Supporting adherence in adolescents and young adults living with HIV

Author: C Foster
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Introduction

Poorer adherence to medication is normal during adolescence (10-19 years) and young adulthood (20-24 years) and is one of a range of risk-taking behaviours common during a developmental stage that encompasses enormous cognitive, physical, sexual, social and emotional change.[1] For adolescents and young adults living with HIV (AYHIV), poor adherence to antiretroviral therapy (ART) confers two significant challenges: HIV associated morbidity/mortality and the additional burden of potential onward transmission to partners and to offspring.[1-4]

Some adolescents and young adults (AY) with perinatally acquired HIV will enter adolescence with acquired drug resistance mutations – a legacy of reduced ART options, unpalatable formulations and care giver dependence associated with early childhood and more complex ART regimens.[5] The subsequent period during transition from paediatric to adult care, if poorly managed, has been highlighted as an additionally vulnerable time for disengagement and poor adherence, and the impact of HIV related stigma on adherence cannot be underestimated.[6,7] AYHIV first diagnosed during adolescence may face particular challenges including adjustment to their diagnosis, and in the case of perinatally acquired HIV this age group often present late with advanced disease.[8]

This toolkit outlines practical steps working with AYHIV to support adherence whilst recognising that ART is only a small part of holistic care for this population and that behavioural change is a complex, multifactorial and dynamic process.[9]

Barriers to Adherence

Barriers to adherence are typically multifactorial and can be related to the individual, family and community and to healthcare systems, with many factors intersecting.[10]

Factors	Examples
Individual	Simply forgetting Education, understanding and belief of benefit of ART Mental health diagnoses Learning disabilities Alcohol and substance use Conflict of ART with cultural health beliefs Poverty Orphanhood Adverse childhood experiences

	Regimen; side effects, administration, pill characteristics, pill burden and fatigue Internalised stigma HIV disclosure and social support
Family & Community	Family support Care giver support Family dynamics: HIV-negative siblings, relationship with parent living with HIV HIV associated stigma and discrimination Lack of HIV awareness Beliefs about ART
Health Systems	Relationships with healthcare workers Lack of access to Youth Friendly services Distance and/or cost of travelling to services Age defined transition to adult services Limited access to emerging ART by age and cost barriers e.g. long-acting injectable (LAI) therapy only licensed from 18 years in the UK

Antiretroviral therapy: choice of regimen

All AYPHIV should be on ART and "treatment breaks" are not recommended.[11,12] The choice of ART regimen should consider age appropriate national guidance; PENTA/European AIDS Clinician Society for those under 18 years (https://eacs.sanfordguide.com/eacs-part1/paediatric-hiv-treatment) and British HIV Association Guidance for those aged 18-24 years (https://bhiva.org/clinical-guideline/hiv-1-treatment-guidelines/). Both guidelines address issues specific to adolescents and young adults and agree on the basic principles outlined below.[10,11]

1. Palatable single tablet regimens (STR) with a high genetic barrier to resistance based around a second-generation integrase inhibitor (preferred option) or a boosted protease inhibitor (alternative option) are recommended.
2. Dual therapy is currently not recommended to those <18 years outside of a clinical trial.
3. Prior to achieving peak bone mass, typically by 25 years of age, tenofovir alafenamide (TAF) is preferred to tenofovir disoproxil fumerate (TDF) to reduce potential for bone toxicity and is commissioned by NHS England.
4. Resistance sequences are recommended at baseline and at virological failure with modification of ART dependent on all past ART history and lifetime HIV-1 associated drug resistance mutations.
5. Treatment options should be discussed at a virtual clinic or within a multidisciplinary team. The Perinatal Virtual Clinic (PVC), a monthly online forum discussing case management for AYPHIV is available at https://www.chiva.org.uk/professionals/clinic-networks/ and https://penta-id.org/hiv/treatment-guidelines/. There is no upper age limit for PVC discussion.

Assessing Adherence

Adherence should be assessed at each clinic visit. HIV viral load (VL) monitoring is the best objective measurement of adherence. Additional assessment by pill count (describing how many pills have been taken), pharmacy records and patient/care giver report can add information.

Language is important when assessing adherence:

"How many days did you miss this week?"
"How many days did you manage this week?"

The first implies judgement, the second acknowledges daily medication can be hard.

By far the commonest reason for lack of viral suppression is poor adherence, however the following factors should also be considered:

1. ART regimen and resistance – is the AYHIV prescribed a virally active regimen?
2. Drug-drug interactions e.g. INSTI and divalent cations or rifampicin. All medication including over-the-counter, recreational, gym and herbal supplements should be considered.
3. Malabsorption in the rare event where this is of concern, and therapeutic drug monitoring (TDM) may be helpful.
4. Pregnancy - pharmacokinetics of ART can vary, TDM may be helpful.

Facilitating Adherence

Within the UK clinic setting adherence support is typically individualised (see Diagram 1) and starts with identifying the primary barrier to adherence allowing tailored intervention. Discussion within the MDT/PVC is strongly recommended for those who persistently struggles with adherence.

Barrier	**Strategies**
Forgetting	Alarm, apps, dosset box, text reminders, direct observed therapy (DOT), video observed therapy (VOT), LAI-ART, medicine buddy, neurocognitive assessment
Pill swallowing	"Pill school" (teaching pill swallowing to children), liquids, crushed tablets, smaller tablet regimen, LAI-ART, gastrostomy
Pill burden	Regimen review for simplification e.g. STR, LAI-ART
Side effects e.g. nausea	Regimen review, anti-emetic premed
Understanding HIV and ART and U=U[13,14]	Education; Chiva website, NAM and AIDSMap, Peer educators, Chiva's Freedom to Be (F2B) camp
Fear of disclosure	Timing of medication, unmarked pill pots, help to think through what to say to friends, peer support
Lifestyle	Consider change in routine, linkage to constant daily event e.g. teeth cleaning, planning for moving out of home/university/work
Familial adherence	Adherence of family members and beliefs re medication, identify support within the family

Ambivalence "I just don't feel like it"	Motivational interviewing techniques, motivation for change, peer support
Alcohol or drug use	Refer to drug services if required. Offer links to well informed websites for young people and substance use (e.g. www.talktofrank.com), psychology
Low mood	Screen for depression; refer for psychology, CAMHS, GP

Behavioural Interventions

For all healthcare professionals an empathetic, open, non-judgemental approach aiming to build the patient-practitioner relationship, with consistency of providers over time is extremely important.[15,16] Cognitive behavioural therapy and motivational interviewing techniques have both been shown to have positive impact on ART adherence for adolescents.[17-19] Stepped models for psychological support are available and outlined in Chiva and BHIVA Psychology Guidelines.

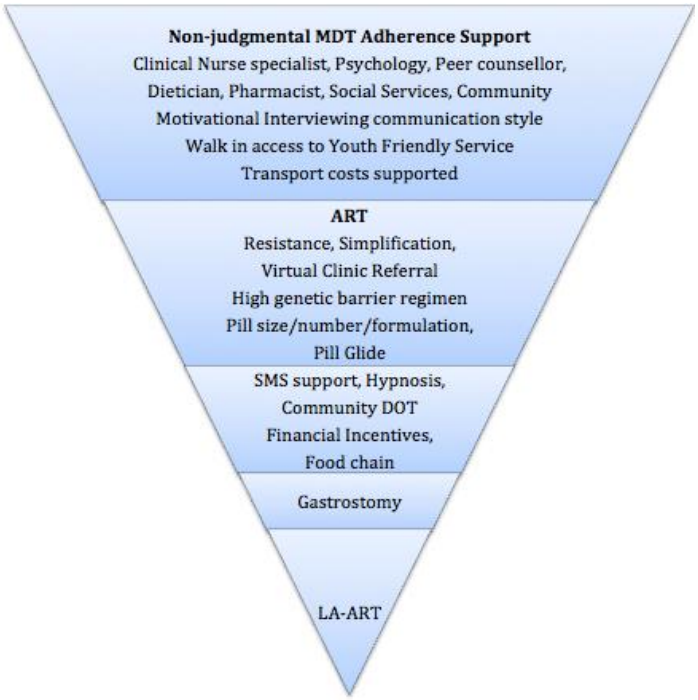
Peer Support

There are many potential benefits of peer support in the management of long-term health conditions including HIV, improving quality of life and potentially adherence to medication.[20] Peer support can be delivered in a variety of models including:

1. Integrated within NHS Clinics
2. Community-based third sector services; regional and national
3. Initiatives such as Chiva's Freedom to Be (F2B) residential camp for 11-17 year-olds and Blueprint programme mentoring and supporting 18-25 year-olds

All AYHIV should be offered access to peer support and for those that decline, further opportunity for engagement given at a later point.

Diagram 1. Intervention model of individualised adherence support[1]



Persistent poor adherence and severe immunosuppression

Despite enhanced MDT input, a small number of AYHIV continue to struggle with ART adherence resulting in severe immunosuppression and risk of HIV associated morbidity and mortality. This can be extremely stressful for the young person, their family and friends and for HCPs involved.

In the UK, competent adolescents below the age of 16 years have the right to consent to treatment, although the legal position on declining treatment is less clear.[21] However the practicalities of enforcing lifelong therapy such as ART on a non-consenting adolescent mean that an alternative route should be sought.

For younger adolescents who are in part dependent on family/carers for their care, referral to children's social care and a multiagency meeting are usually required. For older adolescents and young adults, assessment of their understanding and capacity to make healthcare decisions should be undertaken by the MDT with neurocognitive function assessment where concerns are raised. Involvement of the multidisciplinary team, primary care, community services and with the adolescents' consent, family members/carers/partners and the voluntary sector within a multidisciplinary meeting would be considered best practice.

Additional interventions to consider in the setting of severe immunosuppression:

1. Directly - or video observed therapy (DOT, VOT)[22]
2. Gastrostomy[23]
3. PVC discussion regarding options for long-acting injectable therapy including off licence and compassionate use
4. Reward based interventions including financial incentives[24]
5. Seeing a different clinician

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