Rational use of ARV – How to guarantee the adherence to the treatments in Africa

Windhoek, 22 November 2005

Albert Figueras

Fundació Institut Català de Farmacologia

CENTRO COLABORADOR DE LA OMS PARA LA INVESTIGACIÓN Y LA FORMACIÓN EN FARMACOEPIDEMIOLOGÍA
WHO COLLABORATING CENTRE FOR RESEARCH & TRAINING IN PHARMACOEPIDEMIOLOGY

Living in South Africa, I had grown used to the images.

I'd seen on TV –emaciated black people, dying alone of Aids in dark, forgotten huts in the countryside, shivering under threadbare blankets with huge hollow eyes.

I knew the horrifying statistics. Four to five million South African were HIV-positive. Eight hundred people were dying of Aids each day. I knew all this as well as anyone else who followed the news.

Only that now I was part of that statistic.

Ten o’clock. I can upright now. Time for morning’s ARV. I’m very good with these. In the past eight months, I’ve never missed a dose.

The trick is, you gotta take them at the same time every day. Otherwise you die.

I really should eat before I take them, so I force down some fruit. Three big orange pills first –the plastic rugby ball ones.

Then the white oval one –hate the oval, it always sticks.

Now the other lot –the yellow with its weird vanilla flavour. Uggh, the blues.

The green oval one.

Then the five little blue and yellows –they are the easiest, so I leave them till last one.

Done. I deserve another cigarette. Better lie down again.

knowledge about
treatment

Ten thirty. I switch on my computer. I have been writing for half an hour now, spewing out these thoughts as fast as I can type, sipping on ginger beer to hold back the nausea. But it isn’t working. Better to lie down again.

Today, I begin my first course on Nevirapine –one of the earliest anti-retrovirals.

I also start taking Triptelene, an anti-depressant that is known to bring some relief to neuropathy sufferers.

I’ve been warned that there might be side-effects, as my body rejects or accepts these drugs.

Within a couple of days I feel quite awful. Nauseous and unable to eat, I lie withering on my bed for days.

knowledge about
treatment

knowledge of side effects

The tests are positive.

Elsie must start a course of medication, but she doesn’t want to.

There’s nothing wrong with her, she says.

Privately, the doctor tells Mom he’s sure Elsie has Aids and should be tested immediately. But Elsie refuses. She also refuses to take the TB medicine.

knowledge about
treatment

knowledge of side effects

denial / concealing

Later that night, Dr. D comes over and takes some blood. The following day, I learn that the cocktail is having a dangerous effect on my liver and that we'll have to change it.

My parents write to someone they know in London who works in HIV. He recommends a combination of two new drugs.

knowledge about
treatment

knowledge of side effects

denial / concealing

information

And there were other obstacles. Our country's president had elicited worldwide controversy when he seemed to suggest that he did not believe that HIV caused Aids. He had stumbled across this information on the Internet, apparently, and it was contrary to any medical views. (...)

The Health Minister was not much help. According to her, nutrition was the key to fighting the virus. She prescribed various herbal cures (...).

knowledge about
treatment

knowledge of side effects

denial / concealing

TV, newspapers, friends

information

I resolved to start getting well.

Even if this was beyond my control physically, I could still play some part in my psychological recovery.

I tried to write, but came up with very little. I felt very lost.

knowledge/acceptance of disease

knowledge about treatment

knowledge of side effects

denial / concealing

TV, newspapers, friends

information

Adherence to the drugs is critical. They must be taken at the same time every say.

This is so strict that if you travel across time zones, you will need to wake up at some ungodly hour to maintain the schedule.

If enough doses are skipped, you can build up a resistance to the drugs and they'll never work again. Eventually new drug-resistant strains of the virus are created and some people become untreatable.

knowledge/acceptance of disease

knowledge of side effects

TV, newspapers, friends

ADHERENCE

knowledge of treatment

denial / concealing

information

Seven fifteen. Time for my morphine pills. The liquid doesn’t work for long. If I take three pills now, I’m usually all right until 4 p.m. (...) The government says you can’t take more than two of these per day, but the government ain’t got nerve damage, I guess.

doubts

moods

+

pain

opportunistic infections

malaise

...

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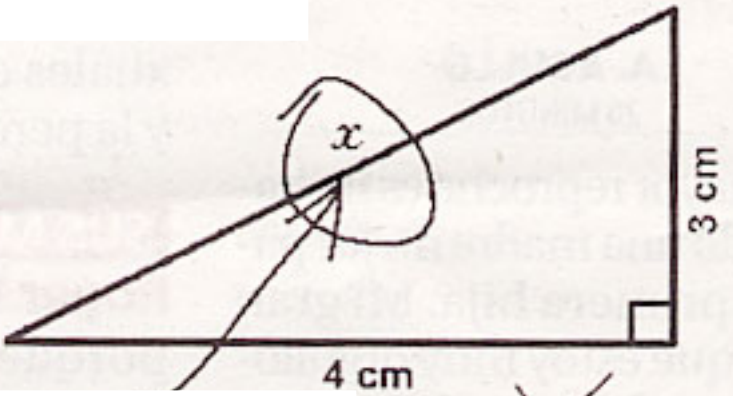
3. Find ‘x’



It’s here

Suboptimal treatment adherence has been associated with:

- virologic
- immunologic
- clinical failure

“In order to achieve an undetectable viral load and prevent the development of resistance, a person on ARV needs to take at least 95% of the prescribed doses on time.”

(Increasing evidence that drug resistance is highest among those taking 70-80% of regimens)

Study / monitoring of adherence

The challenge to understand adherence as a

BIOLOGICAL

and

SOCIAL PROCESS

that changes with time,

and framed within an analysis of access to health care and medications.

Biosocial variables that play a role on adherence to ARV

- Socioeconomic factors
- Health care system
- Social capital
- Cultural model of health and disease
- Personal characteristics
- Psychological factors
- Clinical factors
- ARV regimen

Castro A. PLoS 2005;2:e338

Socioeconomic factors

- poverty and inequality
- war, political violence
- cost of:
    - medications
    - CD4+ counts, viral load
    - transportation
    - changes in lifestyle
    - ...

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Health care system

- health-care infrastructure
- drug stock shortages
- financing mechanisms
- quality of relationship with health-care providers

Social capital

- networks of social support
- social status, homelessness, incarceration

Castro A. PLoS 2005;2:e338

Cultural models of health and disease

- on etiology and transmission
- on health-care providers and healers
- on cure
- on efficacy and toxicity of drugs
- on sick role

Castro A. PLoS 2005;2:e338

Personal characteristics

- age
- sex and gender
- ethnic group
- education
- occupation
- household composition
- substance abuse
- physical disabilities

Castro A. PLoS 2005;2:e338

Psychological factors

- self-esteem and motivation
- mental health conditions

Clinical factors

- immunological or clinical stage
- occurrence and severity of opprotunistic
- side effects
- symptomatology at onset of treatment
- effects of pregnancy or lactation

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ARV regimen

- number of drug regimes per day
- number of pills per regimen
- therapeutic class composition of drug regimen

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How can we improve adherence? (1)

- “Adherence” is a problem related to drug prescription and drug utilization

- HIV/Aids is a chronic disease

- Psychology and knowledge play important roles

- Related to the degree of complexity (pills, schedule)

How can we improve adherence? (2)

It is essential:

- To know the REAL situation (not only to have a guess)
- Local knowledge
- Enough time to explain carefully
- Coaching strategies (family, caregivers, afected groups)

Simple studies to know the reality

Example of adherence scale (Morisky)

1.- ‘Do you ever forget to take your medicine?’

2.- ‘Are you always careful about taking your medicine?’

3.- ‘When you feel better, do you sometimes stop taking your medicine?”

4.- ‘Sometimes if you feel worse when you take the medicine, do you stop taking it?’

Communication skills

- clear message (for users / for health professionals)

- language divide (information / people)

15 October 2003

But money was not the only thing that was saving my life. With my body so weak, I was in desperate need of care and support (...). From the moment I became ill, my parents were the most wonderful caregivers.

Adam Levin. ‘AIDSAFARI’