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Outcomes for Adults Living with Perinatal HIV

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Young People Special Interest Group (YPSIG) Chiva Good Practice Guidance

Authors: C Foster, M Henderson, I Mallik, S Ayres, S Fidler, 900 Clinic, Imperial College Healthcare NHS Trust
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Introduction

The majority of individuals born with HIV and living in the UK have transitioned to adult HIV care, with the oldest survivors now entering their fifth decade of life.[1] Those in their late 20s and beyond, survived the early years of childhood without antiretroviral therapy (ART), potentially due to favourable host genetics and immune responses. However, such individuals have experienced years of unsuppressed viraemia and were frequently exposed to older and more toxic ART regimens. In contrast, many of those born in more recent decades started ART in earlier childhood and are more likely to be reflective of the emerging adult perinatal cohorts globally. These individuals are important in identifying the consequences of lifelong HIV and ART exposure throughout postnatal, childhood and adolescent development.[2]

Whether outcomes will differ for these two groups is unclear, but there is growing evidence of an increased incidence of metabolic, cardiovascular, respiratory, bone, renal, cognitive and mental health impairment in people living with perinatal HIV (PHIV) compared with age matched peers.[2,3] Data also suggests that these changes occur at a younger chronological age when compared to those who have acquired HIV in later life (NPHIV). The aetiology of these increased co-morbidities is yet to be fully elucidated but includes lifelong systemic inflammation and immune dysfunction, despite suppressive ART.[3,4]

Summary outcomes adults with PHIV compared to age-matched peers

Whilst data are limited, emerging evidence from high income settings suggests that when compared to aged and ethnically matched peers, adults with PHIV have an increased risk of:

- Mortality x 10 associated with advanced HIV[5-9]
- Malignancy x 10 driven by lymphoma[10,11]
- Psychosis x 6 age-matched peers, not living with HIV[12,13]
- Pregnancy: poorer maternal and infant outcomes (prematurity, small for gestation age) with higher rates of neonatal and social care[14-17]

Mortality and hospitalisation for adults with PHIV

Despite the successes of modern ART, mortality remains an estimated 10 times greater than aged-matched peers. Unlike adults with non-perinatally acquired HIV (NPHIV) this is predominantly driven by HIV-related causes. Mortality in later adult life is predictable as young people exit paediatric care; PHIV with HIV

viraemia, lower CD4 count and a prior CDC-C diagnosis in earlier childhood are at the greatest risk.[5-7]

Maternal mortality is also greater in the years post-partum for PHIV; reported in 11% in a US cohort and after adjusting for age, the survival rates for NPHIV were 3.23 higher than that of mothers with PHIV.[8] In Spain, 36% of those with PHIV who died (median age 25.8 years) following transition to adult care were already mothers.[9]

Risk of hospital admissions for adults with PHIV in the UK, excluding those related to pregnancy, were four times higher in those older than 20 years, when compared to adolescents; findings which are reflected in US data.[18,19]

HIV Care Cascade

Rates of viral suppression are lower in young adults with PHIV when compared to adults with NPHIV, although there is considerable variation by setting.[2,19] Rates of disengagement in care are higher in young adults with PHIV than in older adults with NPHIV. The early years following transition to adult care is a particular time of risk for disengagement.[2] Rates of triple class drug resistance are higher in adults with PHIV, when compared to aged-matched adults with NPHIV, and reflect historic reduced ART options and potency in paediatric care.[20]

Malignancy

Early data suggests rates of malignancy in PHIV are approximately 10 times that of age-matched HIV-negative peers, mainly driven by lymphomas.[10] Rates of human papilloma virus (HPV) infection, persistence and cervical dyskaryosis are higher in PHIV and occur at a younger age than NPHIV. Data for non-cervical HPV driven malignancies in this cohort are lacking.[21,22]

Cardiovascular and metabolic health

Increased rates of the metabolic syndrome, type 2 diabetes mellitus and cardiovascular events are reported amongst adults with PHIV. Cohorts in the US report incidence rates of type 2 diabetes-mellitus at 19%, hypercholesterolemia 40% and hypertriglyceridaemia 50% by the age of 30 years.[23] Despite suppressive ART, higher rates of cardiovascular disease are reported, when compared to age-matched peers, with abnormalities in both cardiovascular structure and function.[3,24] While rates of obesity are comparable to the general population, rates of hepatic steatosis are increased in people with PHIV; more

prevalent with increasing age and only partially explained by metabolic factors.[25,26]

Renal

Chronic kidney disease (CKD) is common in PHIV; 4% of PHIV adults in the US met international CKD criteria, 25% had abnormally low renal function (eGFR <90ml/min/1.73m2 for >3 months), the incidence of which increased with advancing age.[23,27]

Bone

Peak bone density occurs around 25 years of age. Low bone mineral density (BMD) is common with prevalence estimates of between 12.5% - 16.4% in adolescents and young adults with PHIV. The aetiology is likely multifactorial, related to both HIV-associated and traditional risk factors including HIV-related immune activation and inflammation, timing and duration of ART, older age, female sex, physical inactivity, low BMI and vitamin D deficiency.[3,28,29]

Neurocognitive function

Rates of learning disability are higher in adults with PHIV compared to peers without HIV, associated with lower nadir CD4 count, prior CDC-C diagnoses (particularly HIV encephalopathy) and late diagnosis. Impacts on higher order functions, particularly executive function, processing speed and working memory, are prevalent amongst PHIV cohorts with evidence of structural brain changes.[3,4,30]

Mental health

PHIV adults have higher rates of depression, anxiety and substance use than the general population, although comparable to their HIV exposed seronegative siblings, suggesting that social factors including living in a family affected by HIV and increased rates of adverse childhood experiences are important drivers.[3,31] Emerging data suggest that psychotic disorders may be over six times more prevalent than in age matched individuals without HIV, with recurrent episodes reported in 75%.[12,13]

Sexual health

The onset of sexual activity and rates of sexually transmitted infections amongst PHIV groups are broadly comparable to their peers.[32,33] Despite high rates of

knowledge around U=U, many continue to worry about the potential of HIV transmission despite an undetectable viral load, with a minority avoiding sexual relationships.[34] In young adults with PHIV, unlike peers with NPHIV, personal sharing of HIV status has the potential to also share the status of their mother and other family members, posing an additional complication and source of worry. Rates of intimate partner violence are high and associated with the sharing of HIV status outside the family.[35]

Higher rates of HPV infection and persistence highlight the importance of early and ongoing prevention strategies, including vaccination and screening. However, gaps exist in the optimal vaccine schedule and age of screening onset, both for cervical and other non-cervical malignancies.[21,22]

Pregnancy

Rates of unplanned pregnancy in youth with PHIV are high, with adverse maternal and neonatal outcomes, when compared to aged-matched peers, including higher rates of preterm birth and low birth weight infants.[14-17] Rates of maternal viraemia and immunosuppression are higher than in those with NPHIV, who are on average a decade older; however vertical transmission rates are reassuringly low.[14] Adverse maternal health outcomes in those with PHIV are a growing concern, driven by co-morbidities that impact on pregnancy, such as hypertension, diabetes and renal disease, and advanced HIV disease, which result in higher rates of mortality in the years post-partum, when compared to NPHIV and to aged and ethnically matched peers.[8,9]

Management considerations

Young people with PHIV should have access to integrated HIV, sexual, mental health and third sector services. Appropriate adjustments are required for those with learning disabilities and for those who find it difficult to engage including open access services. Continuity of care is important during the vulnerable period of transition and into adult life, particularly the first five years post transition to adult services. Communication strategies should be flexible and appropriate for youth and may include clinic mobile phone (without a withheld number), use of encrypted messaging services such as WhatsApp, email and letter. As young people age, the presence of co-morbidities should prompt referral to allied adult services such as cardiology, endocrinology, obstetrics and gynaecology. Careful referral to holistic services who understand the complexity of this vulnerable cohort is particularly important to promote engagement and to reduce discrimination within healthcare.

Antiretroviral therapy

Where drug resistance allows, high genetic barrier single tablet regimens containing a second-generation integrase inhibitor or boosted protease inhibitor are recommended. For those eligible, consideration should be given to long-acting injectable therapy. Other recommendations include:

- Tenofovir alafenamide (TAF) is preferred to tenofovir disoproxil fumarate (TDF) in those under 25 years, prior to peak bone accrual, unless metabolic considerations favour TDF
- Abacavir should be avoided in those age >18 years due to cardiovascular concerns in later adult life as per BHIVA Treatment guidelines [36]
- ART optimisation should be discussed at a virtual clinic/regional multidisciplinary team meeting prior to switch.

Vaccination

Vaccines titres wane with time from last vaccination and following a period of prolonged immunosuppression. For those migrating to the UK vaccine status is frequently unknown.

Vaccine	**Primary course PHIV**	**Considerations**
HPV	3	UK schools program moved to a single vaccine in 2024
Hepatitis B	3	Those born in the UK before 2017 will not have had HBV vaccination within the childhood program and require monitoring of HBsAb with booster vaccination as per BHIVA guidelines.
Measles, mumps, rubella	2	Serology should be monitored and (re)vaccination provided as appropriate
Varicella	2	Serology should be monitored and (re)vaccination provided as appropriate
Mpox	2	As per BHIVA guidance

Screening: cervical and anal PAP smears

Data is lacking regarding the optimal age of onset for screening in those with PHIV but earlier onset should be considered given the lack of data and increased HPV persistence.

Metabolic and cardiovascular health

Lifestyle interventions addressing diet, exercise, smoking avoidance or cessation and limiting alcohol are the mainstay of treatment for dyslipidaemia, metabolic syndrome, metabolic dysfunction–associated steatotic liver disease and obesity. Guidance that recommends the use of statins from 40 years for adults with HIV should include those with PHIV.[37] Blood pressure, HBA1C and lipid profile should be monitored annually.

Summary

Young adults who have grown up with lifelong HIV have specific additional medical, psychological and social support needs compared to those who acquire HIV in later life. Whilst many can be anticipated, some of the long-term consequences of lifelong HIV remain unknown. Care for adults with PHIV should ideally be provided through thoughtful, co-ordinated multidisciplinary patient-centred services designed to acknowledge and address these complex concerns.

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