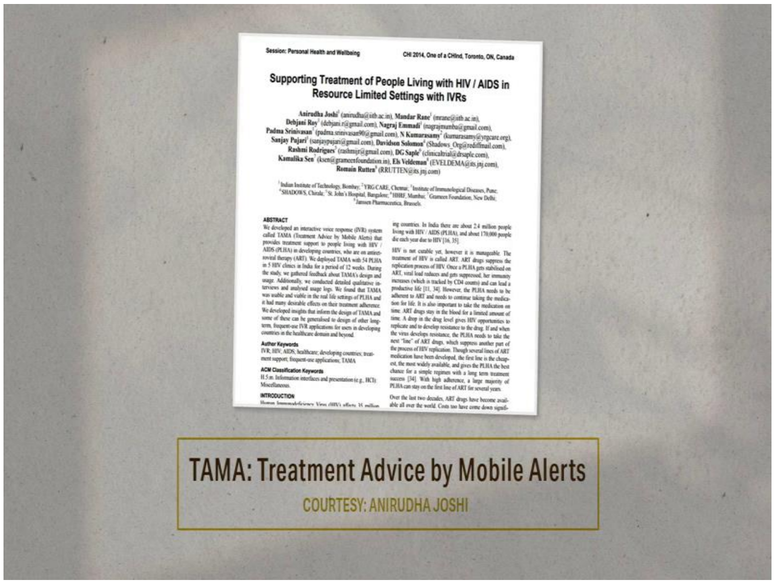

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Supporting Treatment of People Living with HIV / AIDS in Resource Limited Settings with IVRs

Anirudha Joshi[1] (anirudha@iitb.ac.in), Mandar Rane[1] (mrane@iitb.ac.in),
Debjani Roy[1] (debjani.r@gmail.com), Nagraj Emmadi[1] (nagrajmumbai@gmail.com),
Padma Srinivasan[1] (padma.srinivasan90@gmail.com), N Kumarasamy[2] (kumarasamy@yrgcare.org),
Sanjay Pujari[3] (sanjaypujari@gmail.com), Davidson Solomon[4] (Shadows_Org@rediffmail.com),
Rashmi Rodrigues[5] (rashmijr@gmail.com), DG Saple[6] (clinicaltrial@drsaple.com),
Kamalika Sen[7] (ksen@grameenfoundation.in), Els Veldeman[8] (EVELDEMA@its.jnj.com),
Romain Rutten[8] (RRUTTEN@its.jnj.com)

[1] Indian Institute of Technology, Bombay; [2] YRG CARE, Chennai; [3] Institute of Immunological Diseases, Pune; [4] SHADOWS, Chirala; [5] St. John's Hospital, Bangalore; [6] HHRF, Mumbai; [7] Grameen Foundation, New Delhi; [8] Janssen Pharmaceutica, Brussels

ABSTRACT

TAMA: Treatment Advice by Mobile Alerts

COURTESY: ANIRUDHA JOSHI

A quick background about HIV in developing countries. So, even as recently as in 2017, about 37 million, 3.7 crore people in the world are living with HIV AIDS, and majority of them are in developing countries. In fact, 69 percent are in Africa alone. And one of the challenge with HIV is that you cannot remove HIV from the body.

Once a body is infected with the HIV virus, it just stays in your body more or less forever. So, you have keep taking your medication all your life. And one of the challenges is that a lot of this medication is fairly expensive. And so financial status is one of the common reasons why people stop taking medication. However, governments have responded, already now more than 10, 15 years now ago by providing free medication through government hospitals. In India, for example, a lot of medication is available for free for treatment of HIV.

However, in spite of this a people who are in fact receiving free medications were also found to be having lower adherence.

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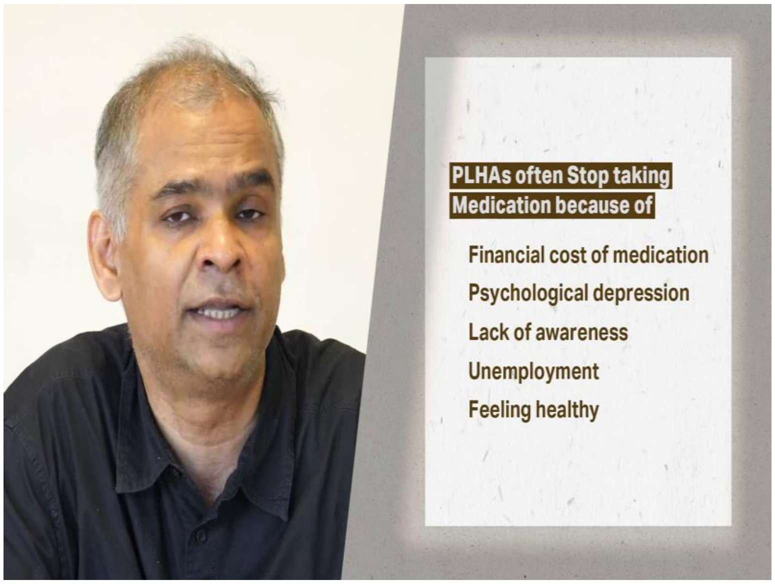

PLHAs often Stop taking Medication because of

Financial cost of medication
Psychological depression
Lack of awareness
Unemployment
Feeling healthy

So, other than financial status, other reasons were, you know, people were just depressed or just were not educated enough to understand that you know you have to keep taking your medicines throughout. They were unemployed or strangely because they felt healthy. So, they felt that they had overcome the disease. So, they do not need to take the medication anymore.

Like most of the medication, once you once you become healthy, you stop taking the medication. But that does not happen with HIV. So, as a result of all of this, in 2009, when we started the project, every year, about 170,000 people in India die related to HIV. And this was in spite of the fact that antiretroviral therapy, which is the medication used for treatment of HIV, was available, affordable and even free in the government hospitals.

So, one of the things that we learned very early in this project is that there is a large information component in the treatment of HIV. And so the objective of our project was to see what can we do about that. And opportunity that was growing at that time was all over the world. Mobile phone penetration was improving.

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Can we **use mobile phone technology to support** the treatment of people living with HIV-AIDS **(PLHAs)** in developing countries?

So, the question that we were asking was that can we use the mobile phones in some way to help support HIV treatment in developing countries?

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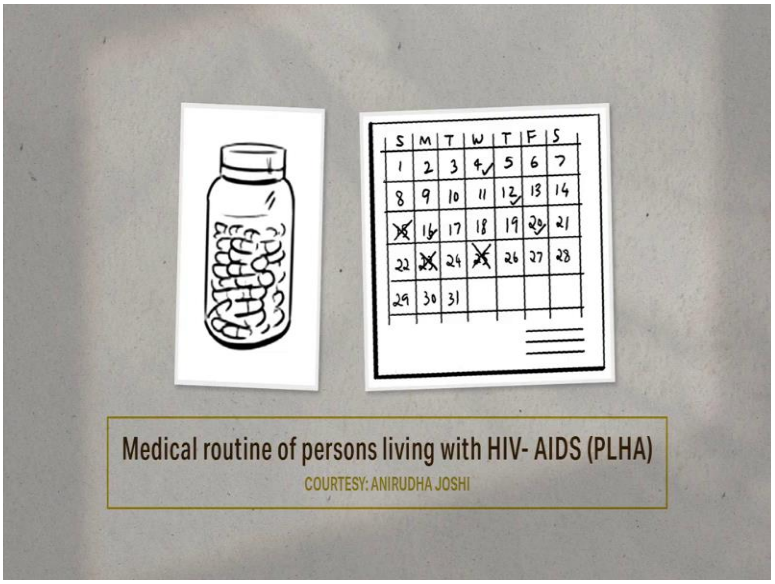

Medical routine of persons living with HIV- AIDS (PLHA)

COURTESY: ANIRUDHA JOSHI

So, we went and looked at operations of clinics, how clinics work, what are the information needs of people, how people take pills? What are the social-cultural issues? What are the financial issues? So, we went and looked at the whole ecosystem of people living with HIV AIDS in India.

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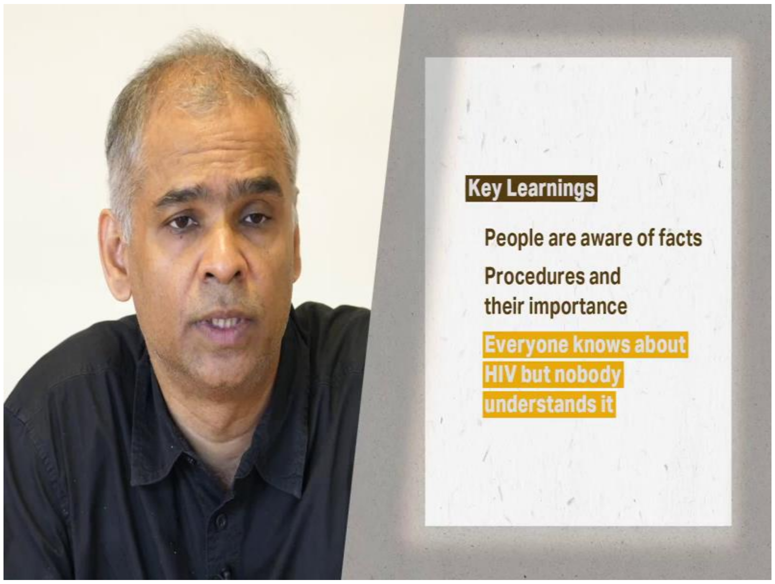

So, what we found is that large number of people know fact. Are no procedures, so facts would be what is CD4 counts or what is your HIV law and so on? So, these will be facts. Procedures will be things like you should take your pills on time, you should not miss taking pills, you should have high adherence, you should eat healthy food and so on.

But very few people actually understood concepts. You know how HIV works. Why should I take my pills on time? What happens if I miss my pills and so on? So, HIV was this disease, which everybody knew about but nobody understood. So, of course, in HIV treatment is always associated with counselling.

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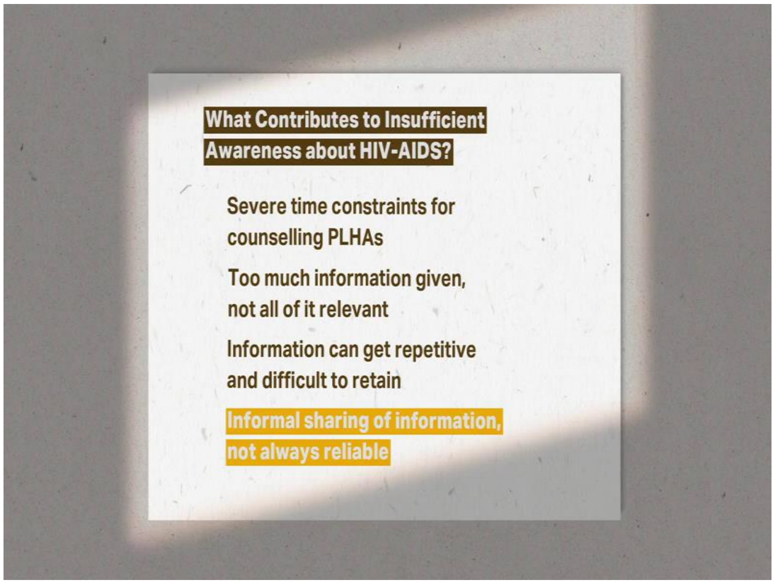


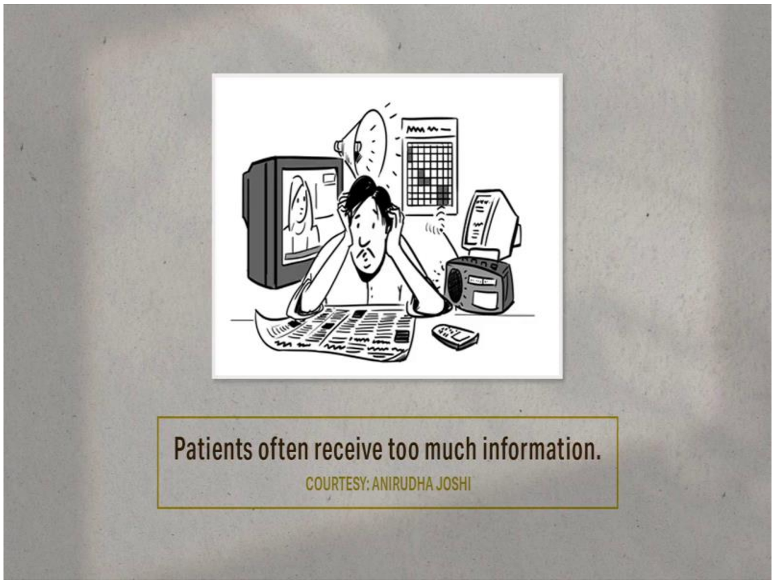
What Contributes to Insufficient Awareness about HIV-AIDS?

Severe time constraints for counselling PLHAs

Too much information given, not all of it relevant

Information can get repetitive and difficult to retain

Informal sharing of information, not always reliable



Patients often receive too much information.

COURTESY: ANIRUDHA JOSHI

And counselling is provided by professional counsellors. But counselling is insufficient and it is always under time pressure. So, there is a long queue waiting outside of the counsellors' room and it tends to get repetitive and difficult to retain. Also during counselling, the purely the person living with HIV AIDS gets too much information and gets it all in one go. Sometimes some of that information is relevant, but not all of it is relevant.

And then the information that they get outside the counsellors' room is not very trustable. So, we found a lot of opportunities to provide information.

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So, we used to call this drinking from the waterfall. So, like you can only drink so much from the waterfall. So, you needed smaller chunks of information. One of our interesting findings was that this was a study done in 2009-2010. So, by this time already mobile phone penetration was very high, but SMS use was very little in India almost, almost half the people that we interviewed and had mobile phones did not use the SMS had never read the SMS in their life.

So, SMS use was not very nice or what not very extensive, but one of the things that we did was that we sent SMS to people at their pill times and those SMS reminders, helped people with their pill adherence. We also investigated a lot of social and cultural factors. So, we found that there are different kinds of people living with HIV AIDS. Some people had extensive family support, so people in their family were taking extensive care of some of them.

On the other hand, some people had kept their HIV status as a secret from their family members, and they had not disclosed. In fact, they did not care about disclosing to all unknown people, all and sundry people that they met.

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But they were very particular that they did not want to disclose their HIV status to their family members. And this was a very important aspect to them. In fact, this is something that we learned because of our relationships that we could develop with the people that we were interviewing that for them retaining their relationship with their family, as it was originally, was very important, and they did not want to disclose to their family members. We also investigated

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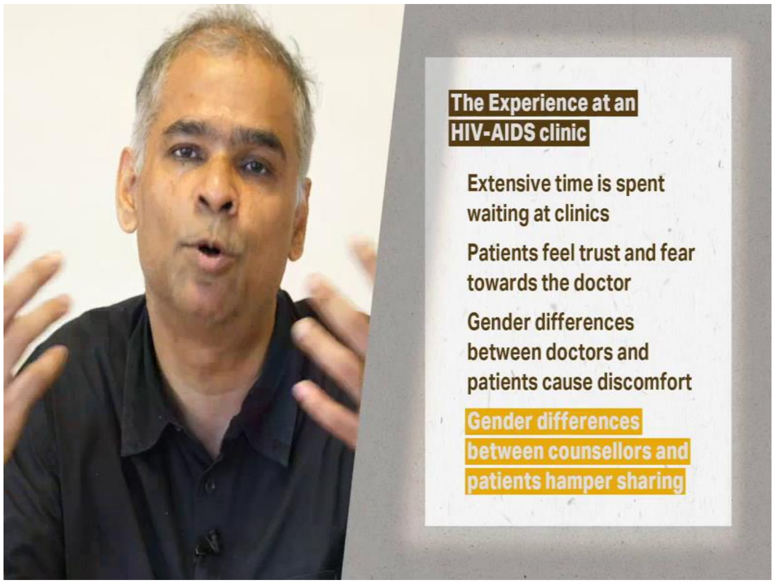
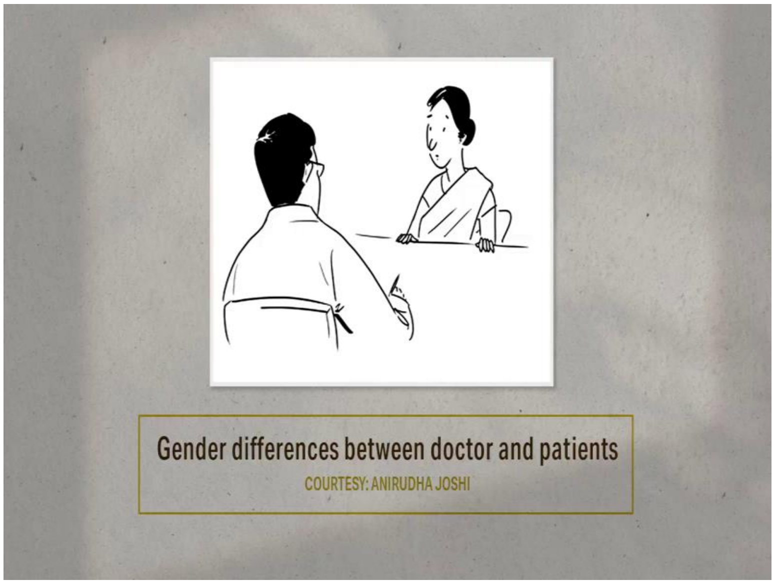


The Experience at an HIV-AIDS clinic

- Extensive time is spent waiting at clinics
- Patients feel trust and fear towards the doctor
- Gender differences between doctors and patients cause discomfort
- Gender differences between counsellors and patients hamper sharing



Gender differences between doctor and patients

COURTESY: ANIRUDHA JOSHI

So, one of the things that came out very strongly was that people, the people living with HIV AIDS had to spend a lot of time in the HIV clinic waiting for the doctor and so sometimes you wait for a long time with the doctor, the doctor said, you come after six months, so you should do better to do some tests and then do this test and meet me so that you have to do those tests and wait for the report and bring those reports and give it to the doctor and then see the doctor again.

And this used to take a lot of time, but people had a lot of respect the HIV patients who got cured, had a lot of respect for the treating doctors. In fact, this respect and trust also created a lot of fear about the doctors, like they did not willingly want to share many of their mistakes or like they missed their pills. They would not tell the doctor that I missed this pills or so there was this sort of this very high powered distance relationship with the doctors.

There were some gender issues with the in the clinics, like female patients did not want to talk to the male doctors. There were a majority of doctors that we interacted with were males. There were few female doctors. And the female patients did not like to talk about some of their issues with their doctors. Many of the counsellors that we talked to were female, and many of these counsellors were also very young girls, maybe just out of college kind of people with relatively less experience about the world, as you might say.

So, the male patients, some of them in their 40s and 50s found it very odd to discuss their very personal intimate sexual lives with these very young girls, in a closed room, so it was a very odd situation for many of them. So, many of these sort of gender issues were coming up. We also found that clinics struggled because of poorly maintained health records. Health records the treatment history particularly made a big impact on future HIV treatment, even now it makes.

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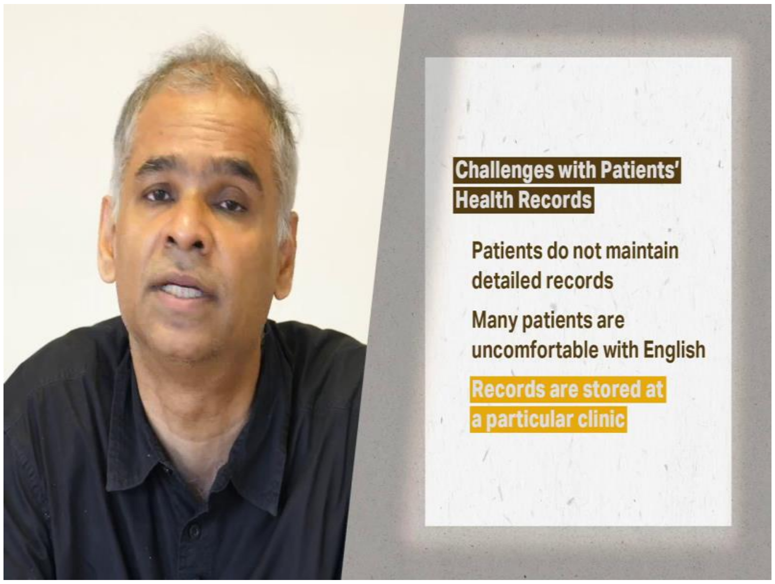

Challenges with Patients' Health Records

Patients do not maintain detailed records

Many patients are uncomfortable with English

Records are stored at a particular clinic

But because of the stigma associated with HIV, a lot of patients either do not maintain their health records or do not maintain the complete health records they keep minimum. The most recent prescriptions or something like that. One of the challenge was that many of these health records were in English, and people could not read English for them. These health records were meaningless information.

So, they did not know which of this is important and which is not. So, as a result, many of the clinics maintain their own health records for the patient. Now, this reduced patient mobility. So, if there is a migrant worker, and if it goes from here to his hometown for a few days, he cannot access a clinic there. He cannot carries his health records with them. And so there are lots of issues about maintenance and updation of health records.

So, socialisation is the primary method by which information spreads in society. So, most of the information that we learn, we do not necessarily learn by reading about it. We learn from friends or from family members or from somebody else. So, socialisation is therefore very important.

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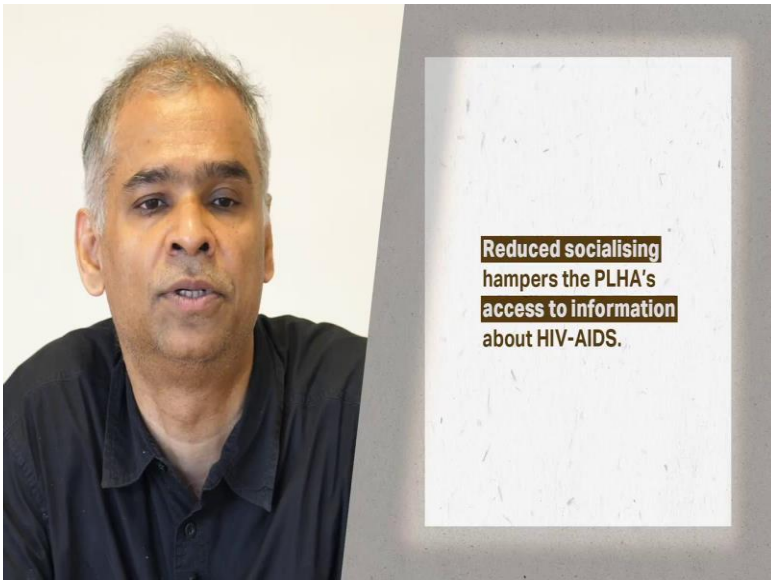

Reduced socialising hampers the PLHA's access to information about HIV-AIDS.

But HIV, people living with HIV and AIDS tend to socialise less, partly because they are already under financial pressure and partly because they are depressed. So, they do not want to really talk to people. They do not really enjoy socialisation. And then even if they do socialise, they really do not end up talking about HIV because firstly, most people havn't disclosed their family and friends about their HIV status. And even if they did, this is not a topic of conversation for most people.

So, information about HIV then did not spread easily within the society. And so maybe technology can help with that. One of the things, though, that we came up with and we understood really I mean, we knew this, but we understood from the inside, richly, as you might say in ethnography is that solutions need to operate under very tight financial constraints. So, you cannot expect people to buy gadgets or equipment only for the treatment we need to develop solutions which will work on existing equipment or existing platforms.

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So, based on our findings, we came up with some solutions. So, we mainly came up with, as I said, a interactive voice response to support people living with HIV AIDS we evaluated this. We came up with several prototypes. Some of our early prototypes did not work with people who are new to technology. So, we redesigned it. We went through several iterations and then once we, we were confident, we came up with our final system. So, the system had some interesting features.

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Firstly, it provided post-pill time reminders to patients. So, just after it was time for people to take their medication and why just after, well, what we found out is that sometimes people get over-reliant on technology. And one of the things that we wanted people to do was be less reliant on technology. So, say if my phone gets discharged, I might not get a call if I do not get a call, I do not want to be in a condition that I forget to take my medicine.

So, every time we gave a call to the person, we said, by now you should have taken your medicine. If you are taking your medicine press 1 else, press 3.

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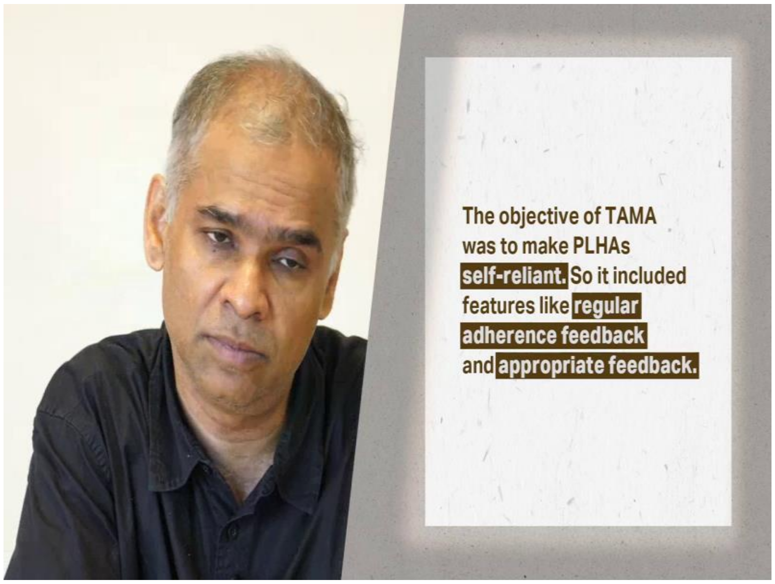

The objective of TAMA was to make PLHAs self-reliant. So it included features like regular adherence feedback and appropriate feedback.

So, we used to always assume that you are independent and then we are just checking if you have done that. So, all the dialogues and the way we had written up the IVR system was like that. Then when they said, yes, I have taken my medicine, then the system would give them adherence feedback. Or if they said, I am going I am not going to take my medicine today, it will give them adherence feedback or sometimes there was also an option to say that I am going to take my medicine later after some time.

Then if they did that and you say, okay, you should not delay it too much, take it as soon as you can because it is important that you take your medicine, so appropriate feedback was given based on that.

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We also provided what we called as personalised health tips. So, all the counselling information we can of broke it down into small 30-second nugget's, which were easy to absorb for people. One of the things that we found was that a lot of people had not disclosed their HIV status to their family members and partners.

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So, we protected this system with a pin, with a number. So, when the system calls you music plays and people are just keep listening to the music. So, if somebody else picks up your phone and phone sharing is very common in our society also. So, if somebody else picks up the phone, they will hear the music, and they will not understand what it is and they might disconnect the call. But every patient that we deployed the system with we use to train them that this is your pin, this is your number you have to keen, the number, it will not prompt you to do that.

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So, it is protected with a PIN, and it is localised to a clinic. So, although it was a single system that was deployed across 20 clinics for each clinic, it would say, hello, I am TAMA calling from this particular local clinic. It was localised to the clinic. And so we were here trying to leverage the respect and the relationship to the doctor, the treating doctor has with that particular patient.

So, what we did was this is a second ethnographic study of sorts, not really ethnographic field study.

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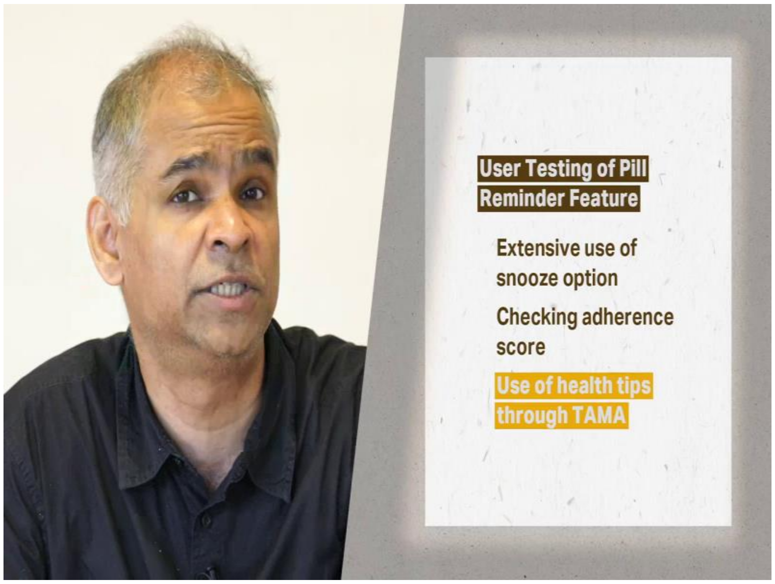

User Testing of Pill Reminder Feature

Extensive use of snooze option

Checking adherence score

Use of health tips through TAMA

Where we went and looked at how these 54 people who had tried TAMA for 12 weeks, how they actually have been using one of the things that we found was that the pill reminders was used extensively and especially that snooze like feature. So, in fact, every patient on an average for every pill time snoozed twice. So, it was consistently being used so it was extensively and everybody was surprised with that.

People used to complain about things like, you know, when I miss one pill, you know, I used to be take for 10 days, I take a pill my adherence shows up 100 percent eleventh day I miss a pill it becomes suddenly 90 percent. In the twelfth day, it becomes 91 percent. So, when I lose lose a lot and when I gain, again, very slowly. So, people have started understanding that this is how it works. The health tips, the information that we are providing was a great hit.

In fact, originally when we had talked to the doctors, the doctors are really not very convinced that we needed to provide information because they said that we provide all the information that they need. They do not need to get additional information. We should not provide them any additional information because this might confuse people. However, what the doctors did not realise was that although they were providing the information, they were all providing the information in one go.

And that is just too much of information and people did not retain a lot of it. So, in this round, when doctors came back, and they said they were very happy that actually, we were providing all this information, the system was then subsequently developed more and currently it is being used as of December, about 800 people were using it in Mumbai district. And hopefully this will get scale up to other HIV patients and for other conditions beyond HIV also. Okay. so, that it. So, I wanted to close by saying that contextual inquiry is a method that uses ethnographic approaches for the needs of the design process.

As we saw from Professor Joshi's presentation, the ethnographic approach can help us gain a nuanced understanding of everyday phenomena. There are layers of complexity in the most common of tasks. It is by understanding these layers that we are able to design products and services that fit into the context and the needs of the participants.

Professor Joshi made an interesting point while he was talking about his project that provided medical information to AIDS infected persons. The project team made a conscious decision not to remind participants to take their medicines. Instead, the program was designed to check if the participants had taken the medicines. The team felt it was important that people do not become dependent on the service; instead, the service was designed to empower people to be responsible for their own care.

In some way, what this signifies is that the researchers and designers working on this project did not think of the participants as perpetual users dependent on the services given to them. They believed in and decided to enhance the agency of the patients by providing information and timely checks. We could say this is a manifestation of empathy and respect among the researchers for their participants.

Professor Joshi's, work gives us an opportunity to see how these qualities filter into the products and services we design for the other. In our next section, we will meet Professor Athwanker, who also uses the ethnographic approach in design. He brings an element of play and interactivity into it. Let us see how he does this.