

**International Seminar on  
SOCIO-ECONOMIC AND MENTAL HEALTH BURDENS  
OF HIV/AIDS IN DEVELOPING COUNTRIES**

*21 – 22 November 2011*

*Palace of the Golden Horses, Kuala Lumpur, Malaysia*

**Session 3: Care Delivery and Response from the Frontline**

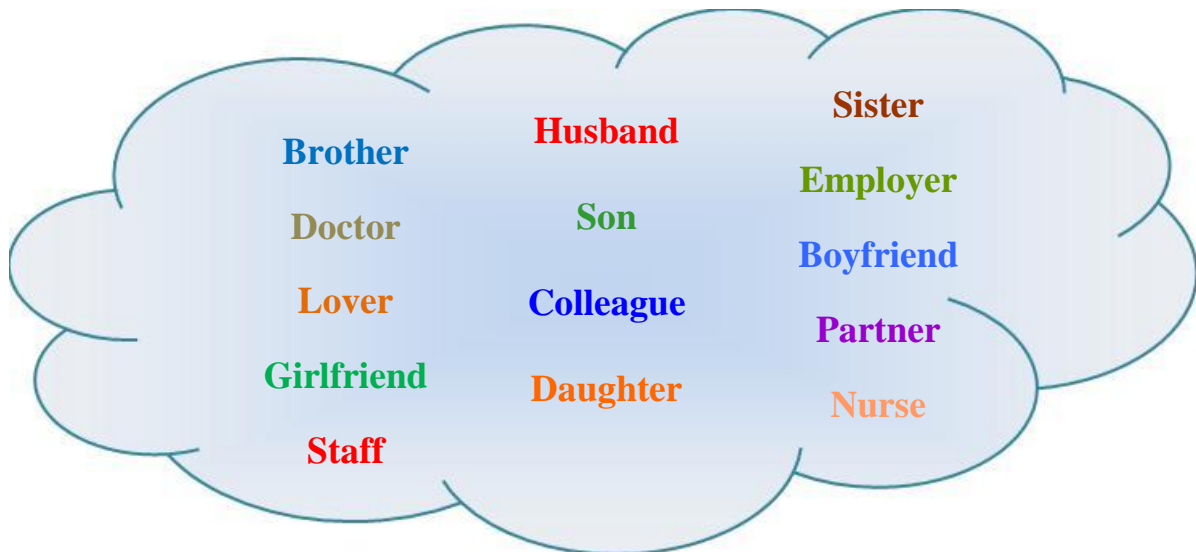
**Session chair: Mr. Azrul Mohd Khalib (UNTG)**

**PLENARY SPEECH**

**Mr. Andrew Tan** (*President Malaysian Positive Network: Myplus  
Kuala Lumpur AIDS Support Services Society: KLASS*)

**Counseling for Newly Diagnosed HIV Patients in Malaysia:  
Challenges and Best Practices**

**Who are PLHIV?**



**We are**

- People who come from all walks of life
  - The mother sending her children to school
  - The hawker selling chicken at the Pasar Tani
  - The quiet computer programmer at your office
  - The smartly-dressed executive in the next car
  - The grandmother sitting beside you on the bus
  - The much loved teacher at school

- We come from all sectors of society
  - From fishermen to grand fathers
  - From drug users to transgenders
  - From straight men to men who have sex with men
- We come from different levels of education
  - From the illiterate to the PhD holder
- We live in the small kampongs in remote rural areas and also in the largest cities in the country
- We are people who have a chance to live due to the free treatment provided by the government
- People who work, pay taxes & contribute to the economy.

# WE ARE YOU!

## Challenges of PLHIV

- Diagnosis
- Post diagnosis
- Follow up
- Self limitation
- Pre HAART
- Starting treatment
- Responding to treatment
- Rebuilding self-image
- The future

### Post diagnosis

- DENIAL / ANGER / LONELINESS / DEPRESSION
- What it means to be HIV+
- Understanding the virus
- Realizing that it's not the end
- ACCEPTANCE of the diagnosis
- Disclosure
  - Do I tell my wife/partner? How do I tell?*
- Questions, question, question
  - When will I die? How long do I have? Why me? Who did I get it from?*

### Follow up

- Importance of follow-up monitoring
- Nutrition
- Exercise
- Understanding blood tests

- Managing finances
- Reorganizing workload
- What is CD4? What is Viral Load?

### Self limitation

- What can I do? What can't I do?
- Should I quit my job?
- Can I still get promoted?
- Can I look for a new job?
- Need to reorganize workload
- Mind → Physical → Economic
- Managing stress
- Managing OIs

### Pre HAART

- Preparing to start treatment
- Fear of starting treatment
- Treatment literacy
- Treatment comprehension
- Discussing with the Dr
- Asking more questions

More knowledge = More understanding = Less fear = Less stress

### Starting treatment

- Understanding Adherence
- Understanding compliance
- What are the medicines doing in my body?
- Trusting the Dr.

### Responding to treatment

- Understanding the side effects
  - Lipodystrophy
  - Lipoatrophy
  - Increased cholesterol level
  - Liver functions
  - Skin problem (eczema psoriasis)
- Managing the side effects
- Determination to continue meds
- Feedback and discussion with Dr.

### Rebuilding self-image

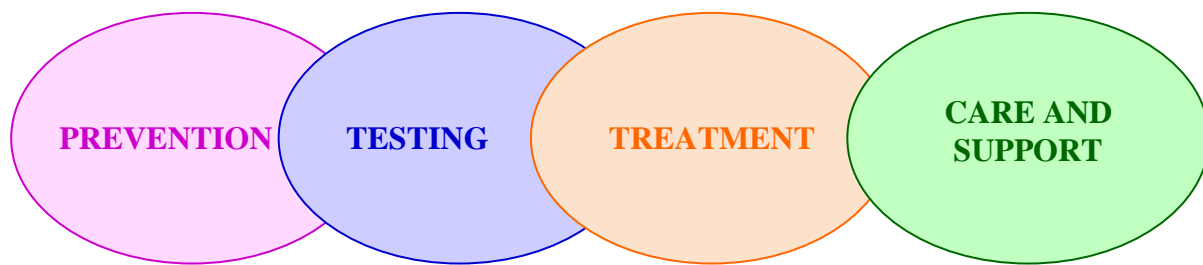
- Moving forward
- I am alive!

- Seeing the medicines effect on CD4 and Viral Load

### The future

- Married and their spouse / Unmarried and their partners
- Do I still have the right to be loved?
- Looking for a life partner
- Positive Health, Dignity & Prevention
- Do I have to use a condom every time?
- How do I negotiate to use a condom?
- How do I reveal my status
- When do I reveal my status
  - When we first meet? Before? During? After?*
- Will they still be interested?

### Continuum of care



### The essential

Addressing individual / psychological barriers:

- Community agencies
  - Address barriers such as self-stigma, lack of self-esteem, alcohol / drug use
  - Through drop-in centres, peer counseling and self-help support groups
- Government
  - Advocate for providing client-centered counseling (in every government treatment centre) and addressing individual/psychological level barriers faced by PLHIV including all marginalized groups (IDU / MSM / TG)

### Counseling

## Why do we need it?

### WHAT

- Provide accurate information
- Clarify facts
- Dispel myths
- Encourage acceptance
- Source of emotional strength

- Assist in psychological stability
- Ensure moral support
- Reinforce adherence and compliance

#### WHEN

- Counseling must be provided soonest possible after the patient is informed of the HIV positive diagnosis
- Counseling must be provided **BEFORE** the patient leaves the testing centre
- The initial counseling session must be tailored to the needs of the individual

#### WHERE

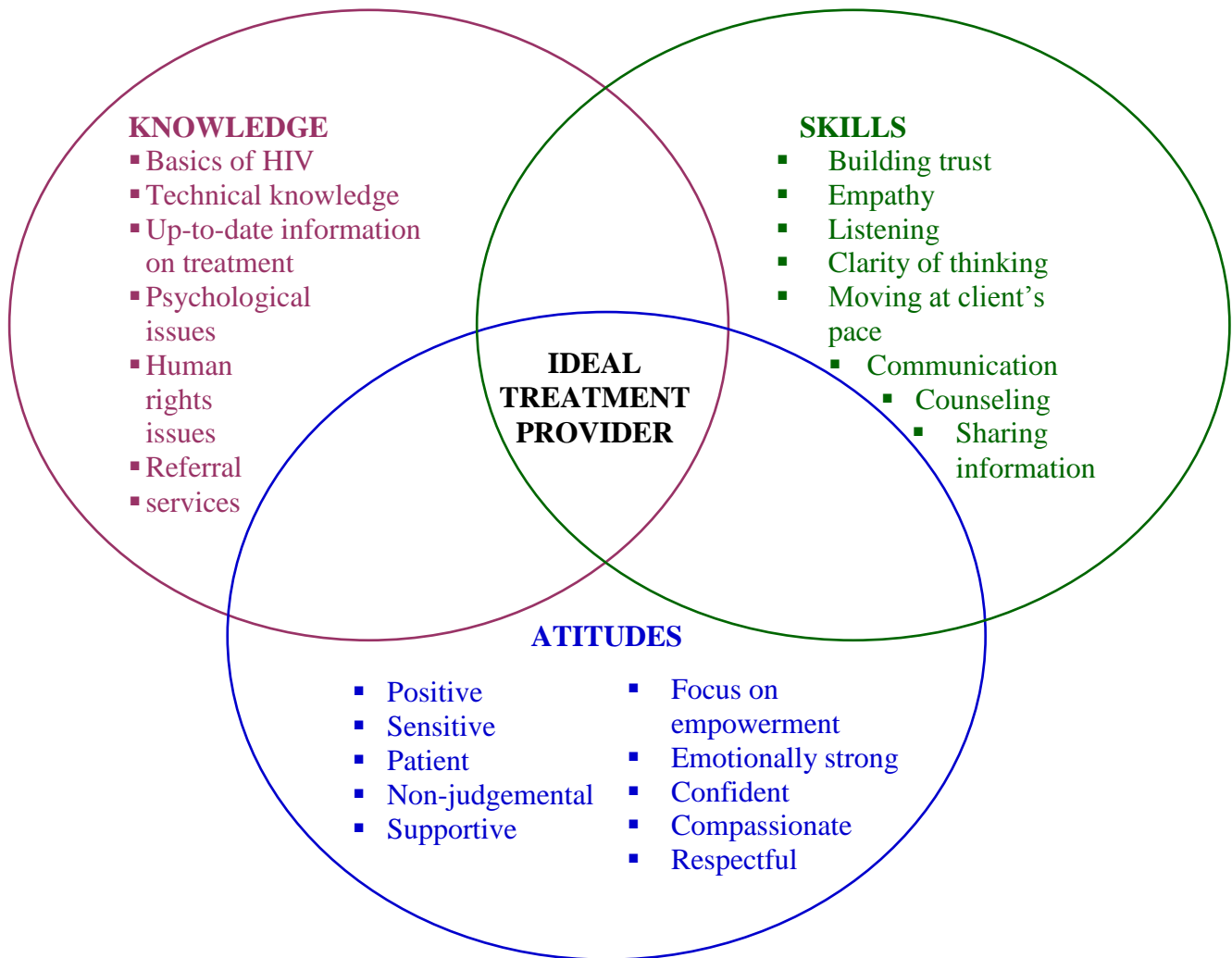
- HIV screening venue:
  - VCT centres
  - All private labs
  - Clinics
  - Hospitals
- As long as we accept the responsibility to provide testing services, we **MUST** be prepared to follow it up with counseling services

#### WHY

- The patient must be provided with:
  - Sufficient counseling
  - Referral to treatment centre
  - Helpline contact number
  - Information on available support service
- We must ensure that patients are aware of:
  - Availability of treatment
  - NGO support groups
- Failure to provide counseling **IS NOT** an option

#### WHO

- PLHIV
  - Stable emotionally and medically
  - Well trained with skills and knowledge
  - Community-focused
  - Understands their own limitations



### Challenges

- Identifying potential peers
- Providing training
- Selecting a location that is convenient
- Ensure privacy and confidentiality
- Presenting a strong case to the key stakeholders to encourage acceptance
- Securing funding to ensure sustainability

### Hospital peer support programme

HPPS is currently being provided by many Partner Organisations of the Malaysian AIDS Council.

- CAKNA, Terengganu
- CASP, Penang
- ILZ, Johor
- KASIH, Sabah

- KLASS, KL
- MTAAG, KL

### Why does it work?

- Close collaboration between doctors, nurses, counselors and volunteers
- Acceptance by the hospital authorities
- Availability on clinic days
- Linkages with NGOs with PLHIV Support Groups
- Referrals to:
  - Shelters / homes
  - Palliative care services

### P2P Growth & Healing programme

- KLASS pilot tested 4 different approach in Peer-to-Peer Support in July & August 2011.
  - Small group of 8 – 10 persons
  - Similar background
  - Created a facilitated 8 week journey which was experienced together
  - More manageable compared with a larger support group
  - Develop friendship
  - Flexible & portable

### P2P discussion topics

Group grows and heals together by facilitated discussions on:

- Diagnosis
- Changes experiences
- Effects
- Impacts
- Disclosure
- Side effects
- Forgiveness
- Stress

### P2P created

Opportunities for

- Learning
- Understanding
- Sharing
- Growth
- Healing
- Strengthening
- Empowerment
- Leading

These are the people who can change the future.

### Considerations

- Understand your patients

- Which communities do they represent
- What are their unique needs
- Ensure community-specific services are available
  - Addressing needs of marginalized peoples
  - Providing appropriate information
- Providing the right information at health status
  - Awareness of the patient's health status
  - Just diagnosed? / OIs? / starting treatment? / managing side effects?

## If you do it well

### Benefits for HCPs

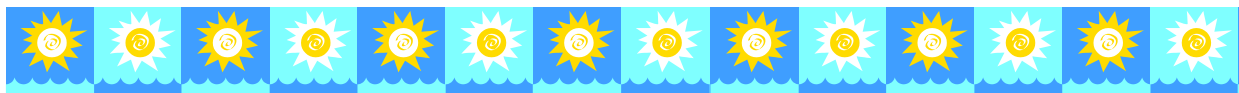
- Spend less time on counseling
- Focus more on management of OIs
- Focus more on treatment
- Patients are more prepared to start HAART
- Lessens the amount of questions from patients
- Patients more well adjusted
- Shortens individual treatment time
- Increases turn around time in the clinic

### Benefits for PLHIV

- Current timely information
- Stronger long term support
- More stable psychologically
- Easier to be adherent & compliant
- Back to a sense of normalcy
- Back to life
- BACK TO LIVING (with HIV)

### Benefits for counselor

- Clients will appreciate the support
- Some may volunteer to help others
- Trained to run their own groups
- Formed into teams based on:
  - Language
  - Background
  - Gender
  - Geography





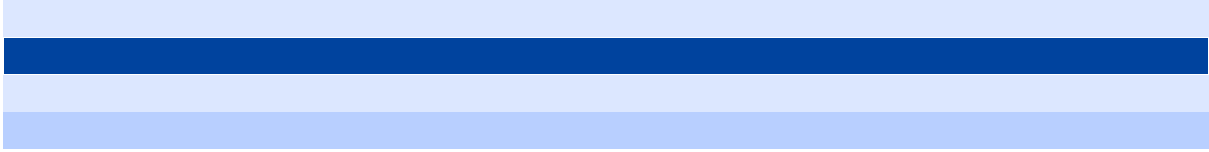
**Outline**

**Follow up**

**Table 1:**


**Table 3:**


**Table 5:**

# Yes We Can!!!

