'Mood swings and layabouts'
Take Home Messages!

- We have all been teenagers, so we know they show their feelings in different ways to adults – it doesn’t make them mad, bad or dangerous!
- Chronic illnesses including HIV increases vulnerability and interferes with adapting to other challenges of adolescence
- Prevention and reducing stigma are still the main messages!
Why is there a need to discuss adolescents at this time?

- Greatest increase in HIV and std infections is in young people (interrupted)

- Children with vertically and childhood acquired HIV infection are now growing up and getting older (managing?)

- Millions of children and adolescents are or have been carers of parents and/or siblings with HIV (neglected/marginalised)

- There are millions of young people who are not yet HIV infected but.... (future legacy)
Managing vs. Preventing

- One third of all HIV positive people in South Africa were infected during their school years.
- A further third of young people acquired HIV infection within two years of leaving school.

What steps are needed to stop more young people getting infected?

What can we all do to reduce the stigma and ignorance about HIV?
Both common and unique issues

Understand normal adolescence
Identify challenges for more vulnerable groups
Plan interventions and services
Definitions in adolescence
“to grow to maturity”

- The transitional stage of growth and development between childhood and adulthood (2 transitions).
- Egocentric and self-focused time—one of the most sensitive and vulnerable times of life cycle.
- Cultural and legal variation exists as to which ages are considered childhood or adolescence or adult e.g. age to vote, age to marry, consent, transfer to adult services, etc.

Adolescence
- WHO: the period of life between the ages of 10 and 20 years.
- UK: 12 to 20 years.
- South Africa?
What is known about transition process?

- Takes time
- Not linear but multidimensional
- Sub stages – early, middle and late
- Gender differences (boys mature more slowly)
- Individual differences (constitutional and experiential)
- Cultural influences
  
  e.g. sometimes children perform work-like or adult tasks from a young age, few years in ‘education’ Does this make transition from child to adulthood less challenging? (Mead 1975)

Mabey & Sorenson 95, Adams and Marshall 96
MAIN Tasks of adolescence

- Establish personal identity both outwardly and internally (the SELF)
- Individuation/autonomy/independence
What society expects adolescents to achieve by adulthood!

- Social, emotional and financial independence including selecting and preparing for an occupation
- Accepting one’s physique and sexual role – and be knowledgeable about these
- Negotiating relationships with peers of both sexes
- Conform to surrounding community norms
- Socially responsible behaviours
- Establishment of own personal value system – spiritual, attitudes etc
- Cognitive skills to plan ahead
- A partner, a career, a future
Adolescence - don’t forget the family!

By adulthood: Sure of who you are & how you are connected to others
Understanding changes during Adolescence

Swings and roundabouts
Adaptation & consequences
What increases vulnerability
‘Swings’
Continually having to adjust to challenges

Ups and downs/ highs and lows
Irregular rhythms - changes
Pushes and pulls - who’s in control?
Uncertainty
Stop, start, timing
Alone and together
Common Presentations – young adolescence

- Emotional reactivity
- Problems in control and regulating – minor incidents producing exaggerated responses
- Decreased ability to tolerate
- AMBIVALENCE
- Egocentric
- Attention seeking
- High Awareness of ‘Shame’
- Changed personality
- Learning blips, disaffection
- Challenge established norms in family and community (conflicts)
- More susceptible to influence of others
ROUNDABOUTS:

Decisions, demands and consequences

Where, when to get on and off
Can I change my mind?
Where is road ahead going?
Recognising signs for ‘adulthood’ exit?
Influences and obstacles
Who’s driving?
What went before, what comes afterwards

Adults want a tunnel or underpass ‘hidden away til adolescent emerges the other side’
But its more like a flyover – out there on show!!
You want me to decide?

Who do I want to be?  
I want to be the same as my friends.
I want to but I'm not sure..

What do I want?  
I want to be the same as my friends.
I want to be the same as my friends.
It's my life - you can't tell me what to do.

It's not fair!
It's not fair!

Overwhelmed, overloaded
Inner confusion

No-one understands

It's my Right!

Can't be bothered

Grown ups can't help

Shan't!
Biological Changes during Adolescence

**HORMONAL & PHYSIOLOGICAL**

**PHYSICAL**

- GROWTH
- BRAIN & CNS
- PUBERTY, SEXUAL
Developmental consequences of biological changes

- Physical changes – appearance, size, body image
- Sexuality
- Psychological
  - cognitive
  - emotional and behavioural
- Social – new relationships
- Moral and Spiritual ideas
Brain changes

- Significant changes pre and post puberty
  - Pre: slow down in brain function 11-12y as gets ready for new organisation
  - Post: A. increased synaptic proliferation in frontal lobe (increase in white matter)
  - B. synaptic pruning and strengthening (more myelination + faster transmission of messages)

Frontal lobe controls executive functions such as impulse control, doing 2 things at once, inhibiting and selecting actions.

Ventral striatum “reward centre” more active in adolescence.

Areas related to emotion and its connections still maturing.

No wonder adolescents need more sleep!
Psychological consequences

Adolescent data shows increases in:
- Depression (and how it presents) hopelessness &/or anger low self esteem
- Suicidal ideation and self harm (girls > boys)
- Anxiety
- Eating disorders, self esteem
- Violence, conduct and antisocial problems (boys > girls)
- Risk taking behaviours
(First presentations Psychiatric disorders – psychosis, OCD)

Meltzer et al 2000

Overall 10-12% of adolescents have psychological problems serious enough to warrant psych interventions.

Increased problems:
- Social class \(\uparrow\) never worked
- Looked after children (~50%)
- Chronic illness (15-16%)
What enhances coping through adolescence?

Communication
Quality relationships
Partnerships & Participation
Emotional as well as learning support
Peer contacts (later)
Talking to Teens

I wouldn't worry about his communication skills... Grunting is quite normal at his age.
Effective communication skills

1

Active listening:

- Empathetic approach (but don’t have to act like them!)
- Move focus onto them
- Listen as well as tell
- Seeking clarification – knowing when to use open and closed questions
- Relationship and believing
Wearing masks

Is it all an Act?

I act stupid
I act nice
What ya mean act?
I'm cool
I act confused
Sometimes I act tough...
Sometimes I act like I knew it already

I act MLEEP
Effective Communication Skills

2

Non judgemental approach:

- Body language and facial expressions
- Tone of voice
- Awareness of language – not too much/patronising
- Not just problem focussed – try neutral or positive framing
- Non authoritative approach
Clinicians and Young People

“Clinicians who discuss with their adolescent patients the way in which illness affects social interaction may be communicating more effectively than practitioners who focus solely on signs and symptoms of physical disease”

Millstein, Adler & Irwin 1981Ped Vol 68
Concepts of illness in young adolescents
Brain and cognitive changes: suggest important learning interventions

- Secondary and tertiary education important for new learning
- Maturing of emotional and behavioural responses as executive function area enhanced – returning to learning
- Need information and knowledge reviewed, repeated and updated and made relevant to them e.g. HIV and sex education messages
Participation: HARTS Ladder (1997)

8. Child initiated, shared decisions with adults
7. Child-initiated and directed
6. Adult initiated, shared decisions with child
5. Consulted and informed
4. Assigned but informed
3. Tokenism
2. Decoration
1. Manipulation

Aim: to get higher than 5
What can make adaptation to changes more difficult?

STRESSORS

- Lack of significant relationship or attachment
- Previous changes, losses, deaths
- Family – strife, illness
- Abuse, rape, exploitation, trauma, adversity
- Lack of opportunity and normality
- Overprotection, repression
- Secrets, confusion, exclusion
- Inappropriate role models
- Chronic illness
Chronic Illness: extra challenges on adolescents

- Effects on appearance and functioning
- Overprotection and identity issues
- Managing demanding treatments, sustaining adherence
- Slightly higher levels of emotional and behavioural difficulties than non ill adolescents
- Who is appropriate peer group?
- Access to support and acceptance by ordinary peers may be affected
- ‘difference’
Forming an identity/ gaining independence

- Chronic illness or disability can cause a feeling of an imperfect/tainted identity
- Fear of future illness or disease progression can slow the process of forming an identity
- Fewer opportunities
- Fewer role models
- Which group do you belong to?
Adolescents: Living with HIV (added stressors)

- Managing ordinary changes during adolescence
- Living with a chronic illness and treatment demands!
- Coping with a sexually transmissible condition!!
- Dealing with stigma, secrecy and family impact!!!
Vertically infected adolescence

Differ from behaviourally infected:
- Less mature
- CNS & functional vulnerability (learning, behaviour, growth etc.)
- Reduced quality of life: Less energy, limitations to education
- Multiplex medical complications and treatment history
- Long term side effects of ARVs
- Less sexual experiences and knowledge

Differ from other chronic illnesses:
- Managing knowledge of HIV, who to share it with
- Increase loss and bereavements, attachments
- Carer changes?
- Family illness & shame

STIGMA + SECRETS
Children who have grown up with HIV: common difficulties

- No emotional breakdown after learning name of diagnosis
- 10-12% definite neurological signs
- Coping and adjustment problems (not psychiatric disorder)
- Attention deficit problems common in younger
- Executive functioning problems common in older
  - Poor memory, concentration, and learning, disorganised
- 40-50% require extra help with learning at school
- Adolescence want more help with wider disclosure
  - Who, when, how to tell
- Adherence a challenge
- Gaining independence, planning ahead
- Forming relationships

SMH family clinic. Melvin, Biggs & Krechevsky 08
What helps?

- Getting past naming
- Attend to help with wider disclosure
- Psychosocial approaches including new learning opportunities
- Group interventions
Building a knowledge TIMELINE
Conversations about health, getting past name early!!

6 to 11 years
Conversations about health and keeping well. Medicines as helpers

9 - 13 years
Open/confirming conversations about HIV: its effects on present and future. Sharing responsibility for medicines

13-17 (Adol) years
Sexual health, transmission routes, independence. Self management of medicines

Open talking about HIV as a health condition before secondary school
Balancing: Rights, Responsibilities, Protection
What does the evidence show?

- Children/ young people can cope
- Timing important
- Big concern is what to do after knowing the name – who to share it with – wider disclosure etc.
- More time to build understand before having to cope with transmission issues
- MORE support for parents/carers
Evidence of other useful psychosocial interventions

- **PROACTIVE**
  - A support partner
  - Sharing responsibility
  - Repeating messages
  - Recording success
  - Motivational not punitive
  - Learning support
  - Access to normal

- **Peer group- befriending, mentoring sharing ideas**

- **Support for CARERS**

<table>
<thead>
<tr>
<th>Young person</th>
<th>Clinic nurse /doctor</th>
<th>Significant other (Parent, partner, mentor etc)</th>
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<tbody>
<tr>
<td>I will........</td>
<td>We will.....</td>
<td>I will help by ........</td>
</tr>
<tr>
<td>How to achieve this</td>
<td></td>
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<tr>
<td>How to monitor</td>
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Some cases to illustrate

Managing adolescence with HIV
A Marginalised adolescent
At risk adolescent
DAVID aged 12 years

How to manage with loss and HIV

- Diagnosed last year with HIV whilst in hospital being treated for TB
- During this stay in hospital his mother died but David too unwell to attend the funeral
- David now lives with an uncle and aunt who were trained to help support taking ARV medicines. They do not want him to be told he has HIV. (think he will be too upset)
- David is poorly grown, has no pubertal signs.
- He attended school for a short while when younger but not lately. He is a long way behind and struggles with his memory
- At the clinic the nurses are concerned that he is very withdrawn and uncommunicative.

1. **What might be contributing to David’s poor communication?**
2. **What strategies might be helpful for David to help with medicine taking?**
3. **What might support grandma and uncle?**
4. **Who could help David?**
Beatrice aged 13 years
An adolescent or an adolescent at risk?

- Beatrice has lived with her grandma since she was a toddler.
- Her mother works in the nearby city. She rarely sees her dad.
- She was a happy and hard working girl with many friends until recently.
- Since the summer, when she went to stay with her mother she has changed; having temper outbursts or sullen and uncommunicative periods.
- She has also started to be less motivated to go to school and her teachers think she is not concentrating so well.
- Recently she became very upset during a health education class and ran out of school in distress.
- Her grandma does not know what to do and has asked the school for help?

Is this just adolescence?

Who would be someone that Beatrice might talk to?
Shakila aged 14 yrs

A marginalised adolescence

- S. is the oldest of 4 children. Her siblings are 9 years and twins aged 6 yrs. Both twins have HIV infection and are on ARV medicines.
- Up until a few months ago the children all lived with their grandma. Their mother had died a few years ago. Father’s whereabouts is unknown but the relationship between her parents had been quite violent.
- Grandma is now sick herself – she has angina and breathlessness.
- S. has had a little schooling when younger (where she achieved well). She can no longer attend as she has to look after her grandma and siblings (and there is no money).

1. What does Shakila need to be told about HIV in the family?
2. Should she be tested herself?
3. What might help support her?
Calvin aged 17 years
An adolescent at risk?

- Calvin lives with his mum in a reasonably affluent part of town.
- He’s doing well in school and hopes to go to college soon.
- He is popular with many friends. Their view of ‘HIV infection’ is that it happens to ‘others’ who are not careful or not educated.
- He had some sex and health education in school when younger.
- He’s had a couple of girlfriends and has been sexually active for a couple of years (now uses a condom, but not when younger)
- He has just heard one of his earlier girlfriend is in hospital and others are saying she has AIDS
- He is worried about whether he has ‘caught it’.

- ? Who should he talk about his fears
- ? where can he go for testing
- What strategies might have reduced the possibility of putting himself at risk of infection?
Behavourially Infected adolescents

An interrupted adolescence: a reduced future

- More intact – physically and cognitively
- But psychologically - extra difficulties
- Adjustment to living with chronic illness and transmissible one (other STI’s?)
- Knowledge of HIV lacking
- Testing – where? Access, confidentiality, contacts
- Services – paediatrics or adults?
Services - build on the strengths of adolescents

Upside: opportunities for
- Friends/Relationships
- Freedom
- Invincible and believe in success
- Creativity:
- Excitement and fun
- A love of life

Proactive not reactive
More accessible resources – - identify problems early
- refer on early
Partnerships
Back up expertise
Include young people
Delivered in places where young people are
Together we can can progress
Vertically infected: services need to change with the needs of the population.

1990: A life with AIDS

1990-2000: Growing up with a chronic condition

2009: Support for a meaningful future living with HIV

PREVENTION & getting rid of the stigma!!!
Thanks

To all my colleagues in London and in CHIVA/Africa
PHP group
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To you all for listening