Adherence and Disclosure

Challenges for Adolescents Living with HIV

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Key Principles

- Adherence and disclosure intrinsically linked
- Need to build a body of knowledge in the growing child – foundations for a healthy adolescence and adulthood
- Conversations with adolescents also need to be cognitively and developmentally appropriate

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Disclosure

Two key aspects of disclosure that affect adolescents with HIV:-

1. Learning their own diagnosis

2. Onward disclosure to family, friends, partners, employers etc

The Evidence

Positive outcomes of disclosure include:-

- promotion of trust (family and healthcare staff)
- improved access to support services
- better adherence
- improved family communication
- improved mental and physical health [1-7]

- however, other literature suggests negative outcomes of disclosure [8]

The Evidence

Our understanding has also changed:-

- Growth of child/youth rights movement
- Survival of HIV-infected children into adolescence and adulthood
- Need for long-term adherence to ART
- Cognitive development of children that demonstrates understand concepts such as ‘illness and ‘death’ [3, 9 – 11]

Disclosure Cont …

Disclosure presents particular challenges to health workers, including:-

not sure what to say
not sure how to say it
not sure what they already know
not sure what the right answers are
fear of upsetting adolescent
fear of upsetting caregivers/partners
fear of defaulting healthcare

Disclosure Cont …

The reality is that:-

- saying nothing is often worse than saying something badly
- we need to ascertain what is already known – this is often more than health workers think!
- build our own knowledge and skills
- by sharing knowledge we can improve confidence, knowledge and skills of adolescents
- retention in care is improved if clients understand why they are attending

When and How to Disclose

- In vertically infected children, disclosure should have occurred prior to adolescence!
- A process not an event?
- Avoid ‘disclosure of diagnosis’ – negative
- Prefer ‘discussing’ or ‘sharing’ HIV status
- ‘Confirmation of knowledge’ – elicits baseline knowledge

Disclosure Cont ….

- Health workers have a pivotal role in supporting families to disclose
- Not enough to tell them it is important that they do it – needs a partnership
- Have we made HIV ‘special’ again?
- Need to promote benefits of informing children and adolescents

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Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV-Infected Children in Uganda [12]

Bikaako-Kajura et al, online pub 22 June 2006, Springer Science + Business Media Inc.
http://link.springer.com/article/10.1007%2Fs10461-006-9141-3?LI=true

- In-depth interviews with 42 children taking ART +/- CTX
- Complete disclosure of HIV status and strong parental relationships were related to good adherence
- Structural factors including poverty and stigma were barriers to adherence even for children who had complete disclosure and a supportive relationship with a parent

Disclosure Type	**Missed doses**			
	Never	**Occasionally**	**Frequently**	**Total (%)**
Complete parental disclosure	8	4	-	12 (29)
Non-disclosure	3	8	3	14 (33)
Partial disclosure	1	5	10	16 (38)

Adherence

- Adherence in adolescents is more challenging than children and adults
- Adherence wanes over time
  - Week 48, only 27.3% of adolescents were virologically suppressed (SA)[13]
  - Week 48, 50% less likely to maintain adherence and 70% less likely to achieve virological suppression when compared to adults (SSA)[14]
  - Only 62% of adolescent respondents indicated adhering 95% of the time (UK national survey)[15]

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Adherence - Challenges

- Often highly treatment experienced
- Drug resistance
- Maintaining life long treatment
- Preserving future drug options

Increased drug resistance seen in paediatrics with 91% of virologically failing children having drug resistance (SA study) [14]

21% of adolescent patients in a London clinic already had dual class resistance[17]

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The Evidence

- Prospective studies in adults and children have demonstrated the risk of virological failure increased in proportion to the number of missed doses[16-20]
- Long term adherence for vertically infected adolescents is particularly challenging[21-23]
- Poor school attendance, alcohol or drug abuse, depression and advanced disease are correlated with non-adherence[23]
- Pill counts, pill trays, pharmacy checks and self-reporting of missed doses all useful strategies to assess adherence[17, 20-23]
- Cell phone reminders also successful intervention for adolescents on ART[24]

Adherence in Adolescents

- Increasing independence – self identity
- Peer pressure/preference
- Increasing autonomy and self-reliance
- Physiological and psychological growth and development
- Long term side effects – body image
- Transition to adult services
- Transition from adult-focused communications to the YP

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Interventions

- Assess adherence in a way that empowers the adolescent – non-critical (holistic)
- Ensure adolescents understand why they need to adhere
- Assist adolescents to fit ARV's into their lifestyle and not the other way round
- Privacy and confidentiality
- Provide youth-friendly services – one stop
- Support– peer and professional
- Novel technologies – Mxit (i.e. cell-life; HIV 360)
- Good communication

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Opportunities

- Adolescence is a time of opportunity and threat
- Know your population
- Improving knowledge of HIV/health and rationale of interventions should assist adherence
- Our role is crucial: open, non-judgmental attitude, welcoming environment, holistic care
- To interrupt ART? Research vs real world
- Peer support can be a powerful intervention – can also reduce burden on staff
- We can communicate without using the idioms!

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pozitude

www.pozitude.co.uk/apps

Phone Apps

To help you remember to take your medication we've developed a smart phone app. The idea behind it is that it will remind you to take your medication on the days, and at the time you need to take them. Then once you've taken them you can add them to a chart to keep track of when you've taken them.
We've even added a hospital appointments section so you can be reminded to go to the doctor or hospital.

To download the iPhone iDiary app click here
To download the Android iDiary app click here
To download the Blackberry iDiary app click here

While we've tried our best to make sure that everyone can access the apps, unfortunately due to the phone company limitations we can only supply the app to iPhones with an iOS 4.3 or greater and Blackberry OS 7 (you also need a SD card).
Once downloaded please leave your reviews if you like the app!

Conclusions

- Good communication a key component of successful disclosure (primary and onward)
- Also essential for adherence
- Knowledge empowers adolescents to make informed choices
- Establishing and maintaining supportive relationships with adolescents increases adherence, retention in services and improves long-term outcomes
- Holistic approach crucial (i.e. HIV, school/work, relationships and SRH)
- Wealth of resources available to assist

Conclusions

- Adolescents can be difficult, frustrating, challenging, demanding, unreasonable, unreliable …….
- They can also be accommodating, entertaining, supportive, giving, responsible ……
- Often the greatest barriers to working successfully with adolescents is our own fears and anxieties about the areas we need to address with them (most notably sexuality and sexual health)
- Communication underpins all interventions
- As providers, we need to ….

Say what we mean ….

… and mean what we say!

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Thank you for your attention

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Selected Resources

- Saranne Meyerfeld & Marnie Vuyovic. *Sexual and Reproductive Health for young HIV positive adolescents: The club concept in support groups.* Anova Health Institute 2011
- WHO 2010. *IMAI One-day Orientation on Adolescents Living with HIV: Participants Manual*
- WHO 2010. Adolescent Job Aid: *A handy desk reference tool for primary level health workers*
- Pathfinder International 2004. *Certification tool for youth friendly services*. Can be found at http://www.pathfind.org/Publications_RH_Resources_ASRH
- *Rapid Assessment Tool for Sexual & Reproductive Health and HIV Linkages: A Generic Guide*. Prepared and published by IPPF, UNFPA , WHO, UNAIDS, GNP+, ICW and Young Positives, 2009. Published in London, United Kingdom, September 2009
- www.chiva-africa.org Adolescent section with numerous free resources

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