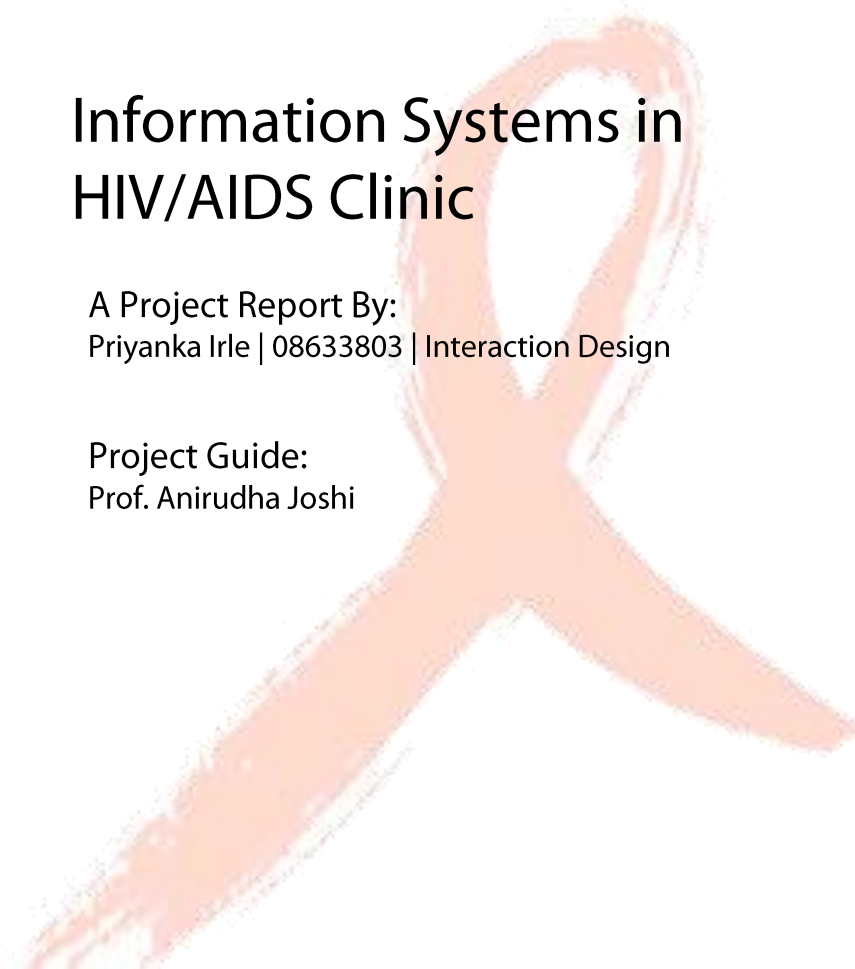

Information Systems in HIV/AIDS Clinic

A Project Report By:
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Approval Sheet

The Interaction Design Project III entitled 'Information System in HIV/AIDS Clinic' by Ms. Priyanka Irle; Roll No.08633803 is approved in partial fulfillment of the requirement for the Masters of Design degree in Interaction Design

Signature: _____

Project Guide: _____

Chairperson: _____

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Declaration:

I declare that this written submission represents my ideas in my own words and where others' ideas or words have been included, I have adequately cited and referenced the original sources. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated or falsified any idea/data/fact/source in my submission.

I understand that any violation of the above will be cause for disciplinary action by the Institute and can also evoke penal action from the sources, which have thus not been properly cited, or from whom proper permission has not been taken when needed.

Signature

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Abstract:

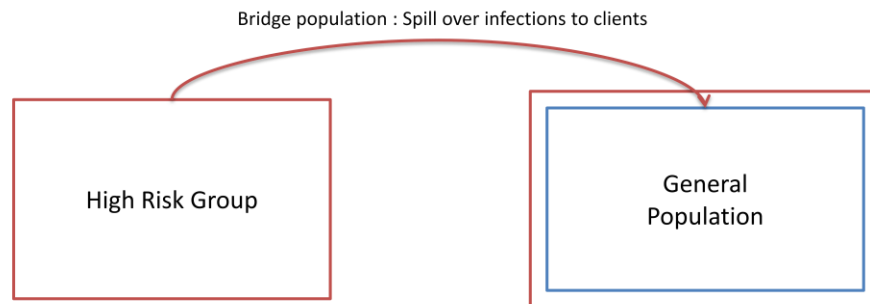
Health education along with proper treatment is the need of a PLHA to fight against the HIV disease. The project aims at understanding the current methods of education like print, brochures, television, radio, internet etc. and their association with spaces like hospitals, HIV clinics, and HIV testing centres which are visited by a PLHA on a regular basis. It was observed that a major amount of a PLHA's day was spent in the waiting areas of these spaces during his visit to an HIV clinic.

The goal of this project is to study the effectiveness of the waiting area and come up with designs solutions which would help the PLHA's to use their waiting time more constructively. It was found that the waiting area would serve as an excellent ground to provide health care information and also as a place for networking with other PLHA's who were present in the clinic for their medical visit.

The design solution consists of a hand held tablet PC which is used to provide authentic information using interactive videos based on various parameters like personalization, repetition and localization of the content provided. Information thus reaches the PLHA in an interactive form making it more dynamic and organized. The tablet PC also consists of scenario based quizzes that evaluate the knowledge levels of the PLHA and provide feedback which in turn acts as a trigger and source of information gain. Networking amongst the PLHA's has many benefits like information sharing, experience sharing, motivation but disclosure of a PLHA's status being the greatest drawback. A clinical radio is the proposed solution which maintains the confidentiality of the PLHA and at the same time allows him to connect to other PLHA's and share thoughts and experiences.

Introduction

Despite increased efforts in recent years and widely varying prevalence estimates, the HIV epidemic in India is not yet controlled. Government interventions of various forms have not proved to be the best remedies to curtail the disease from entering the general population. The HIV epidemic has already moved from the high-risk groups via the bridge population into the general population.[1] [Figure 1]



In India there is an epidemic shift from the High risk population to the Bridge population and then to the general population

Figure 1

High Risk Groups: Sex workers, Truck Drivers, IDUs (Injecting Drug Users), MSM (Men having sex with Men)

Bridge Population: Clients of Sex workers, People who come in direct contact with the HRG

General Population: Indirect contact through the bridge population (Full site sensitization on HIV/AIDS seminar, 2010)

The HIV infected group in the country includes all strata of people differentiated on the basis of economy, education, standard of living,

profession etc. With such a wide variety of population in our country living with HIV, the information required by them also varies based on their context, needs and requirements.

Efforts are made by the Government and also by organizations like NACO (National AIDS Control Organization) to provide relevant information to PLHA's which would help them monitor their health and gain a positive way of living with HIV. This information is readily available in clinical spaces in the form of brochures, pamphlets, books, posters, magazines etc. Also with the availability of internet the information has become digital penetrating the everyday living of people and the society.

Considering the various economic and educational backgrounds of people living with HIV, the current sources of information prove to be ineffective when it comes to low literate or economically challenged PLHA's where access to such information is very limited. The clinical space is a common ground where patient education is possible irrespective of their differences. PLHA's associate with their clinics for their treatments, check-ups, counselling sessions etc. and thus this space can be effectively used to identify their needs based on their history, demographics, location etc and educate them on the same.

Patient education is a combination of learning experiences influencing behavioral changes, producing changes in knowledge, attitudes and skills needed to maintain and improve health. There is an increasing pressure to provide more informed and standardized information resources to patients at less cost and the urgent need to provide structured educational interventions to enhance patients' health behavior[2]. Improvement in patient knowledge about their illness

and treatment could provide great benefits for both patients and their doctors.

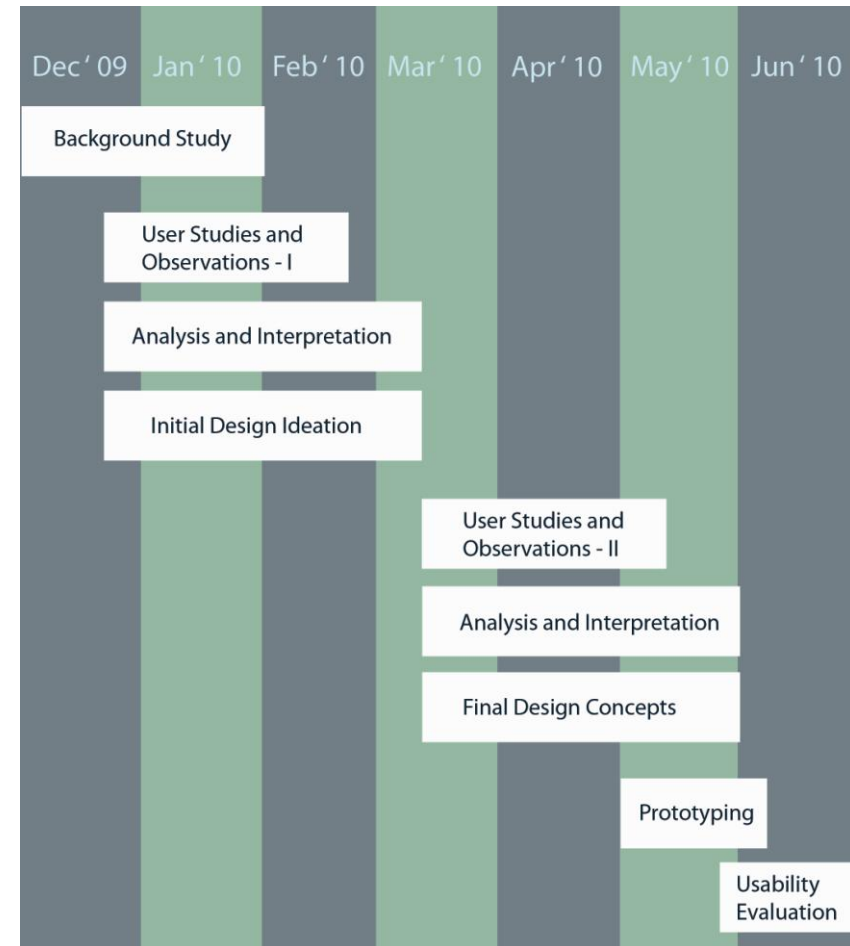
The aim of this project is to use the clinical space effectively for patient education and in turn provide information which is best suited to the needs and context of the patient by using the best interactive mediums available. An attempt is made to make efficient use of computer based technology and study its pros and cons in terms of providing health education. Also the sensitivity of the subject is taken into account while coming up with design solutions which not only disseminate information but also act as an aid to collate authentic and structured information.

The project also deals with the various issues related to a PLHAs life at a social level like networking, socializing where disclosure of their HIV status acts as an important factor to determine their acceptance in the society. Networking as a concept proves to be an effective way of knowledge sharing where peer to peer discussions could solve a large amount of problems in a very subtle manner using self experiences, motivational support, building a positive hope in a PLHAs life. The HIV clinical space is a ground where all present patients are positive in their status which eliminates the issue of stigma and disclosure. This space provides peers with the same HIV status reducing the fear of discrimination resulting in strong networking.

Thus the long unproductive waiting times of the patients during their visit could be constructively used to provide relevant information and as a ground for networking with other PLHA's. This would help them monitor their own lifestyles and in turn get a more healthy life.

My Approach

The design approach considered during the project included the following activities



Background Study

The project was initiated with a study which involved the study of HIV (understanding the spectrum of the disease). This included HIV in India, the medical definition of HIV, HIV stages in the life of a PLHA.

HIV as a disease

Having limited information about the subject, it was very important that I myself have a thorough understanding regarding the topic before moving further in the project. Thus constant interaction with doctors, counsellors and patients helped me understand the theoretical as well as the practical relevance of the disease and thus relate it to the daily life of a PLHA.

It also gave me an insight about the geographic penetration of the disease and a further more insight to the main reasons of transmission in the Indian context. India's population is more than 1 billion where 5.2 million of the population is HIV+ (NACO, National AIDS Control Organization). The states where the prevalence of HIV is highest are Andhra Pradesh, Goa, Karnataka, Maharashtra, Manipur, Mizoram and Nagaland. (NACO statistics, 2006). The main reasons for the transmission for HIV in India are heterosexual behaviour, injected drug usage and mother to child transmission, the high risk groups in the country being sex workers, truck drivers and IDUs (Injecting Drug Users).

What is HIV?

HIV stands for Human Immunodeficiency Virus. It differs from other viruses like bacteria in the manner of its functionality and associations with the body cells. The body's immune system generally protects us from foreign invaders like viruses and bacteria. This keeps us protected from various diseases which would otherwise cause harm to our body making us weak and sick. But, in the case of HIV, the virus attacks and destroys our immune cells called CD4 cells (T- cells or lymphocytes). HIV infects these cells and uses their cell parts to replicate itself. This results in the formation of many new HIV particles and the cycle of infection continues. The infected CD4 cells gradually die, due to which a person's ability to fight foreign invaders decreases and he becomes more susceptible to infectious diseases. HIV or Human Immunodeficiency Virus itself does not kill a human being. What it does is weaken the host's defence system, leaving the body vulnerable to all sorts of disease-causing germs. [3]

Over a period of time the HIV virus captivates the immune system to such an extent that many infections attack the body simultaneously making the person weak and vulnerable. Uncommon infections hover around the person due to an impaired immune system which no longer can protect the body from foreign invaders. These infections are known as opportunistic infections and the resulting syndrome is known as AIDS (Acquired Immunodeficiency Syndrome). Thus HIV and AIDS is not the same thing. HIV is the virus that causes AIDS. Thus it can be said that not every HIV+ person has AIDS.

What is the treatment for HIV?

Research efforts have not yet resulted in a vaccine to protect against the HIV infection. However, medications known as ART (Anti Retroviral Therapy) are available for infected individuals that control the replication of HIV virus in the body. These medications limit the amount of HIV present in the body but they cannot bring down the virus count to zero. Thus ART does not cure a person of HIV but helps him improve his immune system by limiting the viral load in the body.

Even though ART medications considerably reduce the amount of HIV virus in the body, they have Adverse Drug Reactions (ADRs) acting as major obstacles in their success. As a result many individuals put on ART treatment show poor adherence to the medication resulting in treatment failure.

Initially a PLHA is put on 1st line ART treatment. This treatment is currently available free of cost in the government hospitals. If the 1st line treatment fails, the PLHA is shifted to 2nd line treatment which is more costly than the previous treatment and only very few hospitals provide them free of cost. Thus it becomes very important that the PLHA adheres to the initial treatment increasing his time period for the 2nd line treatment thus leading to a healthy life.

Along with medication as a treatment, education also plays a very important role to modify the life of a PLHA in a positive direction. An infected individual needs knowledge about the available medications, his care and support, his daily lifestyle monitoring, eating habits in order to live a healthy life. Also correct information about the drugs available and their proposed side effects will help in acceptance of the medication. Thus education also acts as an aid to improve adherence.

Non adherence to the medication is seen due to many factors like side effects from medication, low level of education, lack of proper counselling, inappropriate ways and methods to adhere to the medication etc. Non adherence leads to treatment failure and the virus develops resistance.

NGOs (Non Governmental Organizations) actively take part to disseminate such information to PLHAs who are associated with them. Some NGOs also offer support and medication to PLHAs and provide ART medication under the supervision of a doctor.

Schematic progression of the virus over time (ART 1st line)

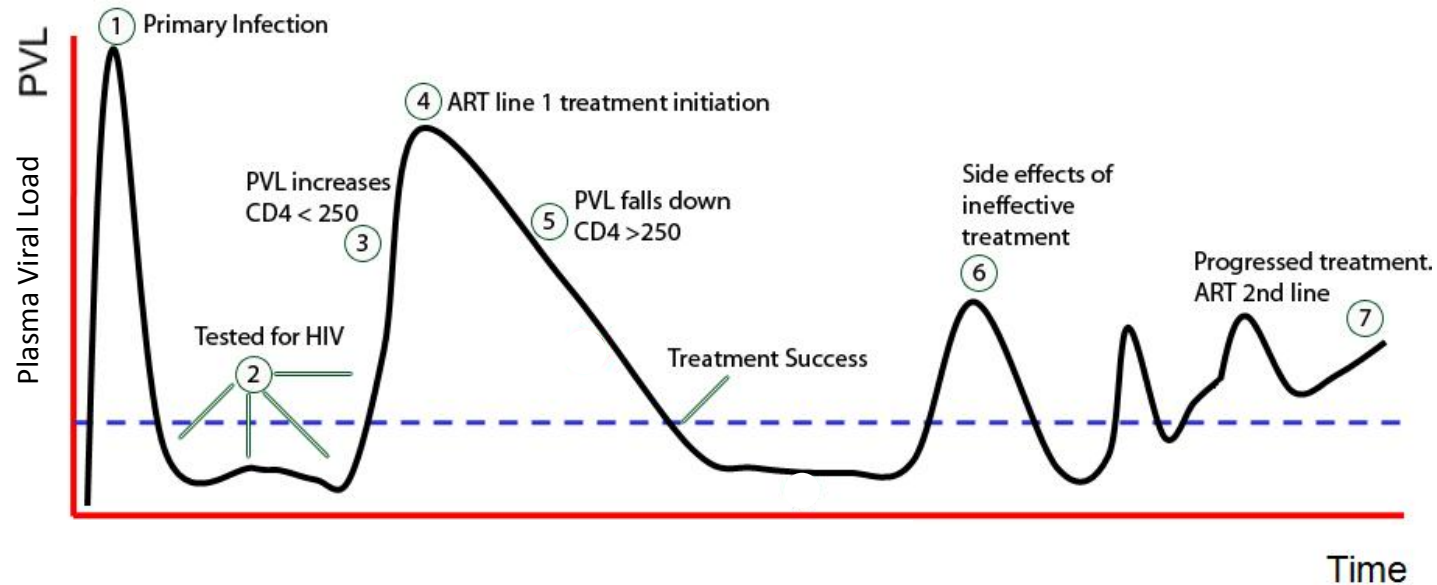


Figure 2

1. Person suffers from primary HIV infection (symptoms of HIV) like fever, sore throat, swollen lymph's etc. During the infection the PVL (Plasma Viral Load) i.e. HIV virus present in the body increases considerably
2. If a person gets tested for HIV during this period (on suggestion by doctor, voluntarily etc) he gets tested as HIV+. It may also happen that the person neglects the test and gradually the infection subsides. In such cases HIV remains undetected.
3. Gradually the PVL (Plasma viral load) i.e. amount of HIV virus in the body increases resulting in the decrease of CD4 cell count (number of T cells) in the body which form the immune system. Medical threshold being 250 for the CD4 count.
4. The CD4 count falls below 250 and the person is put on ART (Anti Retroviral Therapy), 1st line treatment.
5. The treatment shows results if taken regularly and PVL (Plasma Viral Load) begins to fall increasing the CD4 count. This results in treatment success.
6. But due to various reasons like side effects of the treatment and non adherence the treatment becomes ineffective. As a result the viral load again rises.
7. The PLHA is then initiated on the 2nd line treatment of ART[4]

User Studies and Observations

After gaining a fair amount of knowledge about the disease the next step was to focus more on the problem area. Field studies were conducted by visiting the clinics, understanding the needs of the users and identifying the problems in the current system. Certain observations were made while interacting with the PLHAs, doctors and counsellors who were all a part of the clinical suite.

The following places were visited as a part of the study

Government Hospitals: Sasoon Hospital, Pune [Figure 3]; Nair Hospital, Mumbai and JJ hospital, Mumbai

Private Clinics: Dr. Pujari's Clinic; Pune and Dr. Saple's Clinic, Mumbai

NGO: JSK (Jeevan Sahara Kendra), Thane; CCDT, Mumbai

As my project revolved around the clinical space and the waiting time of the patients in the area a major portion of the study was conducted by interacting with patients during their clinical visits and understanding their pattern of the visit. The observations in the clinical space were mostly based on patient's behaviour, and their interactions with the information materials present in the clinics. Information thus provided by the clinics was studied understanding the benefits and loopholes in the current system of health education. Detailed interviews with doctors and counsellors were also a part of the study which helped me to authenticate the gathered information based on my interactions with patients and study of the available material.



Figure 3

Sasoon Hospital, Pune

Findings

The user studies led to certain findings which I have categorized accordingly

- Clinical Space Related** -Frequent visits to doctors allowed me to understand and observe the clinical space in detail. I got an opportunity to understand the various activities that take place in the clinic. These findings include visits to both government and private clinics
- Information Related** - Information is available in the clinical space in the form of brochures, pamphlets, magazines, books etc. Also counsellors in the clinic play an important role to provide HIV related information to patients in the clinic. These findings include analysis of the current methods of information
- User (PLHA) Related** – PLHA visiting the clinics belong to different economic strata, education levels etc. These findings reflect the target users based on the needs and requirements.

Findings – Clinical Space

- Interaction of the PLHAs with the clinical space forms a sequential pattern during each of his clinical visit. [Figure 4]



Figure 4 Sequential Model of clinical space (Government Hospital)

1. PLHA visits the clinic on the day of his appointment
2. Depending on the purpose he visits
 - Registration Desk – All PLHAs register themselves using their PID number (Patient Identification Number) during their every visit to the clinic (Target User Group)

- ICTC (Integrated Centre for Testing and Counselling) – purpose being testing for HIV, pre-test counselling, post-test counselling (1st time visit)
 - Pathology Lab – purpose being getting a blood test done
3. Once registered, the PLHA waits for his turn to meet the counsellor by sitting in the waiting area.
 4. On his turn, the PLHA meets the counsellor who analysis his health and provides health related information accordingly.
 5. The PLHA again waits for his turn to meet the doctor and sits in the waiting area
 6. On his turn , he meets the doctor who monitors his health and prescribes medication based on the same
 7. The PLHA again waits in the waiting area for his turn in the pharmacy along with the doctor’s prescription
 8. On his turn the PLHA collects his medication from the pharmacy
 9. PLHA returns home
- 3, 5, 7 indicate that a lot of time of a PLHA is spent in the waiting area of the clinic. As the number of patients in the clinic increase, the waiting time per patient also increases.
 - An average time spent by a PLHA in a clinic is around half a day of which major portion is spent in the waiting area. This waiting time of the PLHAs is spent idle.
 - PLHA visits a clinic once in 15 days, 1 month, 3 months respectively based on his health status.

Findings - Information Available

- Modes of Information available in the clinic

Printed Materials – This consists of brochures, pamphlets, posters, magazines, books etc which provide a lot of information related to HIV like awareness, prevention, positive living, care and treatment etc. [Figure 5]

Advantages – Effective as teaching aids. Information reaches at a personal level.

Disadvantages – High usage of text makes it difficult for illiterate or semiliterate users. Information provided is not personalized



Figure 5

Mass Media – This consists of television, and the use of DVDs/VCDs.

Advantages: Can address mass population. Can act as both entertaining and informative. Excellent approach to clear conceptual information. Heavy usage of audio visuals enhances learning.

Disadvantages: Do not meet the personal requirements of the users. Non interactive and thus one sided source of information.

Take home materials - This consists of mobile information embedded in key chains, T-shirts, playing cards, murals etc. (only specialized clinics)

Advantages: Quick and short information can be provided effectively. Personalization of information is possible. It provides a strong visual message that can be shared with the society like slogans on T-shirts.

Disadvantages: Information cannot be brief. It needs to be precise and crisp. Not a good medium to explain a concept or a theory.

Technology related – This consists of information through the digital mediums like mobile phones, internet etc. They include reminders, SMS, emails etc

Advantages: Very personal and direct messages can be provided. Can provide timely information based on the need of the hour. E.g. Motivational messages when depressed etc

Disadvantages: Not all PLHA are comfortable using technology as a medium to gain information

Doctors and Counsellors – PLHA receive a lot of information from the doctors and counsellors during their clinical visits related to their health.

Advantages: High degree of personalization, interaction, authentication retaining the human touch

Disadvantages: Fear of the doctor or the counsellor can create a power distance between the doctors/ counsellors and PLHA resulting in loss of information to the PLHA as he may not personally clear his doubts by asking questions. Counselling Sessions are time bound.

- All the mentioned channels of information contain different kinds of information. The content of information varies.
- When the PLHA is provided with HIV information at the first time, he cannot absorb the vast amount of information immediately. Thus repetition of information is important. Also proper chunking of information is necessary
- HIV information can be chunked in following categories
 - General Information – This information should be known by everybody
 - What is HIV?
 - Transmissions of HIV
 - Precautions to be taken to avoid infection
 - Myths and misconceptions e.g: does mosquito bite spread HIV?
 - Dealing with stigma
 - Where can you get tested?
 - Kids and HIV
 - Prognosis
 - Treatment for HIV- which is ART(Anti Retroviral Therapy)

HIV specific information – This information should be known by all PLHAs

- What is CD4, PVL (Plasma Viral Load)?
- Where can I get my CD4 tests done?
- Personal Data Management
- What are the cost implications of my ART medications?
- Links to NGOs
- How to avoid transmission?
- ART related information
- Side effects of ART
- Nutrition
- Disclosure to family and friends

ART related information – This information should be known by all people who are on ART

- Side effects of ART
- Nutrition
- Opportunistic Infections
- 1st line and 2nd line treatment
- How to manage medication (use of alarms, reminders, pill boxes)

HIV + Specific disease information – This information should be known by people who suffer from other diseases like TB, cancer etc specific to their problems

- TB+HIV
- Cancer+HIV
- Diabetes+HIV

- A major amount of information sharing is done in the clinical space in the counselling sessions
- Clinical Counselling Sessions are a strong means to disseminate HIV related information.

Counsellors in the clinic provide personalized HIV related information in a one to one conversation with the PLHA. This facilitates the PLHA to share his doubts and problems with the counsellor and thus gain more knowledge on the same.

The counselling sessions in the clinic are non technical dealing with everyday lives of the PLHA and addressing issues like stigma, adherence, motivation, nutrition etc. These sessions include open ended questions which start from least confronting areas to more challenging ones which open out new information to the PLHA. The sessions being interactive make them more interesting and informative.

But these sessions also have their own set of shortcomings:

Counselling Sessions are Time bound: A specific amount of time is allotted to a PLHA in the clinic as the counsellor has to attend many patients in a same day. Thus at times the sessions could not bring out the best of conversations leading to miscommunication and not all doubts of the PLHA may be addressed. Thus it is very important for the PLHA to keep time as a constraint while attending a counselling session. As a result

the PLHA may tend to forget many relevant doubts which he may realize later.

PLHA may not be attentive during the session: There are times when the PLHA are not attentive during the counselling sessions and thus miss out on important information provided by the counsellors. Currently there is no mechanism other than memory to retrieve back the lost information

Counsellors may use jargons: The counsellor may tend to use jargons which may be difficult for the PLHA to grasp. This may lead to more confusions and at times wrong transfer of knowledge to the PLHA

Power Distance between counsellors and PLHA: Fear of the counsellor may create a power distance between the counsellor and the PLHA as a result of which the PLHA may not be comfortable sharing his doubts with the counsellor. Thus information transfer would be limited to only one direction whereas the PLHA may not be able to solve his personal doubts and queries

Information Repetition: Some common information like basics of HIV, daily lifestyle etc were repeated by the counsellor to each patient. This time could be utilized to solve personal doubts of the patients which were more important.

Findings – PLHA related

➤ PLHA have different knowledge levels related to HIV information

- Some PLHA have “no information related to HIV”
Patients in this category have no information about HIV but have care takers who act as means of information channels and communicate to the patients

“My wife is HIV+. But she is not aware of her HIV status. I take care of all her medications and treatments. She has been told that her medications are for joint pain. I am scared that our family would be neglected in the society if she knows and the news spreads in our community”,
Husband of a PLHA, Pune

- Some PLHA have “Terminological Knowledge”
Patients in this category know the terms and jargons like HIV, CD4, ART etc but do not know the importance and meaning of those terms

“My current CD4 count is 340. I don’t know if its good or bad but my doctor will let me know about it”, PLHA,
Housewife, Pune

- Some PLHA have “Procedural Knowledge”
Patients in this category may not be well aware of the concepts but they are very particular about the procedures and activities which they are supposed to perform like adherence to medication, monthly CD4 testing, exercise habits etc

“I need to take my medications on time. I take 2 tablets in the morning at 8:30am and 2 tablets at 8:30pm at night. The doctor has advised me not to miss my doses. So i take my medications on time”, PLHA, Truck driver, Mumbai

- Some people have “Conceptual Knowledge”
Patients in this category are very clear about the concepts of HIV, ART medication. Thus these people knowing the concepts are very clear about the various aspects of HIV and show high adherence to medication

“It is important to adhere to ART medications because if we miss a does the medications may slowly stop reacting on the body. ART makes the HIV virus sleep in the body and stops it from replicating”, PLHA, Outreach worker, Pune

- Factors like economic background, literacy constraints, disclosure in society etc act as a hindrance to PLHA to access and gain information.

Other Findings

- PLHA are hungry for information. They try to find information through various sources like newspapers, friends, internet etc but doubt the authenticity of information

“I had read in ibody.com that a person is considered to be healthy if his CD4 count is above 250. I don’t believe this as some non medical people have posted it on the site”, PLHA, Pune

Authenticity of information is very important and it was observed that PLHAs trust the information sources from the clinics rather than random information available in the newspapers, internet etc

Thus, providing information in the clinical space has an added advantage of building trust in the PLHA.

PLHA show a great deal of trust in their doctors and counsellors. Any information provided by them is considered to be authentic and appropriate.

- PLHA require personalized information which they can relate to in their everyday lifestyle
e.g.: It would be appropriate to provide information related to personal ART regimes to PLHA regarding their adherence, doses, side effects etc rather than general information on medications

- Information provided may vary according to the financial stability of the PLHA and also his locality. Thus information needs to be very personalized and localized.

“We try to provide him with good meals and enough fruit, that's all. We cannot do more because it depends on our budget.”

Father of a PLHA, Mumbai

“Many NGOs in the locality provide free medications and support for single mothers. I have heard about of it but am not aware where exactly I can find them”, PLHA, Pune

- PLHA are continually concerned about the uncertainty of their health. They are always worried about getting sick or acquiring opportunistic infections.

PLHAs want more information about the progression and different stages of HIV infection, AIDS, and opportunistic infections. Limited knowledge about the different stages of HIV infection and AIDS leads to confusion, anxiousness, and constant concern about the future.

PLHA become very sensitive to any signs of sickness, such as chills, fatigue, and rashes, and are worried that they will die soon

“I always live in fear and concern. Every time there are symptoms of an illness, then I am worried because I don't know if it is due to the disease.” PLHA, Housewife, Pune

- PLHA wish to communicate with others who understand and sympathize with them about their thoughts, feelings, and experiences

But lack of disclosure in the society and stigma issues faced act as a hindrance to effective communication.

“I wish I could talk to people about my HIV status. It will help me overcome my fear and guilt. I visited a NGO far away from my locality so that my status remains undisclosed but travelling long distances is a problem due to my age now.”

- Networking with other PLHA helps to share knowledge, information, experiences and builds support and confidence in a PLHA.

“I have disclosed my status in my family and also the society. There are few people in my locality who are positive and share the same medical regimen as mine. I learnt to manage my pill timings and doses after observing a friend who was on the same medication”, PLHA, watchman, Pune.

- The clinical space can act as an excellent ground for networking as all present in the waiting area are detected positive thus removing stigma and opportunity for disclosure.

However, a lot of resistance is seen in PLHA to interact with fellow PLHAs.

Design Goals

The information system designed should facilitate information gain and networking in the clinical space

Information Gain Design Considerations:

The design should facilitate the spread of HIV information at the general as well as the personal level

It should take in to consideration the confidentiality of the user

The information provided should be authentic and trustworthy

The medium used to provide particular information must be best suited to match the needs.

Solution should be intuitive and not time bound as the target users being semi literate and illiterate

The solution should not replace the human form but rather act as an aid to lower the human (doctor/counsellor) burden

Technology can help in personalization, localization, repetition, socialization

Visual support will make a good aid to education over and added to audio

Networking Design Considerations:

The design should facilitate networking amongst patients in the clinic without disclosure

It should allow peer to peer knowledge transfer

Using the simplest technology available allowing networking for illiterate and semiliterate users

It should take into account the confidentiality of the user

It should utilize the information available in the clinical space and thus expand the existing networks

It should act as a helping aid to patients in the clinic

It should be both informative and entertaining

Should not become a source of overdose information to the patient

Initial Design Ideas

DI 1: Interactive Kiosk based quizzes

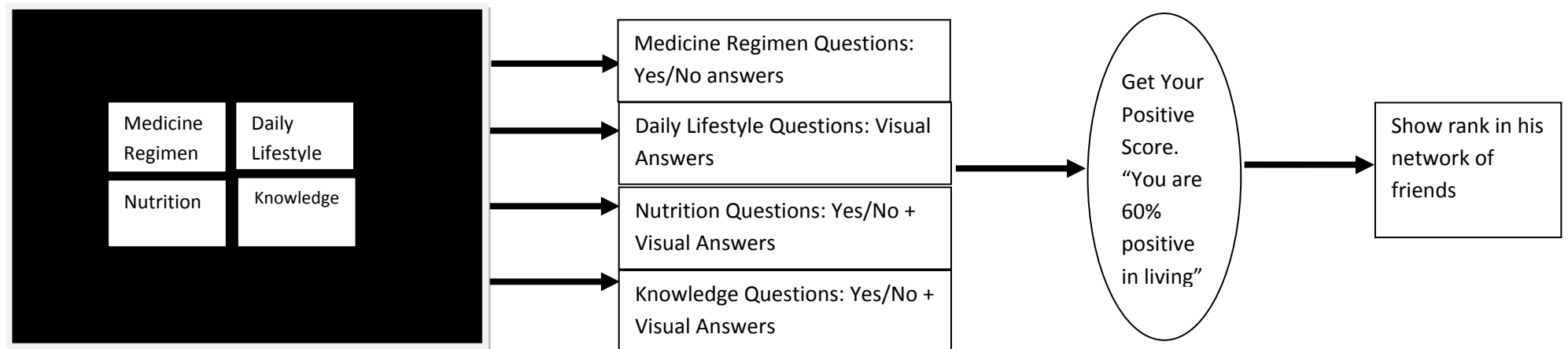
The quizzes can be based on 4 major parameters:

Medicine Regimen: Regularity in taking medicines

Daily Lifestyle: Exercise/work / behaviour

Nutrition: Diet / Habits

Knowledge: Awareness/ Prevention /Precaution



This report can be sent to the doctor's server where he can get a rough idea about the patient's progress

Drawbacks Observed:

- Too many questions imposed on the patient make him lose interest.
- One way input from the user and no feedback from the system can make the system less interactive
- Patients may not like to answer questions in the quizzes as they might get a feeling of an examination
- The current design is dependent too much on the users input whereas the design should provide larger output to the patients
- Raking at the end can demotivate the patients and they might lose confidence if they get a low score
- Does not provide information but acts as a source of collecting user statistics

DI 2: Audio Blogging

People can record their problems (family/ job related / general issues) and send them to the kiosk. i.e “post them”

The kiosk in turn can narrate the story in an audio format

Other patients can hear the stories and leave feedback for the same questions which were posted.

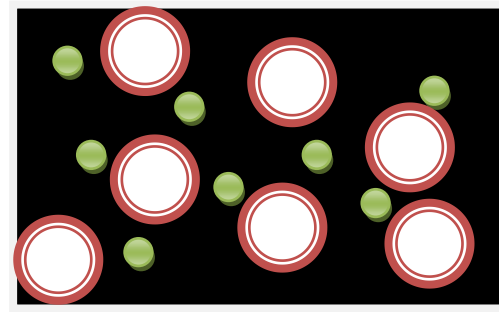
DI 3: Games for networking

Patients can log in by their name (fake name to avoid identity disclosure)

“Purpose is to break the ice between people”

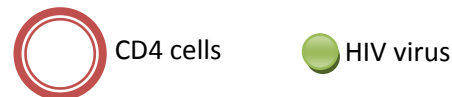
- 2 tablets with two different people
- Both can play a competitive game that leave a message for them when the game ends

e.g. “Kill the virus” – HIV virus shooting game



Place a finger on the virus to shoot / kill it.

Single player / Multi player – challenge a friend



Final Design – Information Gain

System designed for Information Gain

The system consists of a handheld tablet PC placed in the waiting areas of the clinics. These systems act as a personal information kiosk for PLHAs in the waiting area providing them with personalized information using the medium of interactive videos and quizzes

It works in two modes:

- General
- Personal

General: This is the default mode. It contains informative videos which can be accessed by every PLHA present in the waiting area. The information provided is of a generic nature (information which everyone should know) in an interactive format based on videos and quizzes.

Personal: This mode becomes active when the system identifies a particular user based on his PID smart card. (Personal Identification Card). This mode contains information which is very personalized and caters to the current needs of the identified user. Information thus provided is localized, contextualized and personalized to the current user and his needs.

Hardware used

Touch based tablet - (iPad) which provides excellent multimedia output

PID cards – Personal Identification smart cards provided to each user containing RFID tags which store personalized information about the user (PLHA)

Smart Card Reader – A smart card reader that detects the RFID tags on the PID cards and pulls out relevant information required by the user.

Headphones – Provided at the registration desk or individual headphones carried by PLHA during their visit to the clinic

Highlighting Features

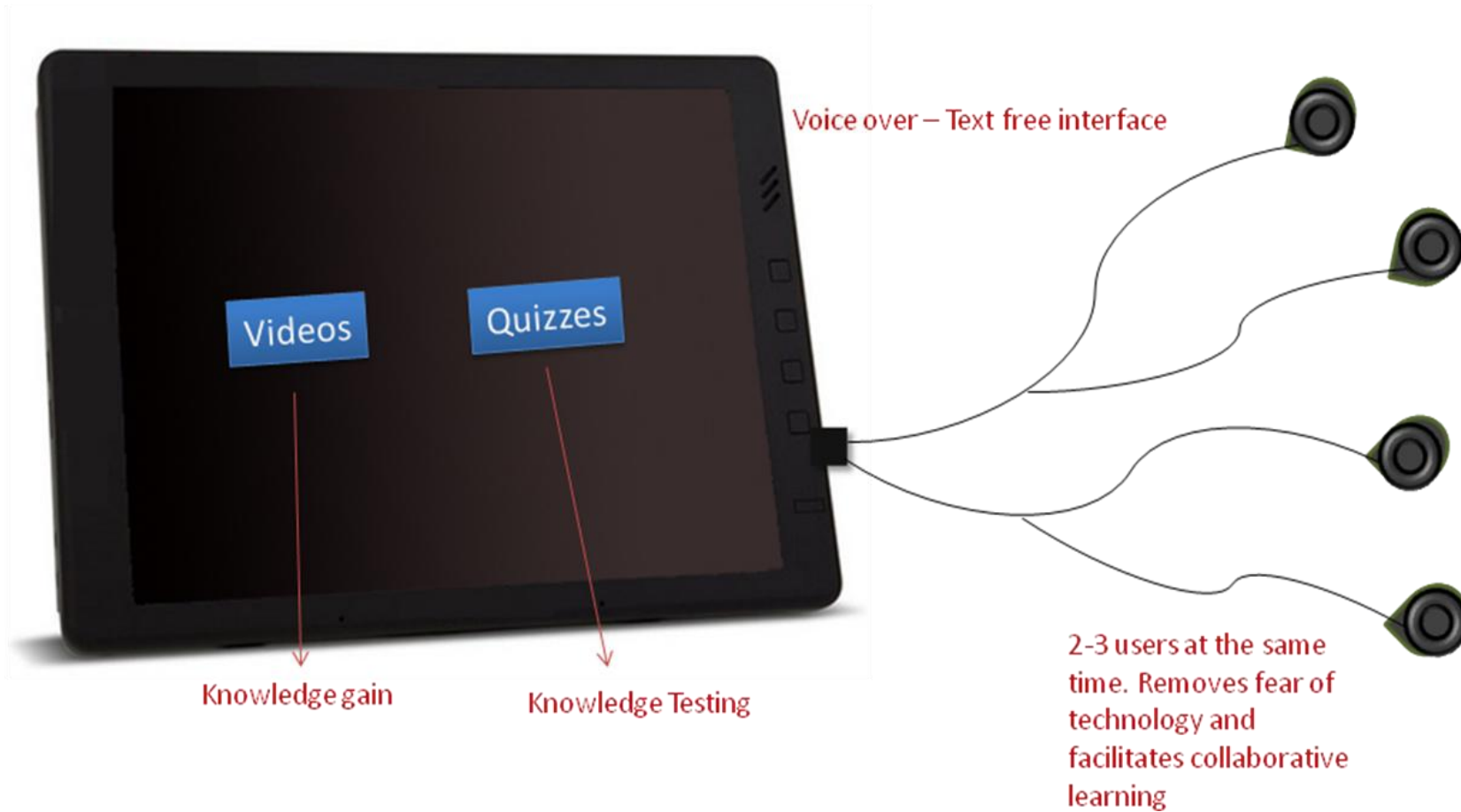
Personalized – Use of a hand held tablet provides a personalized space for the PLHA in his own comfort zone. It facilitates private viewing which thereby minimises the issues related to stigma and disclosure.

Collaborative learning – Dual audio output allows the PLHA to share the tablet PC with the fellow PLHA and use the system simultaneously. This is true when PLHAs access general information.

Sharing the device eliminates the fear of technology and facilitates collaborative learning.

Interactive Information – Use of PID cards facilitates provision of information which is localized, contextualized and also allows repetition of information and increases the redundancy. Thus information can be viewed over and over again and PLHAs can grasp the information at their own pace.

The HIV Tablet





- Interactive video based explanations that clear the concept level.
- Pop up questions in between the videos which triggers the crave for more information gain.
- Public content
- Content design on general topics like basics of HIV, CD4 , ART medications etc

- Interactive video based explanations to clear procedural level information
- Pop up questions related to the FAQs of the users
- Private content which is very personalized
- Content designed on medical regimens, foods habits, personal health monitoring of PLHAs

HIV Tablet – “General Mode” - Content

The general mode provides generalized information which can be viewed by everyone in the clinic. Thus the content designed in this mode relates more to the general awareness of the disease and also preparing the PLHA for his future life with HIV. The content is majorly presented using 2 mechanisms:

1. Set of Interactive Videos

“Conceptual understanding leads to improved adherence”. This was one of the strong findings during the user studies. It was seen that people with strong conceptual knowledge adhere more to their medications as they know conceptually the adverse effects of missing a dose.

Videos being an effective medium to communicate conceptual information were used altering the interactivity like making an IVRS based video which was more entertaining and interesting.

These videos clear basic concepts of HIV like

- What is HIV – mechanism and functioning in the body?
- What is CD4 - mechanism and functioning in the body?
- What is ART - mechanism and functioning in the body?

The videos also address generalized doubts of the PLHA like

- How much time will I live?
- How can I adjust my lifestyle?

- How to protect others from HIV?
- How can I cope up with my mind thought?
- Do I need support from my family?

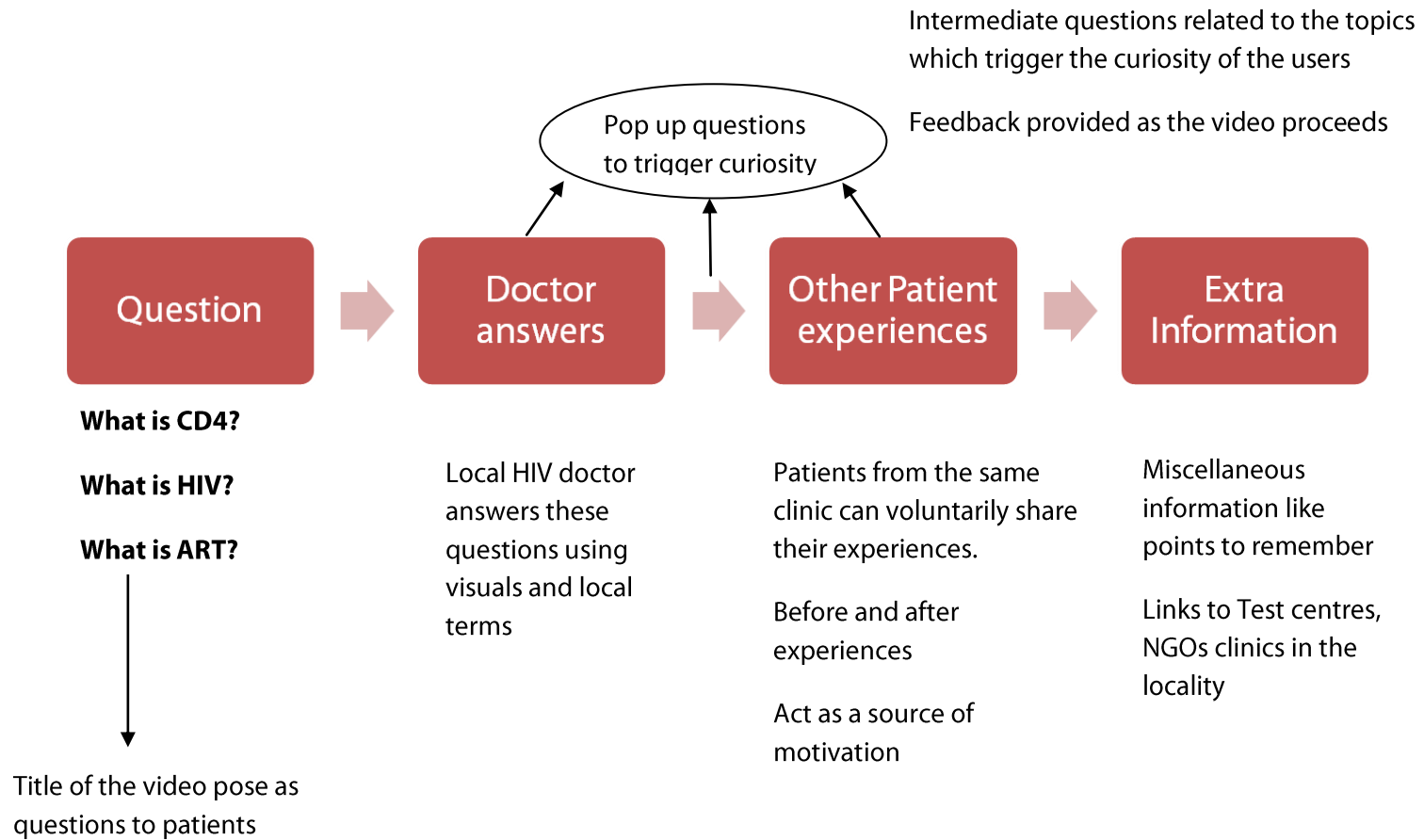
2. Story based Interactive Quiz

PLHA want more information about the progression and different stages of HIV infection, AIDS, and opportunistic infections. Limited knowledge about the different stages of HIV infection and AIDS leads to confusion, anxiousness, and constant concern about the future. It becomes very important to prepare the PLHA for his future stages in HIV and thus help him handle his lifestyle more effectively.

A story based interactive quiz is used to make the PLHA understand the various stages he goes through in his life span. The story revolves around the life of a central character who goes through various stages after being detected HIV+. The PLHA takes decisions for the central character moving the story further and in turn explaining the stages of HIV.

PLHAs can relate their life to that of the central character and thus grasp the concept more clearly rather than explain with a timeline and a graph making it more complex and difficult to understand.

Structure of Interactive Videos



Interactive Video Details

Doctor: Initiates a conversation where he clears concept level doubts by answers the proposed question. Answers by doctors inculcate a sense of authenticity and also patients trust in the information provided.

Doctor can act as an intervention and uses jargons and technical terms just to make the patient familiar with words like CD4, HIV, ART etc which are important as a part of patient education.

Animation/Visuals: Set of visuals are used to clear the jargons used by the doctor. Strong uses of metaphors for the jargons are used to facilitate easy understanding. Illustrations and Audio help people both with visual and audio memory retention.

Patient Experiences: Patients in the clinic can voluntarily share their experiences while they were on treatment. This develops a sense of motivation for other fellow patients and they can learn from others experiences.

Other Details: Miscellaneous details like CD4 test centres, NGOs, other networking group contacts can be provided. Patients can be told what they need to do next and how they can do it.

Pop Up Questions: Intermediate questions in between the videos to facilitate the connectivity of the user with the video and also trigger the curiosity levels of the PLHA. General doubts of a PLHA could be posed as probing questions which make the PLHA think about them and also make them curious to know the answer. The answers could be provided as the video proceeds.

Video Key points

Use of Local Language – Hindi / Marathi/ Manipuri based on the region and country

Localized content – Local Clinical Doctors acting as interventions help to retain the trust of patients in the provided information. Use of experiences of people in the same locality or clinic help to relate more to their ideas and lifestyles.

Use of Metaphors – Using metaphors to highlight and explain medical terms which might otherwise be difficult to grasp for an illiterate patient.

e.g.: CD4 – soldiers of the body /shield the body / friends of body / watchman of your body (house)

HIV: enemy attack / foes / someone who causes harm / thief –steals health

ART – food for CD4/ Protection for CD4/ tonic for CD4

HIV does not attack CD4 – HIV sleeps / HIV is tied / HIV disappears

Storyboarding – Interactive Video

Example video for “What is HIV? ”

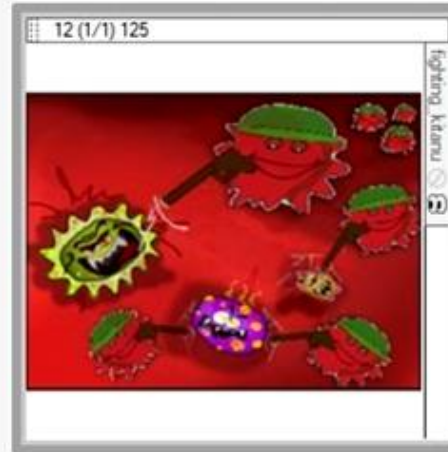
<p>Doctor explains using medical terms</p>	<p>Body of a healthy patient</p>	<p>Zooming</p>	<p>Zooming</p>
<p>These are CD4 cells . They are our friends</p>	<p>They act as soldiers in our body and protect it (use of metaphor of a soldier)</p>	<p>Hey here comes a malaria</p>	<p>And here is Pneumonia</p>



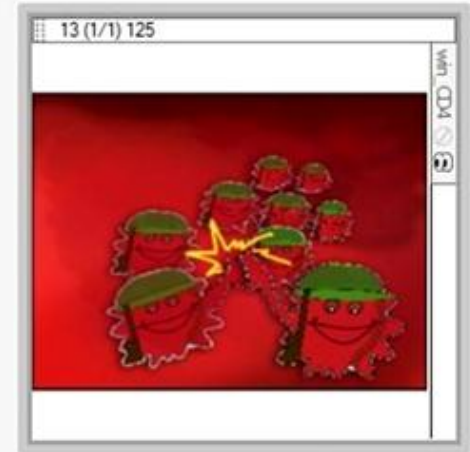
This is Diarrhoea



Lets see how these soldiers fight



CD4 soldiers kill the virus



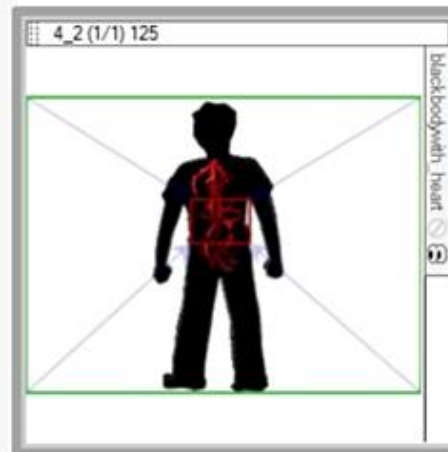
They win the battle keeping the body healthy



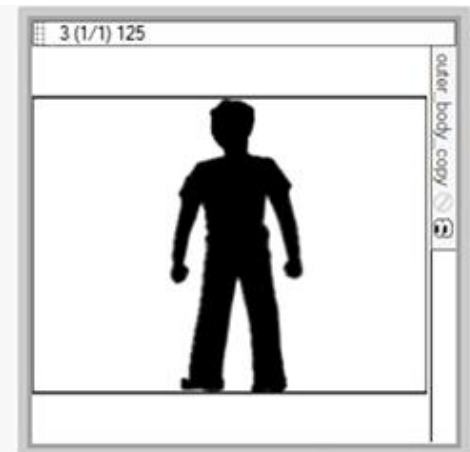
Zoom out



Zoom out of the body



Zoom out of the body



Zoom out of the body



This is HIV virus. Consider him as an invader in your body



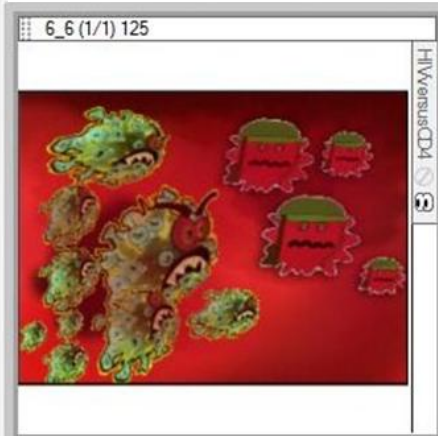
HIV enters the CD4(soldiers)



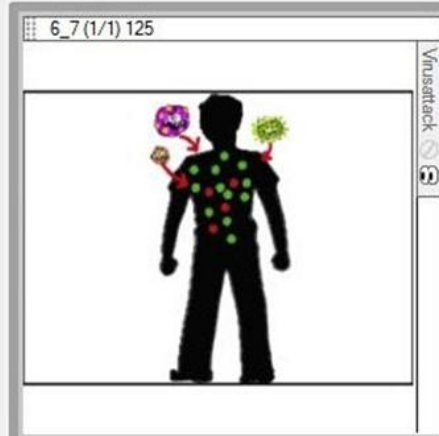
Uses CD4 as its food and multiplies itself



Finally destroys the CD4 cells



Thus the number of HIV virus in the body increases compared to soldiers (CD4) who take care of the body



Thus your body becomes weak and the viruses like bacteria which earlier could not enter the body now find it easy to enter and destroy the body making you sick

Patient Experiences

Recorded interviews with PLHA (voluntarily agreed) in the same clinical space where they can share their thoughts, ideas and everyday experiences . (Localization – experience relating to the same locality)

Miscellaneous Points

Extra information that the PLHA needs to know- contacts for NGO, statistics in their city of HIV, moral boosting messages

Script (Explaining HIV in body)

Doctor: HIV एक विषाणु है, जब ये शरीर में पाया जाता है तो उस अवस्था को हम HIV+ कहते हैं. इसे ठीक से समझने के लिए आपको अपने शरीर में होनेवाली क्रियायों को समझना होगा.

ये एक साधारण व्यक्ति का शरीर है और वोह तंदरुस्त लग रहा है. लेकिन जैसा दिखता है वैसे हमेशा होता नहीं. चलिए अब देखते हैं इस व्यक्ति के शरीर की क्रियायों को.

Animation (voice over): ये सफ़ेद जीवाणु है. इन्हें CD4 के जीवाणु कहते हैं.ये हमारे दोस्त हैं. ये हमारे शरीर की रक्षा करते हैं सभी हानिकारक कीटाणुओं के खिलाफ. ये सरे जीवाणु हमारे शरीर की सुरक्षा कवच होते हैं. इन्हें हम एक रक्षा सेना समझ सकते हैं और CD4 जीवाणु एक जवान है जो हमारे शरीर की रक्षा करता है. जिस तरह अपना शरीर पाचन तंत्र पर निर्भर करता है उसी तरह अपना शरीर सुरक्षा कवच पर भी निर्भर करता है विषाणुओं से मुठभेड़ करने के लिए. इस वजह से अपना शरीर तंदरुस्त रहता है.

"अरे वोह देखो मलेरिया... और वोह दिअर्होएअ ... और उस तरफ से नेमोनिया ...इन्होने तो इस इंसान के शरीर पर कब्ज़ा कर लिया है" ..

"कोई बात नहीं.. अब देखते हैं हम CD4 सेना का कमाल."

CD4 हमारे शरीर के बिमारियों से लड़ता है और हमारे शरीर को तंदरुस्त रखता है.

Doctor: इसीलिए यह बहुत जरूरी है की हमारे शरीर में CD4 की संख्या ज्यादा बनी रही ताकि वो बिमारियों का सामना करे और हमे तंदरुस्त रख सके.

"लेकिन क्या CD4 HIV से लड़ सकता है?"

चलिए अब इस इंसान के शरीर में देखते हैं..ये इंसान किसी भी साधारण इंसान की तरह लग रहा है.. पर ये इंसान HIV से पीडित है..देखते हैं CD4 सेना इस इंसान के शरीर में कैसे काम करता है..

Animation (voice over): ये हमारे वही CD4 है.. पर अब विषाणु कोई और है,.. ये HIV के विषाणु है.. ये बड़े खतरनाक होते हैं...HIV विषाणु CD4 को खतम करते हैं और फिर दुगने हो जाते हैं.इस तरह से HIV विषाणुओं की संख्या हमारे शरीर में CD4 की तुलना में बढ़ जाती है.इस प्रकार CD4 सेना की संख्या शरीर में कम हो जाती है जिसके कारन अन्य विषाणुओं को आपके शरीर पर हमला करने का मौका मिल जाता है.

Doctor : जब HIV हमारे शरीर में CD4 पेशियों को यानि शक्ति कानों को कमजोर और संक्या में कम कर देता है, हमारे शरीर में बिमारियों से लड़ने की शमता कम हो जाती है..और हमारा शरीर दुर्बल हो जाता है.इस

अवस्था में कई बीमारियाँ एक साथ हमारे शरीर में घर कर लेती हैं.. इस अवस्था को AIDS कहते हैं. ये होते होते कई साल लग जाते हैं. इसीलिए ये जरूरी नहीं की हर HIV+ इंसान को एड्स हो. बहुत से लोग HIV+ होते हुए भी कई साल तक साधारण जीवन व्यतीत करते हैं. जरूरत है तो सिर्फ सावधानी और देखभाल की.

Question: क्या असुराखित सम्बन्ध से HIV हो सकता है ?

Choice: 1. हाँ 2. ना (select from the choice)

Doctor: HIV इन कारणों से फैलता है:

- असुराखित संबंधों के कारण
- HIV /AIDS पीड़ित माँ से अपने बच्चे को
- दोषित injection या siringe के कारण
- HIV दोषित खून के कारण.

असुराखित सेक्स यानि बिना कंडोम के सम्बन्ध न रखे. कंडोम का सही और नियमित प्रयोग जरूरी करे.

गर्भावस्था या प्रसव के समय HIV संक्रमित माँ से शिशु को HIV मिलने की संभावना रहती है. इसका बचाव संभव है.

अपने डॉक्टर या स्वास्थ्य सलाहकार से मिलकर पूरी जानकारी ले ध्यान रखे की आप हमेशा नयी सुई या सिरिन्ड्रा का ही प्रयोग करे.

Patient PLHA : २००८ में मुझे पता चला की मैं HIV + हूँ. पहले तोह जिंदगी से मेरा विश्वास ही खतम हो गया था. पर धीरे धीरे मैं संभालता गया. डॉक्टर की सलाह से कुछ दिनों बाद मुझे ART पे रखा गया. तब से मेरी तब्यीत में सुधारना है.

मैं अपनी दवाईयां समय पर लेता हूँ. और अपने भोजन का भी खास ख्याल रखता हूँ. शरीर को तंदरुस्त रखने वाला भोजन लेता हूँ. जैसे बीन, फलिया, मटर , डाले , मूंगफली. दूध पीने से मेरा शरीर तंदरुस्त हो गया है.

पहले मुझे बहुत दर लगता था.. पर अब मैं सोचता हूँ , सही देखभाल से मैं अपनी जिंदगी सुधर सकता हूँ. अपनी पहले की गलतियों के कारण मैं अपनी आगे की जिंदगी नहीं खराब होने दूंगा...मैं एक स्वस्थ जीवन जिऊंगा.

Miscellaneous: आपके सेहर पुणे में १० में से २ लोग HIV + है. (Currently dummy statistics) Pune के NGO: Pathway ph: 45002345, INP+ ph : 43218790 , helpline : 18001800

Screenshots of Video based explanation



Structure of Story Based Interactive Quiz

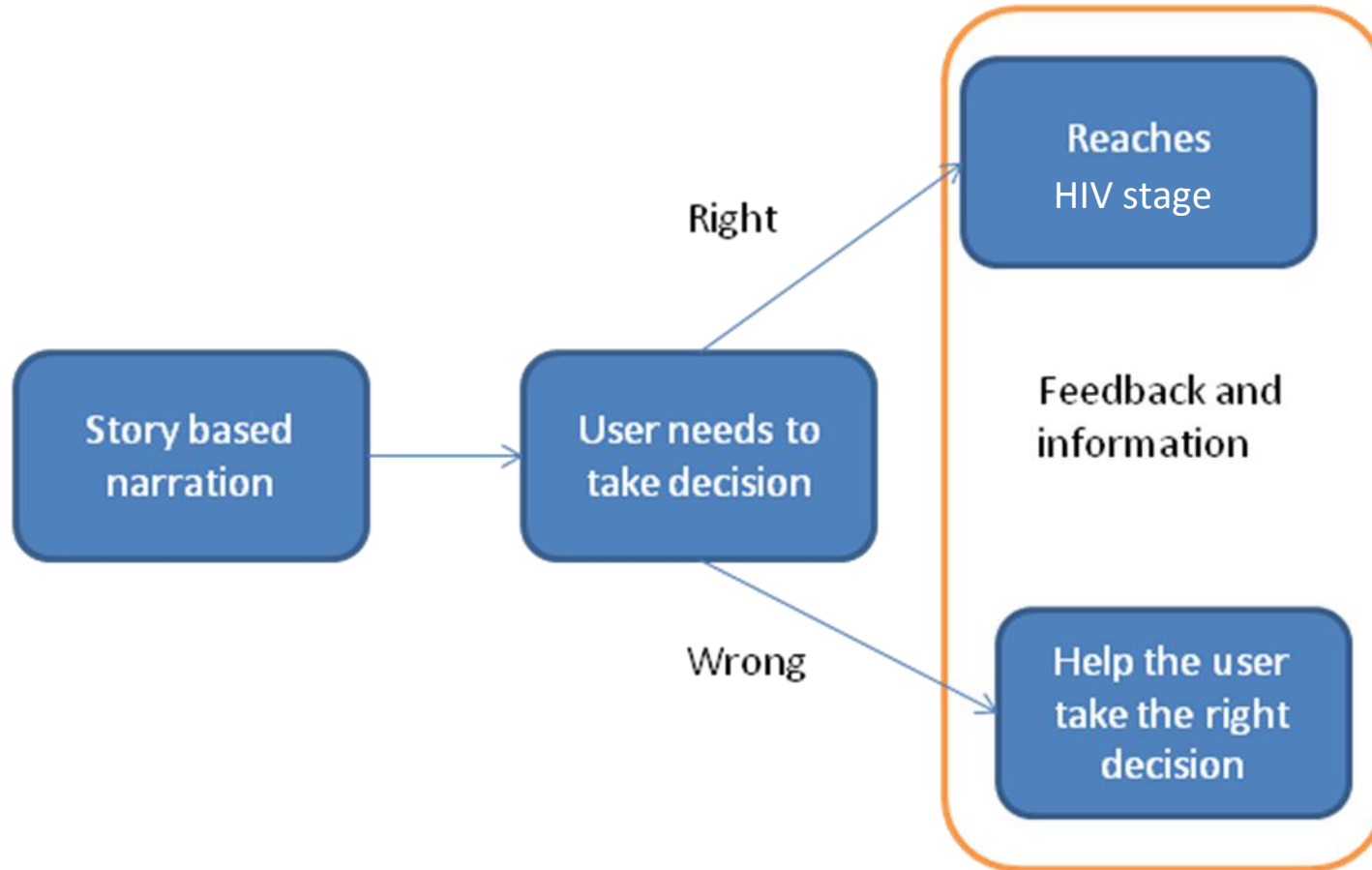


Figure 6

Interactive Story based quiz details [Figure 6]

Story based narration: Story based on the life of a character is narrated with the help of audio and visuals. The central characters life revolves around a series of events which bring about major changes in his way of living. The story continues and takes the PLHA across the life of the central character and helps him relate with the same.

User needs to make a decision: The central character undergoes certain major events in his life where the PLHA (user) is prompted to make decisions for the central characters life. Thus the central characters life is completely controlled by the PLHA and assigns him a sense of responsibility to take responsible decisions. The PLHA plays a role of a decision maker and based on his decision the story continues to the next level.

Reaches Stages in HIV: Based on the PLHAs decision taken for the central character the central character reaches different stages in his HIV lifecycle. In this manner the PLHA is acquainted with the different stages in HIV lifecycle through the life of a central character and thus he is prepared for his future life.

Help User take the right decision: At times when the PLHA is unable to make right decisions, the PLHA is prompted in a subtle manner and thus helped in making decisions. Also appropriate feedback is provided to make him understand the reasons for the decision taken.

Quiz Key points

Metaphors for jargons: HIV is a time bound disease. Thus it is important for a PLHA to acquaint himself with the various clinical stages of HIV he will be going through beforehand. The medical language used to depict these stages is through a timeline or a graph which is cumbersome to understand. Thus without using medical jargons, the timeline of an HIV+ person is efficiently explained using a central character and his life changes in a very subtle manner.

Personalized content: The central character designed can be based on the personal demographics of the PLHA so that the PLHA can more effectively relate to his lifestyles and methods of living. E.g. A Truck drivers story could be used to convey the message to the high risk group of truck drivers.

Thus various high risk groups like truck drivers, sex workers, IDUs (Injected Drug Users) could be addressed using stories of central characters based on their profession and lifestyle.

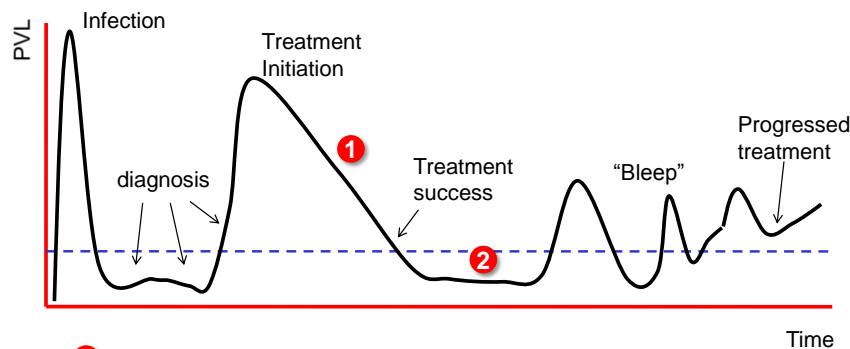
Understanding the HIV timeline

HIV is a time bound disease. Once detected HIV+ it is very important to prepare the patient for the next stages in his life.

[Figure 6] explains the various stages in a clinical perspective till the 1st line treatment. (Dr. Kumarsamy’s presentation. ProjectUNITE).The complex graph is difficult for a illiterate person to grasp and understand. Thus the time bound progression of the graph is converted in a story based platform where the patient is explained each stage using a scenario and its consequences. The scenarios developed were chunked into various stages in the life of a HIV= person to adapt to the daily lifestyle of a person

projectUNITE

Schematic progression of virus over time



- 1 Ineffective treatment may delay “treatment success”
- 2 Ineffective treatment may accelerate the need for “progressed treatment”

Figure 7

The following describe the various considered stages:

Primary HIV infection

Asymptomatic – person looks completely healthy but when tested for pregnancy, during accident etc gets detected HIV+

Symptomatic – Person displays symptoms of HIV like fever, sores, swollen lymph’s etc

“Person is detected HIV+”

Clinical stage 1 - HIV + status

Asymptomatic -For a period of time CD4 levels in the body remain normal. CD4 > 250. Thus the patient is put on vitamin supplements

CD4 < 250, moderate unexplained weight loss

ART (Anti Retroviral Therapy) started (1st Line treatment)

Clinical Stage 3 – ART Line 2

Due to non adherence to treatment, Line 1 treatment fails and patient is put on 2nd line treatment.

Severe weight loss and Opportunistic infections (OI’s)

Clinical Stage 4 – AIDS

HIV wasting syndrome (severe weight loss)

Many opportunistic infections take over the body simultaneously making the body weak

Interactive Story based Quiz – example



Interactive story book that is audio based which narrates the story of Ramkishan, a truck driver (character altered by profession)

Book based interaction that reduces the technology fear

Audio based story narration eliminates the necessity of reading



मिलिए रामकिशन से ...

मिलिए रामकिशन से... यह Mumbai में अपने बीवी बच्चों के साथ रहता है. रामकिशन पेशे से एक ट्रक ड्राईवर है. गाव गाव से सामन वह शेहेर शेहेर पहुंचता है. इस कारन वह अपने घर से महीनो तक दूर रहता है.



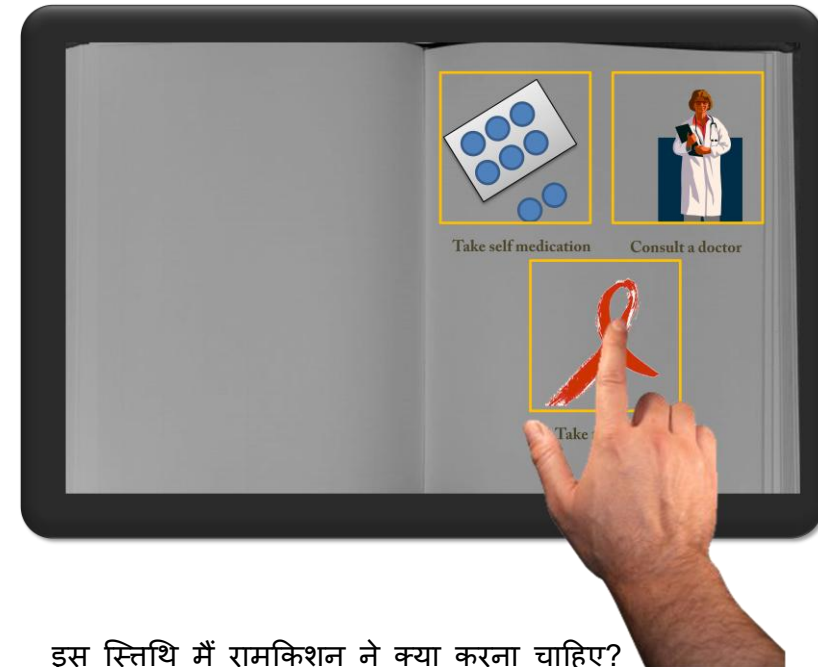
बुरी आदतों का शौक लग गया था.

रामकिशन इस पेशे में १५ सालों से है.

“मैं अपनी जिंदगी से खेल रहा था. मुझे घर से दूर रहना पड़ता था जिस कारन मुझे बुरी आदतों का शौक लग गया था . पर मुझे क्या पता था की जिंदगी मेरे साथ ऐसा खेल खेल रही होगी.”



पिछले २ महीनों से रामकिशन बीमार है. रामकिशन को तेज़ बुखार है. दवाईयां लेने के बावजूद बुखार चदता उतरता रहता है. रामकिशन दिन ब दिन कमजोर होता चला जा रहा है.



इस स्थिति में रामकिशन ने क्या करना चाहिए?

क्या आप ये निर्णय लेने में रामकिशन की मदद करेंगे?

- स्वयं दावा लेले.
- डॉक्टर से जांच कराये
- नजदीकी ICTC सेंटर में जाके HIV टेस्ट कराये

Depending on the answer provided by the user, appropriate feedback is given. Assuming the user selects the 3rd option नजदीकी ICTC सेंटर में जाके HIV टेस्ट कराये

इस लिए यह बेहतर है की
वोह एक बारी HIV की
जांच करा ले.



आपने सही निर्णय लिया है.

आपका निर्णय सुनते हुए रामकिशन ने HIV टेस्ट कराया.
और वह HIV+ है..

“मैं एक लापरवाह जिंदगी जी रहा था. मेरी गलत हरकतों के कारन मुझे आज ये
दिन देखना पद रहा है. काश मुझे सही समय पर सही जानकारी मिली होती तो मैं
अपनी जिंदगी सुधर सकता था”

The PLHA is thus acquainted with the first stage of HIV . i.e Primary Infection and detection. Similarly as the story progresses the PLHA gets acquainted with the remaining stages in the HIV timeline

HIV Tablet – “Personal Mode” - Content

The personal mode provides personalized information which is specific to the PLHA using the system. Thus the content designed in this mode relates more to the personal needs and requirements of the user based on the demographics of the user. The content is presented in the form of interactive IVRS enabled videos that are assigned to the patients by the doctors or counsellors based on the PLHAs requirement.

Set of Interactive Videos

These set of videos are dynamic and are assigned to the PLHA after he is examined by the doctor or the patient. Their main aim is to provide detailed health related information which might otherwise be missed out by counsellors due to lack of time or mismanagement.

They mainly could be used to communicate procedural level information to PLHA with the use of audio and visuals.

Consider the following Scenario:

Patient visits the clinic counsellor. The patient is prescribed 2 tablets of Nevarapin 300mg (ART medication) in the morning and 2 at night.

Important information that needs to be given along with the prescription is:

- Nevarapin has side effects like dizziness. Thus it should be taken as close to the sleeping time.
- It is very important that the PLHA is told the importance of adherence to the tablets.
- PLHA also needs to know details like the “with what should the tablet be taken”, “How to maintain adherence”, “should the tablet be taken before or after food etc”
- The PLHA himself has certain doubts like “Is there any other medication available for HIV”, “Can I ever be negative”, “Will this medicine cure me completely”

The counsellor needs to communicate all this information to a PLHA when he is in the mentioned scenario. But due to time constraints not all the information reaches the PLHA. In such situations the counsellor can provide minimum information during the counselling sessions and post the related videos containing the information to the PLHAs account.

The PLHA can then access the information in the HIV tablet PC once he logs on the system using his PID card.

Interactive Videos – Work flow

Personal demographics – Age, sex, occupation, address, disclosure etc

Medical History – Diagnosed, treatment, ART started, medical regime, OI, side effects

Appointment Records – Doctors consulted, Appointment dates, counselors

Special Needs – Finance, Job, Motivation, Stigma

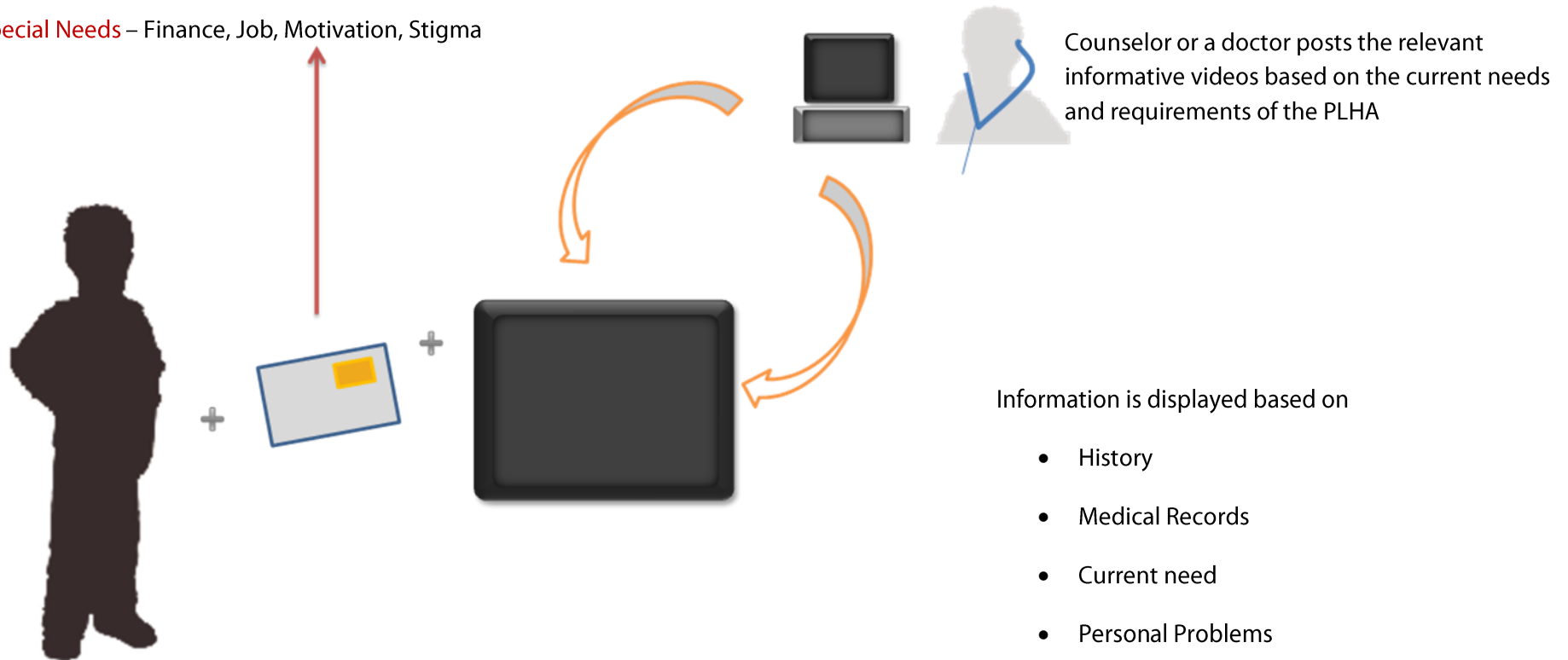
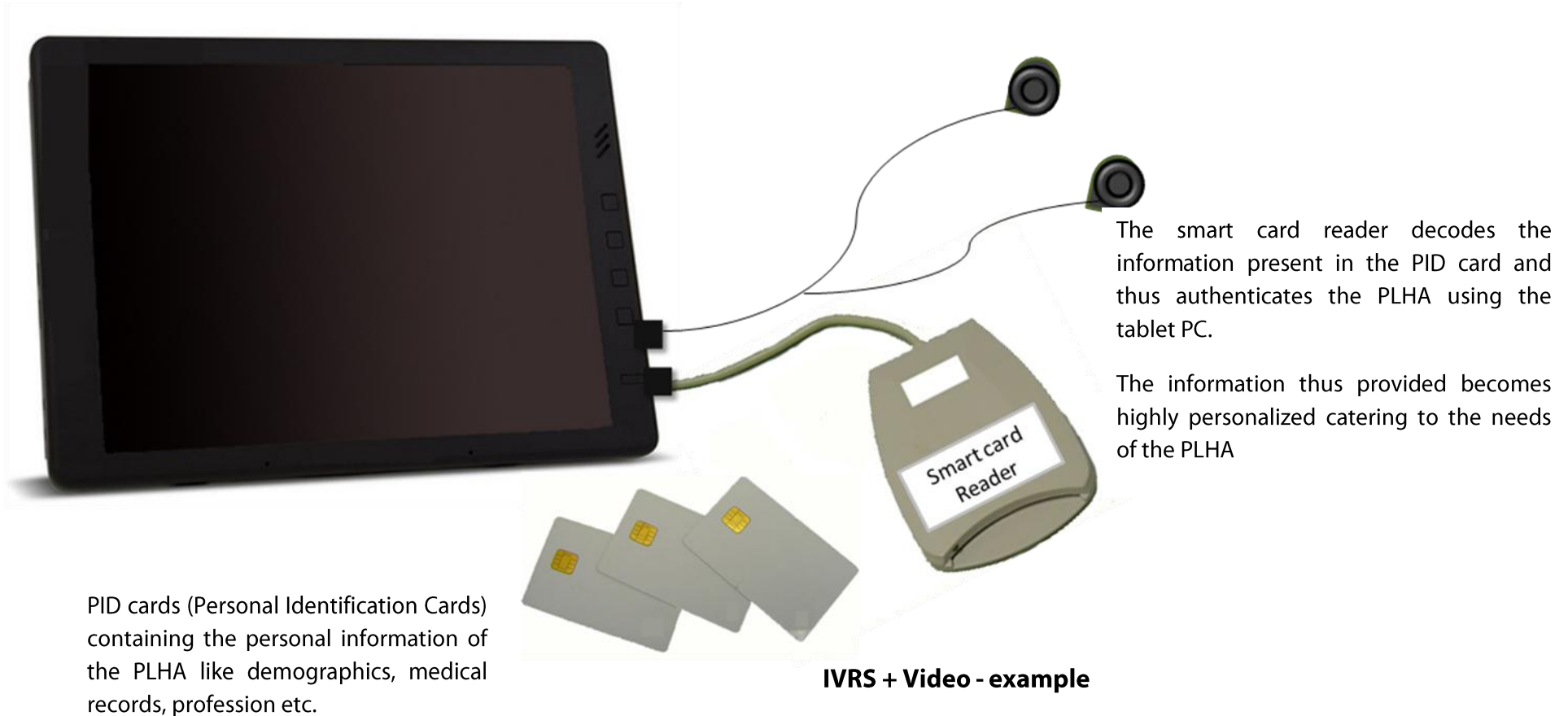
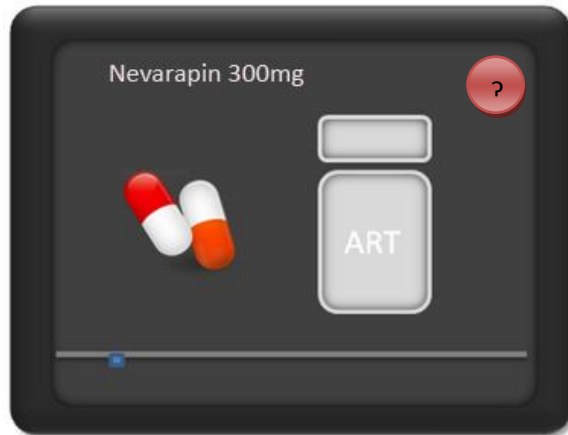


Figure 8

A step further – Personal Information



Scenario: PLHA is prescribed Nevarapin 300mg. Needs more details on the same. Counselor posts the video tagged "Nevarapin" from her database. The following are the screenshots:



The picture on the screen shows the dosage that has been prescribed to you by the doctor. It is called "Nevarapin 300 mg".

You can find the name of the medication on the ART bottle provided by the chemist

The tablets at the left are exactly the tablets that have been prescribed to you. They are half white and half red in colour. (Based on the insight that many people use colour codes to differentiate between their various medications)



You have to take 2 tablets of Nevarapin in the morning after breakfast and 2 tablets at night after dinner.

You can take 2 tablets at 8 am in the morning after breakfast and 2 tablets at night 8 pm after dinner.

The time span between the 2 tablets must be kept 12 hours for the tablet to take effect. If you miss your dose on a regular basis then the tablet can have a negative effect on your body. It will stop reacting to the body cells.

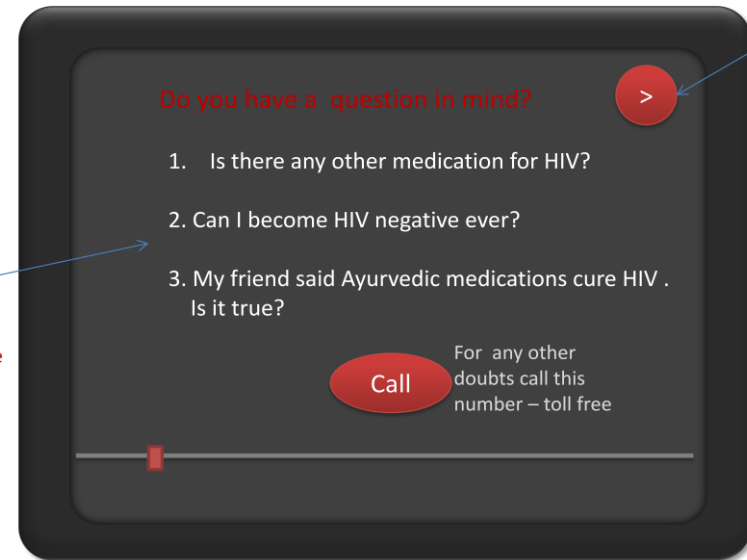


Any time during the explanation a patient can have personal doubts which need to be addressed. They could be addressed by clicking this button.

A list of FAQ's related to that particular chunk of timeline can be extracted from the Database and answered for the patient.

Use of a mobile alarm or placing the ART medicines at frequently visited places can help to improve adherence.

You can also match your medicine timings to the radio programs or your favourite serials on the Television.



Play video/ resume

n+ User
ated FAQ's
on database

Mechanism of the Interactive IVRS videos

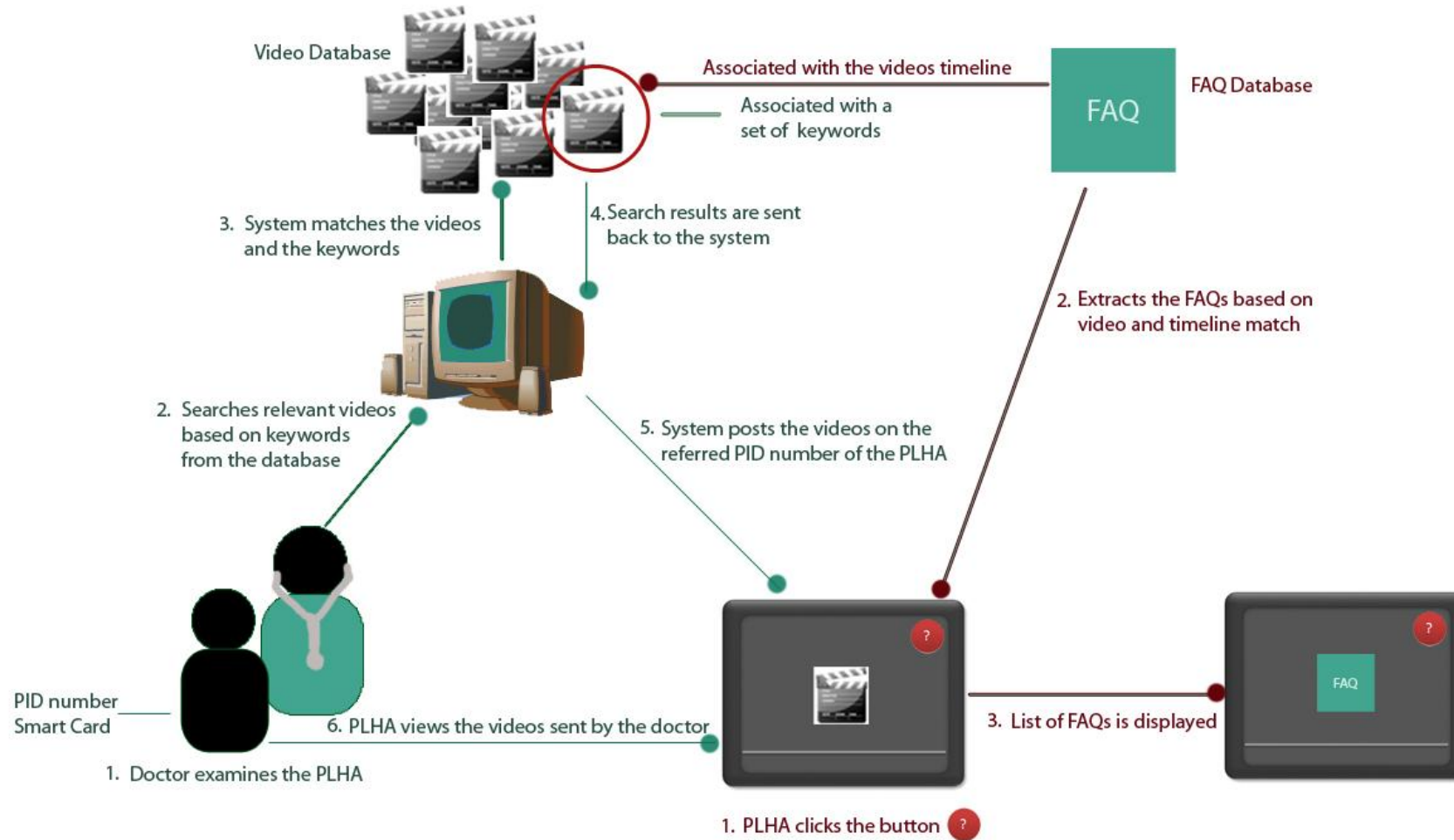


Figure 9

The Video Database

The video database consists of a set of videos each of which is tagged using a keyword. The keywords form as the basis of search for the videos.

Videos could be created based on the following sets of Keywords:

ART Prescriptions:

This set could contain a list of videos related to the various ART regimens of PLHAs. The videos could act as a means to provide procedural knowledge like method of taking medicines, adherence and side effects related to each of the same.

Thus the videos could serve as “Visual Prescriptions” given by the doctors to the PLHAs for easy understanding. The keywords used to tag the videos could be names of the ART medicines

Side effects and OIs (Opportunistic Infections)

This set of videos could be selected by a doctor for a PLHA when he faces a particular side effect or an Opportunistic Infection. The appropriate video could be posted and the PLHA could view information that would help him cope up with the current side effect or the opportunistic infection.

The FAQ Database

After interacting with PLHAs in the clinical space it was evident that the PLHAs have a lot of doubts and queries which remain unanswered. All these doubts found during the interactions with the PLHAs were amalgamated in a space known as the FAQ database.

HIV related FAQs

- MYTHS & MISCONCEPTIONS:

I came to know that a person got HIV after having Pani Puri from the hands of an HIV patient. Can this be true?

I play cricket with HIV positive kids. At times they use saliva to shine the ball. Is there a risk if I use the same ball?

A drop of blood from an HIV positive person fell on my hand / eyes / mouth. What are the chances that someone gets infected with HIV from few drops of blood on his hand?

HIV and AIDS are the same things. Is it true?

Holding hands, kissing, mosquito bites, sharing same room or using the same toilet can spread AIDS

Is HIV immediately fatal?

Is HIV a result of some miraculous curses?

Old people are not affected by HIV/AIDS. Is it true?

- CARE & PRECAUTION:

My spouse has been detected HIV positive. What precaution should I take to not get infected?

No condom is required for oral sex. Is it true?

Both I and my spouses are affected- so is there a need to wear a condom?

How can we find out that the blood that we get from the blood bank is not HIV infected? Is there a chance that the test on the blood is -ve, but I still get infected? (So then what else can I do? What is the window period of the HIV virus?)

I have diabetes and I am also HIV positive? What special care should I take?

Where am I on the CD4 chart now? How often should I check my status?

Why should I do viral load at all, if CD4 count is so cheap / free?

- TESTING for HIV & DISCLOSURE:

I feel perfectly healthy. Is there a need for me to take a HIV test? Where can I get myself tested?

I took a test and was found negative / positive? Do I need to take the test again?

In a test, I was found to be HIV positive. But I feel perfectly healthy. Why should I care?

I was detected HIV positive. Should I disclose to my family?

I was detected HIV positive. Should I get my spouse tested for HIV? Should I get anyone else in the family tested? Is it urgent?

My HIV status was discovered this month. I have a 14 year old daughter. Should I test her for HIV also? After what age children need not be tested for HIV?

Should I tell my general physician about my status? He might tell people in my family / society. In what situations I must disclose to the doctor?

Is it important for me to maintain my records? It is very difficult for me as my parents don't know about my status and I don't want to tell them.

- MTCT (Mother to Child Transmission)

We are a positive couple. Recently my wife delivered a baby. How can we confirm that our baby is not positive?

I am a HIV positive mother. Can HIV virus be transmitted through breast feeding?

ART/Treatment related FAQs

What is the treatment for HIV? Once HIV positive, can I ever become negative?

I got a recommendation from a friend about an Ayurvedic treatment which claims to cure HIV. Can it be true? Should I go there? Can alternative medicine control / cure HIV?

I met with an accident and may have been infected with blood from an HIV positive person. What treatment should I take?

What is ART? How is it different from other medications?

When can I start on my ART? Why not now?

I have heard of many lines of treatment in ART. What is the difference between first line, 2nd line etc. ? I have heard that 2nd line is better than first line ART. Is it true?

Are there any side effects of ART? What might happen if I can't tolerate the side effects of ART?

How do I remember to take my pills? (Family support, alarm in a phone, Google calendar)

Why timely adherence is important to new comers only?

My ART pill fell down from the pocket, and I was locked out of my room. I was 1 hour late in taking my ART tablet. Can I take it at that time? What is the maximum delay permissible? Should I delay my next dose as well?

After taking my ART pill I vomited in 5 minutes. Should I take the pill again?

Are all ART medicines same? Can I exchange my medication with my spouse if we have the same ART tablets?

The pills I got last time were of a different colour / shape than this time. Does this mean that my medicine is different now?

I have been on ART for 6 months. My CD4 is increased. Why can't I now stop taking ART?

I have been taking ART for 6 months from a private clinic. Now I can't afford it any more. What should I do?

Can I have alcohol once in a while? Will it affect my ART regimen? Does alcohol reduce the effect of ART? In case I have some alcohol, should I skip the ART tablet for that evening?

I am having my menses. Should I temporarily stop taking ART?

Due to ART, at times I can't walk because of tingling numbness. What should I do?

Nutrition and Lifestyle

I am a vegetarian. Should I start eating non-vegetarian food?

I am a non-vegetarian. Should I stop eating non-vegetarian food?

I am diabetic, what care should I take for nutrition?

My job involves lot of travelling and most of the time I don't get proper food. What should be the basic food that I should have before having ART?

Final Design – Networking

System design for Networking

The system consists of a clinical radio which serves the major purpose of networking which is flow of experiences and information amongst peer PLHAs.

The radio acts an effective means of networking where PLHAs can share their thoughts and experiences by broadcasting them through the radio frequency without the fear of disclosure of identity.

Requirements of a Clinical Radio Station

Bandwidth frequency to air the radio channel – e.g. 101.4 FM

Trained Radio Jockey – The radio jockeys of the clinical radio station could be a set of trained counsellors who have knowledge about the HIV disease and could address the conversations with the PLHAs on the radio channel.

FM enabled mobile handsets for PLHA – The PLHAs can tune in to the clinical radio using their existing mobile handsets enabled with FM radio

Advantages of networking through Radio

Maintains Confidentiality – The medium of radio being audio, the identity of the PLHA can be protected. Thus networking with other PLHA is possible without the disclosure of one's HIV status.

Reduces fear of Technology - Radio being a familiar medium , PLHAs are comfortable using the technology with the fear of using it. Thus the efforts required to train the PLHA to use the technology are reduced giving rise to better adjustments and more usage in the community

Acceptance – Radio forms a very personal medium where the PLHA has choices to switch information based on his likes and dislikes. Thus the PLHA controls the technology rather than the technology controlling the PLHA. This increases the acceptance of radio on a wider scale amongst the PLHAs.

Personalization - High degree of personalization of information is available using the radio as it includes the human intervention in the form of the radio jockey. The presence of a human in the conversation makes it more personalized and contextualized developing bonds and connectivity with the system

Clinical Radio

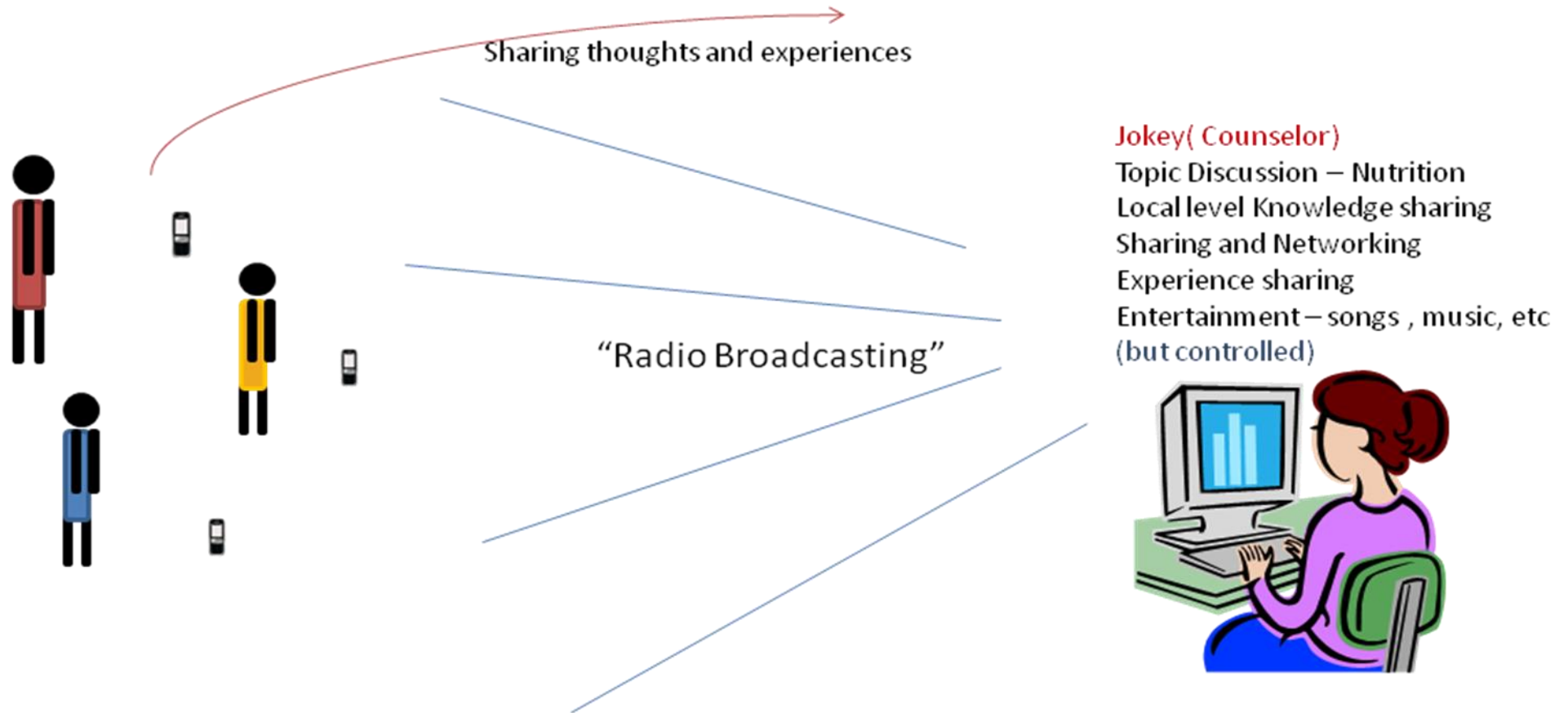


Figure 10

Activities at the Radio Station

1. Topic Discussion

A new topic related to HIV could be discussed everyday by the radio jockey like nutrition, opportunistic infections, HIV in society etc which could be decided by the clinical staff (doctors and counsellors). Patients in the clinic could contribute their thoughts and ideas related to the discussed topic and thus share and gain information. With radio as a medium to transfer information, confidentiality of the patient can be maintained.

2. Problem Solving

Patients in the clinic have issues related to different domains like personal, health, society, finance etc. The radio can act as a platform where patients can vent out their feelings to their fellow patients in the clinic and seek solutions from them. Patients could respond to each other's problems based on their knowledge, self experience and capacity. Solutions coming from peers are considered to be more personal as they are based on similar life experiences.

3. Games and Quizzes

The radio jockey could initiate quizzes and competitive games related to a particular topic and trigger the curiosity of the patients. Patients in the clinic could participate in the game and a winner could be felicitated with a reward.

4. Experience Sharing

Patients can share their life experiences and thus act as a source of motivation for others in the clinic. These experiences could range from small daily life activities like food habits, exercise habits etc to complex ones like dealing with stigma, financial savings, planning the future etc. People can relate to these experiences and find solutions for their own issues.

5. Radio Blogs

PLHAs can create audio blogs which could be aired on a separate frequency. PLHAs could load the blogs with their everyday experiences and their peers could post comments and feedbacks on their topics of interest.

6. Help line

Patients once outside the clinical space could contact a particular helpline number that connects them to the radio jockey and thus can get their doubts cleared. Thus information can be available once outside the clinical space also. The radio could also act as a platform to provide contact details for other specific help lines or NGOs working in a particular domain.

7. Entertainment

Such overwhelming information provided by all sources in the clinic can become an overdose to an HIV patient. Thus entertainment in parts of music, songs, bhajans etc could be a part of the radio where the patient is not flooded with information continuously but in instalments for an easy grasp.

Abbreviations

AIDS	Acquired Immuno Deficiency Syndrome	PLV	Plasma Viral Load
ART	Antiretroviral therapy	PMTCT	Prevention of mother-to-child transmission (of HIV)
ARV	Antiretroviral (drug)	PPTCT	Prevention of parent-to-child transmission (of HIV)
ADR	Adverse Drug Reaction	RFID	Radio Frequency Identification
CD4	T-lymphocyte CD4+	SE	Side Effects
FAQ	Frequently Asked Questions	STI	Sexually transmitted infection
HIV	Human immunodeficiency virus	TB	Tuberculosis
ICTC	Integrated Counselling and Testing Centre	WHO	World Health Organization
IDU	Injecting drug user		
IEC	Information, education and communication		
MSM	Men who have sex with men		
MTCT	Mother to child Transmission		
NACO	National Aids Control Organization		
NGO	Nongovernmental organization		
OI	Opportunistic infection		
PID	Patient identification digit		
PLHA	People living with HIV/AIDS		

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