

HIV for non-HIV specialists

Diagnosing the undiagnosed

A practical guide for healthcare professionals in secondary care to support improved detection and diagnosis of HIV in Europe

EUROPEAN EDITION

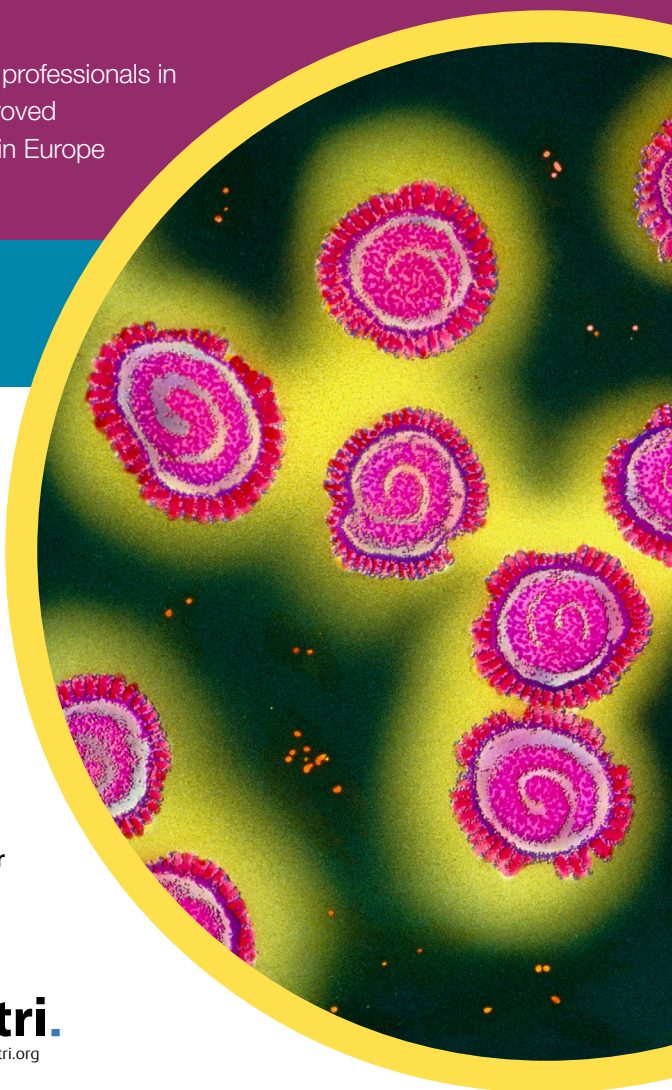
First edition by
Dr Rachel Baggaley

Second edition by Dr Ann
Sullivan, Dr Emma Devitt &
Ruth Lowbury

Adapted for the European
context by Dr Miriam Taegtmeier



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**MEDFASH (Medical Foundation for HIV and Sexual Health)
JUSTRI (The Training and Resource Initiative)**

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HIV particles. © Chris Bjornberg/Science Photo Library

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Forewords



**Professor Fiona
Mulcahy**

The incidence of HIV in Europe continues to increase on a year-to-year basis despite the introduction of public health measures and effective antiretroviral therapy reducing the risk of HIV transmission. In 2014 almost 30,000 people were diagnosed with HIV in 31 countries of the EU/EEA with a rate of 5.9 per 100,000 population. The highest age-specific rate was observed among 25-29 year olds and 42 per cent of new diagnoses were made in men who have sex with men. HIV patients who are receiving effective antiretroviral therapy with viral suppression can expect a lifespan approaching normal.

Unfortunately, in 2014, 47 per cent of all people diagnosed with HIV across Europe had a significantly late diagnosis (with a CD4 count of under 350 cells/ μ L). Late presentation of HIV is associated with increased morbidity and mortality, particularly in the first year after diagnosis. It remains one of the most important public health issues to date. Interventions

to expand testing have been shown to be both acceptable and cost-effective with many examples of routine testing for blood borne viruses being undertaken in Emergency Departments and community outreach centres. However, uptake remains suboptimal.

Clinicians in a range of secondary care settings may therefore be the first contact point for an individual with undiagnosed HIV presenting with symptoms which are not overtly related to HIV infection. It is essential that HIV remains in the normal differential diagnosis of all those presenting for secondary care.

I am therefore pleased to endorse this booklet which identifies clinical indicator diseases associated with HIV infection and provides advice about routine testing of your patients and the appropriate management thereafter. I trust it will be a valuable resource for your team.

Professor Fiona Mulcahy
President
European AIDS Clinical Society



As a woman living with HIV who was tested, diagnosed early and subsequently treated for HIV, I welcome and highly recommend this edition of *HIV for non-HIV specialists*. This is simply because I have first-hand experience of the importance of being tested and diagnosed early. Knowing my diagnosis enabled me to access the invaluable peer support that I needed so early on, as well as continue to engage with health services, vital for my survival at the time.

All too often, diagnoses can be missed on the presumption that certain people do not fit the ‘at risk’ criteria. Or indeed non-HIV specialists may not be sufficiently familiar with the indicator conditions that might suggest an underlying HIV infection. They may also lack the relevant knowledge to provide pre- and post-HIV testing information.

Angelina Namiba

As someone who was diagnosed initially with hepatitis B then HIV, I truly believe that I would not be alive today had my doctor not been quick thinking enough to have spotted my indicator condition and asked me to go for an HIV test. Thanks to him I have been living with HIV for more than two decades now and am able to live a full life, currently working as a Project Manager for a charity.

Early testing and diagnosis enable people living with HIV to access treatment, care and support. These are all key and vital factors in keeping us healthy and able to lead fulfilling lives, continuing to have relationships and safely start families (if we choose), being productive and making a positive contribution to society.

A handwritten signature in black ink that reads "Angelina Namiba". The signature is stylized and cursive.

Angelina Namiba

Preface

About this booklet

This booklet explains the rationale for, and promotes, increased HIV testing in clinical settings to help reduce the level of undiagnosed HIV infection. Originally for use in the UK and based on the successful MEDFASH booklet, *HIV in Primary Care*, by Dr Sara Madge, Dr Philippa Matthews, Dr Surinder Singh and Dr Nick Theobald, the first edition was designed to complement the *UK National Guidelines for HIV Testing 2008*. The content was comprehensively reviewed and updated for the second edition in 2015. Following requests for a version suitable for use in other European countries it has now been adapted for a European-wide audience.

Focusing on HIV testing and diagnosis, the booklet is aimed specifically at non-HIV specialist clinicians working in secondary care settings who are likely to encounter patients with undiagnosed HIV either in specialist outpatient clinics or when admitted to general medical wards. The booklet provides essential information about HIV and its presentation with a range of indicator conditions, as well as case studies and concrete strategies to assist non-HIV specialist clinicians in detecting undiagnosed HIV and implementing HIV testing in their daily practice.

Originally developed by MEDFASH, the booklet is published jointly with JUSTRI. We welcome comments, corrections and ideas or suggestions for inclusion in future editions; please send them to home@justri.org.

If you wish to translate this document into another language or adapt it for your country, we would welcome that. See **How to adapt this booklet for your national context** on page 10 for further information.

About MEDFASH

MEDFASH (Medical Foundation for HIV & Sexual Health), is an independent non-governmental organisation dedicated to quality in HIV and sexual healthcare. It has been supporting health professionals and policy-makers with educational resources and guidance since 1987. A partner in the European OptTEST (Optimising Testing and Linkage to Care for HIV) project, MEDFASH's work in Europe has also included the development of HIV testing guidance for the European Centre for Disease Prevention and Control. MEDFASH is to close at the end of 2016.

About JUSTRI

JUSTRI is a not-for-profit organisation established to work with allies in the healthcare and patient communities, international agencies and the pharmaceutical industry to build successful responses to HIV and related conditions such as hepatitis B & C. In collaboration with these allies it initiates and supports projects and trainings, supplies locally relevant resources, and facilitates international innovation in the provision of care for people living with these infections.

About the authors

Dr Ann Sullivan MBBS DipGUM MD FRCP is a Consultant Physician at Chelsea and Westminster Hospital NHS Foundation Trust. She first worked in the field of HIV in Australia in 1990, and started working at Chelsea and Westminster in 1994, where she obtained her MD in HIV Immunology. She is involved in numerous HIV testing research studies, projects and programmes both in the UK and in Europe, and is co-author of the new European HIV Indicator Conditions Testing Guidelines.

Dr Emma Devitt MB BCH BAO BA MD DFSRH FRCPI is a Consultant Physician at Chelsea and Westminster Hospital NHS Foundation Trust. She completed her training in Infectious Diseases and General Internal Medicine in Ireland in 2009. She was awarded her MD in Hepatitis C from University College Dublin. She has been working at Chelsea and Westminster since 2009 where she has a specific interest in the medical complications of HIV and management of viral hepatitis.

Ruth Lowbury is Chief Executive of MEDFASH. Under her leadership MEDFASH has reviewed national policy, developed standards and guidance, and published educational resources for health professionals with a particular focus on improving rates of HIV diagnosis in the UK and Europe. Ruth was a member of the UK government's Expert Advisory Group on AIDS and has been active in a number of other national policy groups.

Dr Miriam Taegtmeier BM BCH, FRCP, PhD is a consultant physician at the Royal Liverpool University Hospital and a Reader at the Liverpool School of Tropical Medicine. She has a research interest in the global scale-up of HIV rapid testing and has research projects and partnerships in 11 countries.

How to adapt this booklet for your national context

This booklet was originally designed for use in the UK. In the process of adapting it to the European context we have included Europe-wide epidemiology and reference to European guidelines. We have selected new case studies relevant to the European context and have consulted with colleagues working in infectious diseases and sexual health across the continent.

If you wish to translate and/or adapt this booklet for a specific national context, the following checklist may help you to identify which aspects to adapt.

1. Include country-specific epidemiological data in Section 1.
2. Review text that says 'refer to national guidelines' and insert relevant national guidance, for example on HIV testing, post-exposure prophylaxis (PEP), or HIV treatment.
3. Take out and/or add case studies to ensure it reflects common presentations of HIV in local practice.
4. Remove, amend or add content to ensure that the national legal framework is accurately reflected in the booklet on subjects such as the legal age of consent to testing or criminal prosecution for wilful transmission of HIV.
5. Update the references to include peer reviewed publications from the national context.
6. In Section 8, add useful organisations and websites to fit the needs of clinicians and patients in your country, including organisations that can be contacted by patients for support and information.

We provide this edition, including illustrations, without charge on the condition that any translated or adapted versions will also be made available without charge. (For commercial use, an extension or further licence must be obtained for the use of images in the booklet.) Please contact home@justri.org for further information.

Section 1

HIV in Europe: an overview

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HIV in the UK: an overview

Background

Human immunodeficiency virus (HIV) is one of the most important communicable diseases in Europe. At the end of 2013 there were an estimated 2.1 million people living with HIV infection in the WHO European region¹, around a third of whom were unaware of their status^{2,3}.

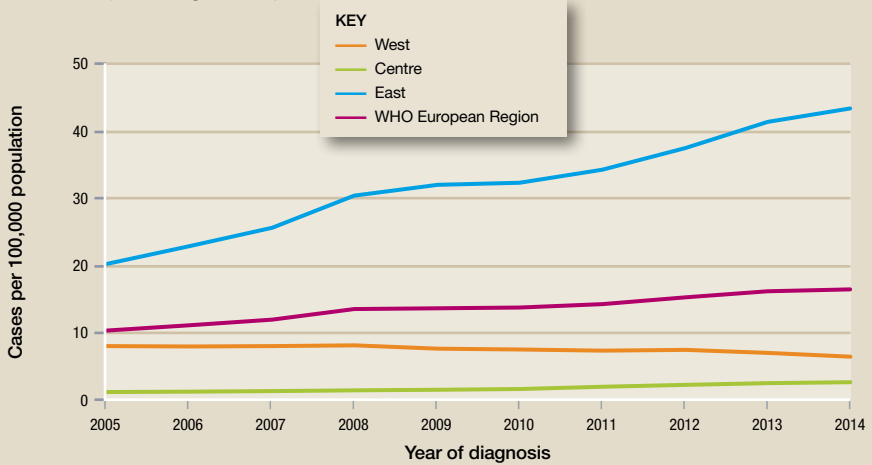
Across Europe, different groups are most affected by HIV infection. Broadly, key populations at highest risk are often those who are socially marginalised or people whose behaviour is socially stigmatised, such as men who have sex with men (MSM), migrants from countries of higher HIV prevalence, transgender people, people who inject drugs (PWID), sex workers and prisoners². These populations will be different in different countries, and health workers need to be aware of their local epidemiology.

The annual number of people diagnosed with HIV in the WHO European region has increased year-on-year since reporting started in the 1980s, with 142,197 diagnoses reported in 2014⁴ (see figure 1).

The availability of effective antiretroviral (ARV) therapy (ART) since the mid-1990s has resulted in a dramatic decrease in HIV-related morbidity and mortality in Europe for those who can access it; most infected people in Europe are now living with HIV as a chronic condition rather than an inevitably fatal illness.

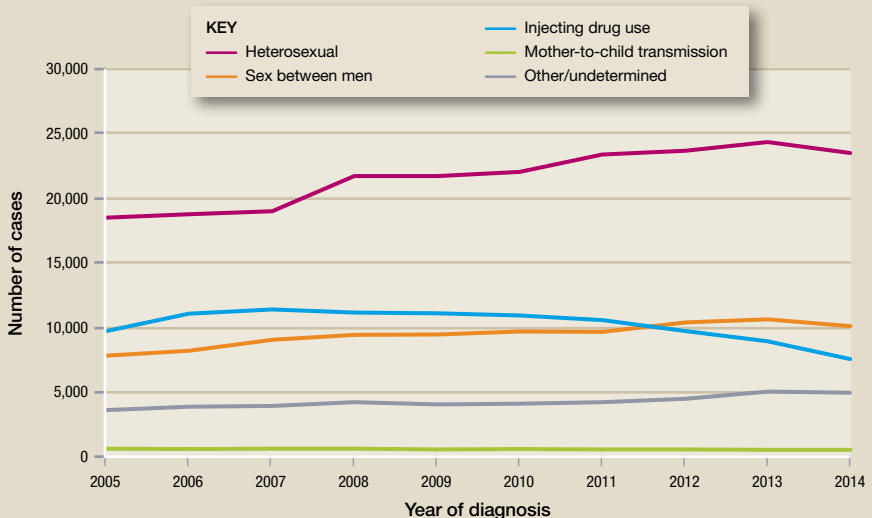
Most people diagnosed with HIV in Europe are thought to have acquired it through heterosexual sex (see figure 2). The number of people infected through injecting drug use has been falling since a peak in 2007; diagnoses in MSM have surpassed diagnoses in PWID since 2012⁴. 22 per cent of people were thought to have acquired HIV outside the WHO European region.

Figure 1 | Rates of new HIV diagnoses, by year of diagnosis, WHO European Region, 2005-2014 (including Russia)



European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2014

Figure 2 | New HIV diagnoses by exposure category: WHO European region 2005-2014



European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2014

Late diagnosis

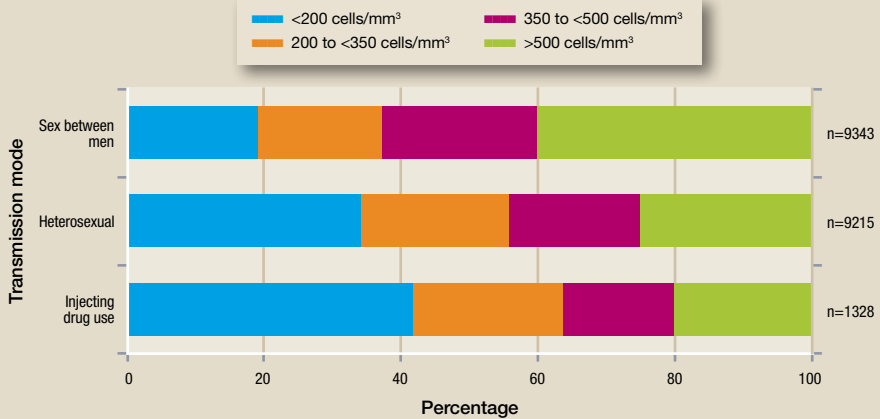
Of those people living with HIV in Europe, it is estimated that approximately a third in the European Union and European Economic Area are unaware of their status³. This varies across countries and populations across Europe: 60 per cent of all people living with HIV in some eastern European countries are estimated to be undiagnosed^{2,3}, as are 80 per cent of men who have sex with men in Ljubljana and Bucharest, for example⁵. HIV-related morbidity and mortality are increasingly concentrated among those who are diagnosed late. Although many of these patients will do well, some will be left with permanent disability, many will respond sub-optimally to treatment and some will die. On average, people in Europe who are diagnosed late with HIV have up to a 13-fold increased risk of death or progression to AIDS within a year of diagnosis compared to those diagnosed promptly⁶, though this varies across the European region.

In addition to improving individual wellbeing, earlier diagnosis is more cost-effective, as the timely initiation of ART leads to better health outcomes, avoidance of high cost morbidity and greater ability to participate in the workforce, thus decreasing calls on the public purse. Furthermore, by radically reducing the risk of onward transmission it has a highly significant impact on public health.

There is evidence from several European countries that people living with HIV have been seen by healthcare professionals in the year before their diagnosis with problems that were, in retrospect, HIV-associated symptoms but were not offered an HIV test^{7,8}. This represents a lost opportunity to diagnose and avoid significant morbidity and possibly mortality.

Definitions of late HIV diagnosis are linked to treatment thresholds and so are variable; in 2011 a European consensus group defined *late diagnosis* as having a CD4 T-cell count below 350 cells/ μ L within three months of HIV diagnosis. They defined a count of less than 200 cells/ μ L as being *very late diagnosis*⁹. Using this definition in Europe in 2014, 48 per cent of HIV diagnoses were late, and 28 per cent were very late; there were more late and very late diagnoses in PWID and heterosexual people than MSM (see figure 3), highlighting that testing behaviours are different in different groups. Significant efforts are being made worldwide to address the late diagnosis problem and different countries have adopted different HIV testing strategies; see Section 2 (recommendations for testing).

Figure 3 | New HIV diagnoses, by CD4 cell count per μL at diagnosis and transmission mode, for those patients where data were available, WHO European Region, 2014 (n=19 886)



European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2014

The natural history of HIV infection

HIV is a retrovirus which preferentially infects cells of the immune system, particularly the CD4 T-lymphocytes. It is present in an infected person's blood, and also in other body fluids, such as semen, vaginal secretions, rectal secretions and breast milk.

The window period

The window period refers to that period between infection and when a test can detect it. Antibodies to HIV often appear within four weeks after infection but may take as long as 12 weeks to be detected depending on the test used. During this period an HIV antibody-only test (third generation) may not detect the infection. However, the newer fourth generation test, recommended in the 2014 European HIV testing guideline¹⁰, also detects the p24 antigen (part of the virus) which can often be detected in a blood sample for a short period soon after infection; it rapidly becomes undetectable once antibodies to HIV start to develop. It is therefore useful in identifying early HIV infection, helping to diagnose some people slightly sooner than four weeks. During early seroconversion this test may report a positive antigen and negative antibody. (See Section 2 for more on types of HIV test.)

Primary HIV infection or seroconversion

More than 60 per cent of patients experience a flu-like illness at the time of infection (also known as acute HIV infection). The symptoms may be mild and non-specific, but they can also be marked and precipitate a referral to, or attendance at, secondary care. The presentation is often clinically indistinguishable from infectious mononucleosis. Two recent studies have shown an HIV prevalence of one to four per cent in patients presenting with infectious mononucleosis-like symptoms^{11,12}. Therefore clinicians should include HIV in the differential diagnosis for this type of presentation, and investigate accordingly.

In some cases, severe temporary immunosuppression at seroconversion can lead to the appearance of opportunistic infections, and sometimes results in an AIDS diagnosis. Furthermore recent evidence suggests there may be a benefit in initiating ART at seroconversion, but the window of opportunity is narrow, and therefore timely testing and follow-up is key^{13,14}.

The risk of onward transmission is particularly high during primary HIV infection, as individuals have a high viral load but are often unaware they have HIV and may even test antibody negative.

Natural history of HIV infection

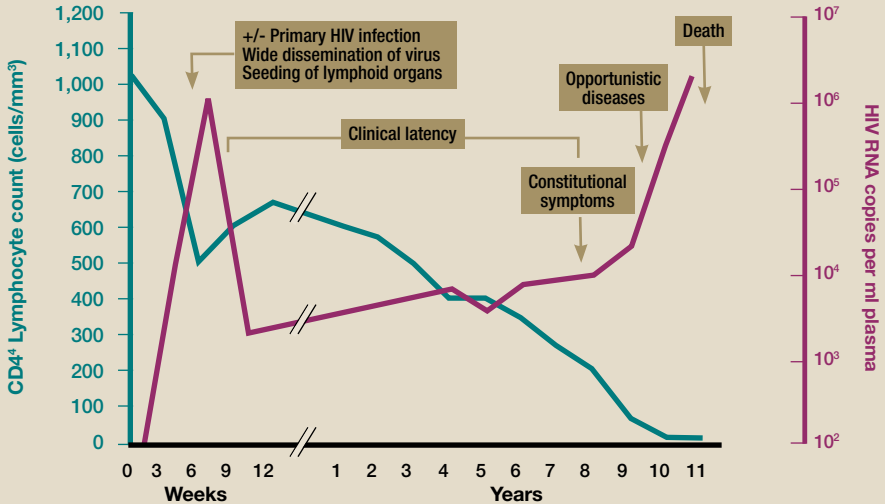
Asymptomatic stage (clinical latency)

Once the symptoms of primary HIV infection subside, if they occur at all, the asymptomatic stage of the infection begins. There are usually no overt clinical signs or symptoms of HIV infection during this stage and the individual may be well for many years. Some laboratory tests may be abnormal, eg anaemia, neutropenia, lymphopenia, thrombocytopenia, high total protein, diffuse hypergammaglobulinaemia, or elevated ESR (erythrocyte sedimentation rate). The finding of any of these abnormalities in the absence of another identified cause should prompt the offer of an HIV test.

The CD4 count declines at a rate of approximately 40-80 cells/ μ L per year in untreated individuals, but some progress faster than others. There is wide variation in the time it takes to progress from primary infection to symptomatic disease (see figure 4).

See Section 3.2
on page 37 for
signs of primary
HIV infection

Figure 4 | Association between virological, immunological and clinical events and time course of HIV infection



Adapted from: Fauci AS. *Ann Intern Med.* 1996 Apr 1; **124** (7):654-63 (with permission)

Symptomatic stage

If untreated, infection with HIV results in progressive immunosuppression which leads to the development of symptoms and disease. Constitutional symptoms may occur, including fevers, night sweats, headache, malaise, fatigue, diarrhoea, weight loss or feeling non-specifically unwell or fatigued. Generalised lymphadenopathy involving extra-inguinal sites may be present.

Other conditions may occur including herpes zoster, recurrent herpes simplex, recurrent or severe/recalcitrant seborrhoeic dermatitis, folliculitis, worsening or recalcitrant psoriasis and oral hairy leukoplakia. Bacterial infections (most commonly *Streptococcus pneumoniae*, *Haemophilus influenzae* and *Staphylococcus aureus*) may occur during this stage, leading to sinusitis, bronchitis and pneumonia.

Opportunistic infections (OIs) are specific HIV-associated infections: certain fungi, viruses, bacteria and other organisms that are usually non-pathogenic or cause only minor disease can behave more pathogenically in the HIV-infected individual.

Symptomatic, AIDS-defining

Certain infections and malignancies are associated with HIV infection and their presence is synonymous with an AIDS diagnosis. Other conditions including certain neurological diseases associated with HIV and excessive weight loss (more than 10kg) are also AIDS diagnoses.

Later stages of infection are associated with infections including *Pneumocystis jirovecii* pneumonia (previously known as *Pneumocystis carinii* and still commonly abbreviated to PCP), cytomegalovirus (CMV), progressive multifocal leucoencephalopathy (PML), *Mycobacterium avium-intracellulare* (MAI), cryptococcosis, cryptosporidiosis, toxoplasma encephalitis and oesophageal candidiasis.

Individuals are also at increased risk of malignancies including Kaposi's sarcoma (KS), non-Hodgkin's lymphoma (NHL) and cervical and anal malignancies associated with human papilloma virus (HPV). Some, although not all, of these conditions typically occur once an individual's CD4 count has fallen below a certain value. For example, the risk of PCP is significant at a CD4 count less than 200 cells/ μ L and of MAI at less than 50 cells/ μ L. AIDS is avoidable for the vast majority with early diagnosis and appropriate therapy initiation. Tuberculosis can occur at any CD4 count but is more likely to be extrapulmonary as immunosuppression progresses.

Disease markers

CD4 count

The CD4 T-cell count is a useful indicator of the degree of immunosuppression in those infected with HIV. In healthy, non-HIV infected individuals the CD4 count is between 450 and 1200 cells/ μ L. The CD4 count can fluctuate and trends are therefore more important than a single reading; however, the CD4 percentage tends to be a more stable parameter. Patients with a CD4 count below 200 cells/ μ L (broadly comparable or equivalent to 15 per cent) are at significant risk of HIV-related OIs and tumours, although some malignancies, eg KS and NHL, can occur at higher CD4 counts.

The CD4 count is a valuable clinical tool in deciding how urgent it is to start ART and whether to start primary prophylaxis against opportunistic infections.

Viral load

This is a measure of the amount of HIV in the blood. The viral load can range from below the level of detection (VLBD, typically 40 copies/ml) to many millions of copies/ml.

The degree of viral replication is linked to the rate of CD4 decline, and hence disease progression; thus the aim of ART is to reduce the viral load to an undetectable level. A rising viral load in a patient on ART can

indicate a range of problems, eg drug resistance may be developing, the patient may not be adhering to their treatment regimen, or there may be an adverse drug-drug interaction.

How the CD4 count and viral load interrelate

If HIV is replicating at high levels over time, a more rapid CD4 T-cell count decline will probably be observed. The CD4 count of patients not taking ART who have a high viral load is likely to fall more rapidly than that of those with a lower viral load. Once the viral load is suppressed CD4 counts usually recover with a decreased risk of developing OIs, tumours and other complications of HIV infection (see figure 4).

The case for earlier diagnosis

48 per cent of people with HIV in Europe are diagnosed at a late stage (ie CD4 count less than 350 cells/ μ L; see 'late diagnosis', page 14)⁴.

This results in:

- a worse prognosis with significantly increased risk of permanent disability
- a significant increase in mortality
- ongoing transmission to sexual partners
- increased healthcare costs.

Section 2

Recommendations for testing

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Recommendations for testing

Who can perform an HIV test?

Local regulatory and legal frameworks should be followed as to who can offer a HIV test; but broadly speaking all clinicians and appropriately trained healthcare workers should be competent to offer an HIV test. The WHO recommends that lay providers who are trained and supervised can independently conduct safe and effective HIV testing using rapid diagnostic tests (see 'which test to use', page 27)¹⁵. This may not be the case in all settings; follow local guidance in all cases. As people with undiagnosed HIV may attend any hospital outpatient department or ward (and with time are more likely to do so whilst they remain undiagnosed) the offer of an HIV test should be considered at every clinical contact. There is no need for special counselling skills beyond those required for routine clinical practice.

Who should be recommended an HIV test?

There has been a dramatic change in the recommendations regarding who should be offered an HIV test, in which settings and how the test should be offered. This has been driven by multiple factors: the marked improvement in HIV treatment, the recognition that those with undiagnosed infection account for a significant proportion of ongoing transmission and that effective treatment in specific circumstances can reduce the risk of transmission to near zero, that current attempts to decrease the undiagnosed and late presentations have to a large extent been unsuccessful and that many people diagnosed with HIV have had recent contact with a healthcare professional, representing missed opportunities for diagnosis.

Individual European countries have developed guidelines on to whom HIV testing should be offered, but there are several guidance documents with a Europe-wide scope detailing who should be offered a test and in which circumstances, including: the *2014 European Guideline on HIV testing*¹⁰, and several documents from the European Centre for Disease Prevention and Control (ECDC) including *HIV testing: increasing uptake and effectiveness in the European Union*¹⁶; and *HIV Indicator Conditions: Guidance for Implementing HIV Testing in Adults in Health Care Settings*

from the HIV in Europe secretariat¹⁷. The WHO has also published *Consolidated guidelines on HIV testing services 2015*¹⁵.

Healthcare workers should be aware of and follow national guidance in the countries where they are working, but taken together the pan-European and WHO guidelines suggest a strategy where HIV testing should be routinely offered in the following circumstances:

- individuals attending specific services
- individuals requesting pre- or post-exposure prophylaxis for HIV
- individuals diagnosed with indicator conditions
- individuals from high risk groups.

Some countries have, in addition, developed a strategy of testing all patients in certain settings when the local (district or region) undiagnosed HIV prevalence exceeds a certain threshold.

The case for routine HIV testing

Routine testing describes HIV tests that are routinely suggested by a clinician or other healthcare worker (provider-initiated). HIV testing is offered to all patients attending specific services (such as TB clinics, antenatal care); all patients with so-called 'indicator' conditions; individuals that belong to a group at higher risk of HIV infection and patients in areas where the diagnosed HIV prevalence exceeds a certain threshold (see Section 2: Who should be recommended an HIV test?). It is a strategy for reducing the proportion of late presenters as most people diagnosed late will have had prior contact with healthcare workers. The effectiveness and acceptability of this approach for increasing uptake has been widely demonstrated. There are several benefits of routine testing:

- HIV testing should be seen as a normal part of the diagnostic or screening process and a duty of care
- Where routine HIV testing is in place, uptake of testing is increased
- The exceptional approach previously seen to HIV testing has been a barrier to clinicians in offering testing and to patients in accessing it
- 'Normalising' HIV testing will help to reduce stigma
- Failure to diagnose HIV leads to avoidable deaths and serious illness
- Effective HIV treatment reduces infectiousness and can reduce onward transmission.

Routine testing for all patients attending antenatal services has been the standard of care throughout Europe for over a decade, and has demonstrated the effectiveness and acceptability of this approach for increasing uptake. Routine testing is recommended in European guidelines for all patients attending sexually transmitted infection (STI) clinics¹⁰.

Routine testing for individuals attending specific services

Routine HIV testing is recommended in certain clinical services where an increased HIV prevalence amongst attendees is likely or where it is particularly important to exclude HIV, including:

Antenatal services. In Europe in 2013, fewer than 1 per cent of incident HIV infections were due to mother-to-child transmission⁴, demonstrating the effectiveness of antenatal diagnosis and treatment.

STI clinics. Risk factors for sexually transmitted infections are the same as those for HIV infection and European guidelines suggest an HIV test routinely as part of a full sexual health screen¹⁰.

Services for sexual assault. Routine testing should be offered to all those who attend these services. Both baseline and follow-up HIV testing are required if an individual is considered suitable for post-exposure prophylaxis for HIV.

Drug dependency programmes. Injecting drug use is a recognised risk factor for HIV infection.

Services for patients with tuberculosis, hepatitis B and C and lymphoma. See 'Routine testing for individuals diagnosed with HIV indicator conditions' (page 25).

Dialysis, blood donation and organ transplant services. Patients with chronic kidney disease are, in most European countries, screened for HIV infection before initiation of dialysis, as are patients being put forward for a transplant, or donating blood or tissues/organs.

Haemophilia services. Blood and blood products are a potential source of HIV infection; screening of blood for HIV and treatment of blood products was introduced in many European countries in the mid-1980s, but the date of introduction and screening practices vary from country to country. Patients who have received blood transfusions that have not been screened or untreated blood products should be offered HIV testing.

Services for people who have occupational exposure to blood or blood products. All healthcare settings should have clear guidelines, referral and support procedures for this eventuality; healthcare workers are encouraged to follow local and national guidelines, including for post-exposure prophylaxis (PEP) if available.

Routine testing for individuals requesting pre- or post-exposure prophylaxis

National guidance should be followed for patients requesting pre-exposure prophylaxis (PrEP) where available, or PEP, but all should be offered HIV testing to prevent inadvertent and unplanned treatment of pre-existing undiagnosed HIV infection. The following points are of note in planning testing:

1. Once on antiretroviral medication, individuals on PrEP or PEP require regular follow-up testing
2. Rapid diagnostic tests (particularly oral fluid tests) are less sensitive in individuals taking ART
3. Fourth generation tests are able to detect infection earlier
4. Delay in developing antibodies in individuals taking ART lengthens the window period.

Routine testing for individuals diagnosed with HIV indicator conditions

Recommendations for testing in individuals with HIV indicator conditions can be divided into three main categories and are summarised in Table 1.

Routine HIV testing should be offered to all individuals presenting for healthcare where HIV enters the differential diagnosis, or where undiagnosed HIV may impact on the proposed treatment outcomes. Some conditions, eg Kaposi's sarcoma and CMV retinitis, are highly associated with HIV infection and, as potential AIDS-defining conditions, their presence should prompt HIV testing. Other conditions occur more frequently in those with diagnosed HIV infection, but data on prevalence are limited. In conditions where the undiagnosed HIV prevalence reaches the proposed cost-effectiveness threshold of 0.1 per cent an HIV test should be recommended. For those conditions where these data are pending an HIV test should be offered, especially where they are recurrent or slow to resolve.

Of particular importance are infectious mononucleosis-like presentations, which may indicate HIV seroconversion (primary HIV infection) and should therefore always prompt testing. This represents an ideal opportunity to effect an early diagnosis, before the long period of asymptomatic infection and at an extremely infectious time point (at seroconversion the HIV viral load is often in excess of one million copies). Diagnosis at this stage affords the individual access to ART which may be of benefit in primary HIV infection.

Table 1 | Definitions of indicator conditions and recommendations for HIV testing

1. Conditions which are AIDS-defining among people living with HIV*

Strongly recommend testing

Neoplasms

- Cervical cancer
- Non-Hodgkin lymphoma
- Kaposi's sarcoma

Bacterial infections

- *Mycobacterium tuberculosis*, pulmonary or extrapulmonary
- *Mycobacterium avium* complex (MAC) or *Mycobacterium kansasii*, disseminated or extrapulmonary
- *Mycobacterium*, other species or unidentified species, disseminated or extrapulmonary
- Pneumonia, recurrent (2 or more episodes in 12 months)
- *Salmonella* septicaemia, recurrent

Viral infections

- Cytomegalovirus retinitis
- Cytomegalovirus, other (except liver, spleen, glands)
- Herpes simplex, ulcer(s) > 1 month, bronchitis/pneumonitis
- Progressive multifocal leucoencephalopathy

Parasitic infections

- Cerebral toxoplasmosis
- Cryptosporidiosis diarrhoea, > 1 month
- Isosporiasis, > 1 month
- Atypical disseminated leishmaniasis
- Reactivation of American trypanosomiasis (meningoencephalitis or myocarditis)

Fungal infections

- *Pneumocystis pneumonia* (PCP)
- Candidiasis, oesophageal
- Candidiasis, bronchial/tracheal/lungs
- Cryptococcosis, extrapulmonary
- Histoplasmosis, disseminated/extrapulmonary
- Coccidioidomycosis, disseminated/extrapulmonary
- Penicilliosis, disseminated

2a. Conditions associated with an undiagnosed HIV prevalence of $\geq 0.1\%$

Strongly recommend testing

- Sexually transmitted infections
- Malignant lymphoma
- Anal cancer/dysplasia
- Cervical dysplasia
- Herpes zoster
- Hepatitis B or C (acute or chronic)
- Mononucleosis-like illness
- Unexplained leukocytopenia/thrombocytopenia lasting > 4 weeks
- Seborrhoeic dermatitis/exanthema
- Invasive pneumococcal disease
- Unexplained fever
- Candidaemia
- Visceral leishmaniasis
- Pregnancy (implications for the unborn child)**

2b. Other conditions considered likely to have an undiagnosed HIV prevalence of $> 0.1\%$

Offer testing

- Primary lung cancer
- Lymphocytic meningitis
- Oral hairy leukoplakia
- Severe or atypical psoriasis
- Guillain-Barré syndrome
- Mononeuritis
- Subcortical dementia
- Multiple sclerosis-like disease
- Peripheral neuropathy
- Unexplained weight loss
- Unexplained lymphadenopathy
- Unexplained oral candidiasis
- Unexplained chronic diarrhoea
- Unexplained chronic renal impairment
- Hepatitis A
- Community-acquired pneumonia
- Candidiasis

3. Conditions where not identifying the presence of HIV infection may have significant adverse implications for the individual's clinical management

Offer testing

- Conditions requiring aggressive immunosuppressive therapy:
 - Cancer
 - Transplantation
 - Auto-immune disease treated with immunosuppressive therapy
- Primary space occupying lesion of the brain
- Idiopathic/thrombotic thrombocytopenic purpura

* Based on Centers for Disease Control and Prevention (CDC) and World Health Organization (WHO) classification system.

** Pregnancy is included in the 'strongly recommended' category because antenatal HIV testing is essential for prevention of mother-to-child transmission.

CREDIT: Adapted from: *HIV Indicator Conditions: Guidance for Implementing HIV Testing in Adults in Health Care Settings*. Published by HIV in Europe, October 2012. Available at www.hiveurope.eu (PLWHIV = people living with HIV).

Routine testing for individuals who belong to a group at higher risk of HIV infection

People from populations at higher risk of HIV infection may attend clinical services other than those mentioned above and, dependent on local guidance, health workers should give consideration to routinely offering an HIV test. Risk assessment, if required, should be carried out in a non-judgemental way in a private setting.

These groups are:

- all individuals diagnosed with a sexually transmitted infection
- all individuals with a current or former sexual partner with HIV
- all men who have sex with men
- all female sexual contacts of men who have sex with men
- all individuals who report a history of injecting drug use, or who have a current or former partner who is or was an injecting drug user
- all individuals from countries of high HIV prevalence*
- all sexual contacts of individuals from countries of high HIV prevalence*

* Publications with information about adult HIV prevalence rates can be found online at www.unaids.org/en/dataanalysis/knowyourepidemic

Consideration should be given to offering an HIV test to individuals who have received injections, blood transfusions, blood products, transplants or other risk-prone healthcare-related procedures in countries without rigorous programmes of equipment sterilisation, screening of blood, organs and tissues or treatment of blood products.

Routine HIV testing in areas where the diagnosed HIV prevalence exceeds a certain threshold

Data from the USA¹⁸ and France¹⁹ suggest that routine HIV testing is cost-effective where the local undiagnosed prevalence is at least 1 per 1000. Some countries (such as the UK) have adopted a testing strategy based on this whereby all patients attending hospital or registering at a General Practitioner in areas whose local prevalence exceeds this threshold should be offered an HIV test. Healthcare workers should follow local guidance if there is a similar threshold in their country.

Which test to use?

Laboratory testing

Fourth generation HIV assays detect both antigen and antibodies to HIV-1 and HIV-2. They are the recommended laboratory test type as they become positive earlier than antibody only (third generation) tests (see 'The window period', page 15). The initial result should be reported as reactive and provisional until confirmed on a separate sample.

HIV RNA quantitative assays are a form of nucleic acid amplification

test (NAAT). These are not often used as an initial diagnostic test for HIV in adults as they are expensive and have a high false positivity rate, especially at the extremes of their range. However, they may be offered in special circumstances, eg following recent potential exposure where post-exposure prophylaxis is being considered. They are now the preferred test to diagnose early infection if primary HIV infection is strongly suspected and the antibody/antigen test is negative.

Point of care testing

Point of care tests (POCTs) are a helpful adjunct for expanding HIV testing in community and hospital settings. These rapid diagnostic tests for HIV antibodies can be performed on oral fluid or on whole blood from a finger prick outside the laboratory setting. POCTs have the advantage that the result is available in 1-20 minutes and can therefore be delivered at the initial consultation, reducing the possibility of the patient not returning for their result and thus remaining unaware of their HIV status. The specificity of rapid testing devices may be lower than that of the standard laboratory tests. In low prevalence settings this is likely to produce some false positive results. It is therefore important to include this information in the pre-test discussion and essential that all reactive POCT results are confirmed with a laboratory based test. The European Guideline on HIV testing states that all point of care testing programmes should be overseen by the local laboratory and have a robust quality assurance programme^{10,16}. There are currently no rapid test devices which accurately detect HIV antigen and rapid testing is not recommended if primary HIV infection/seroconversion is suspected²⁰.

Home sampling

Home sampling programmes are where kits are sent to individuals on request by post and their samples returned for laboratory testing. These often use a sample collection method where dried blood spots are collected on blotting paper.

HIV self-testing

Rapid testing devices are also available for self-testing at home. In this case, the individual reads their own result. Self-testing can empower people to test who are unlikely to access conventional services, and thus have a role to play in reaching people whose HIV infection might otherwise remain undiagnosed. HIV self-testing kits have received regulatory approval in France and the UK, and are being sold over the counter in many countries across Europe; European guidelines suggest that they are 'only recommended where validated tests are available with appropriate support and access to clinical care.' This is an area that is changing rapidly and up-to-date information is available from www.hivst.org/policy-regulations-for-hivst-1.

There are some concerns that people who purchase internet tests may not fully understand their limitations in terms of sensitivity and specificity, and may be unaware of the need for confirmation of results and for re-testing if within the window period for the test used. Also that test kits available over the internet have not been adapted for self-use and the instructions for use may be hard to follow. Individuals who wish to self-test should be advised to check the kit for sale has been passed by the national regulatory authorities and has accompanying instructions for self-use. They should be informed that all HIV self-tests are screening tests that require confirmatory tests to be conducted following any reactive result.

Whatever the type of HIV test used in any location, the benefits to a patient (and to the community at large) can only be realised if that patient is linked to care and treatment. It is therefore key for all services undertaking HIV testing to have clear agreed pathways into local HIV services.

How often to test?

This will be determined by the type of HIV test being used, and the timing and ongoing risk behaviour of the individual. Because of the time taken for antigen (if using a fourth generation test) and antibodies (third generation test) to appear, repeat testing should be offered to anyone who is at risk from recent exposure and is still within the 'window period'. This will range from six to twelve weeks, depending on the test used. Following a single event assessed as carrying a high risk of infection, if a fourth generation test is negative at first presentation then it should be repeated at six weeks following exposure; if a third generation test is used, this should be repeated at 12 weeks following exposure, according to European guidelines¹⁰.

Routine frequent testing should be available for those at higher risk such as MSM, people who inject drugs or sexual partners of people with HIV. National guidelines should be followed as to the frequency of testing, but many guidelines suggest that this should be as frequently as three-monthly.

Because of the success of universal antenatal screening, it is recommended to repeat the offer of testing for women in antenatal clinics who decline testing at booking; their reasons for doing so should be explored at the time. Repeat testing should be considered for any woman thought to be at continuing risk of infection, such as those with ongoing injecting drug use, or a partner with HIV or from a high risk group, because the high viral load associated with primary infection correlates with a high risk of HIV transmission from mother to child.

A POCT should be recommended to women presenting to services for the first time in labour, as even at that late stage preventive treatment can be given to both mother and neonate to reduce the risk of mother-to-child transmission.

Section 3

How to diagnose HIV in non-HIV specialist secondary care settings

IN THIS SECTION

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How to diagnose HIV in non-HIV specialist secondary care settings

This section of the booklet provides a basic overview of the common presentations suggestive of HIV infection that the generalist or non-HIV specialist clinicians in secondary care might encounter. It is divided by speciality, including acute and emergency medicine, and provides further information about how these conditions present in the HIV-infected patient. A separate sub-section on paediatrics provides some background information on HIV in children.

3.1 Acute and emergency medicine

Offering HIV testing in the Emergency Department may be difficult because of the lack of private space for confidential discussion, the busy setting and potential difficulty in following up patients. However, individuals with undiagnosed HIV may attend emergency services for completely unrelated medical or social reasons, or may have signs or symptoms suggestive of HIV infection. Therefore, it is an important opportunity to offer testing which can significantly reduce future morbidity and mortality. This has been reflected in European guidance¹⁷.

Know who to contact locally

Every Emergency Department should know who is on call for HIV-infected patients locally, and those teams can offer advice about the need for urgent testing. Some Emergency Departments may be able to offer rapid testing, but if not, an HIV specialist nurse may be able to arrange the test in the Emergency Department. To accommodate those patients who may be reluctant to undergo laboratory based testing via the Emergency Department but agree to have a test, agreed care pathways can facilitate a patient's attendance at the most appropriate local service.

If the patient requires admission and HIV is suspected, the emergency physician should document the need for HIV testing for the acute team to consider or that a test has been requested but the result is outstanding. The on-call medical team can also access urgent testing if clinically indicated via their local Microbiology/Virology Department and these results should be available within 24 hours, and in many cases much more quickly.

Another important reason why Emergency Departments may need to test someone for HIV is if they present for post-exposure prophylaxis following sexual exposure (PEPSE). The European AIDS Clinical Society (EACS) guidelines for the use of PEPSE stipulate that it should be started no later than 48/72 hours after exposure and, for optimal effectiveness, within 4 hours²¹. Emergency Departments are therefore often expected to provide PEPSE when sexual health/HIV services are closed. The guideline also states that individuals for whom PEPSE is provided must have an HIV test within 48 hours of exposure. On occasion the sexual partner (and possible source of infection) may accompany the individual requesting PEPSE, and if they do not know their HIV status, testing is recommended for them as well.

HIV-related presentations

Non-specific generalised flu-like symptoms can be associated with HIV either during primary HIV infection or with advanced symptomatic HIV. They can also be due to a related opportunistic infection or malignancy. An HIV test should be added to basic bloods such as full blood count, biochemistry and inflammatory markers for people who present to the Emergency Department with symptoms such as:

- malaise
- fever
- weight loss
- night sweats
- skin conditions (especially herpes zoster)
- oral candida
- lymphadenopathy
- chronic diarrhoea

HIV-related acute conditions that may present in the Emergency Department

Many conditions seen in the Emergency Department may indicate underlying HIV infection (see box on page 34). The most common are as follows.

Infectious mononucleosis-like illness. Patients presenting to the Emergency Department should always have an HIV test.

Community-acquired bacterial pneumonia. People with HIV, regardless of their level of immunosuppression, are more at risk of

See Section 3.2
on page 37 for
signs of primary
HIV infection

HIV-related conditions that may present to an Emergency Department

- Appendicitis
- Cerebral toxoplasmosis
- Community-acquired pneumonia
- Cryptococcal meningitis
- Facial palsy
- Foot drop
- Infectious mononucleosis (glandular fever) type illness
- Lymphadenopathy
- Oral candida
- Pelvic inflammatory disease
- *Pneumocystis* pneumonia (PCP)
- Psychiatric presentations
- Recurrent presentations related to alcohol, homelessness & recreational drug use
- Seizures
- Skin conditions (especially shingles)
- TB

bacterial pneumonia; they have similar signs and symptoms to the non-HIV-infected population, eg fever, cough, dyspnoea, increased respiratory rate and sputum production. Everyone who presents with pneumonia and is otherwise well should be offered a test.

TB presents with malaise, weight loss, night sweats, fever, cough, sputum production (may be blood-stained), and lymphadenopathy.

Pneumocystis pneumonia (PCP) presents with exertional dyspnoea, fever, dry cough, normal auscultation and hypoxia. X-ray typically shows perihilar shadowing (ground glass shadowing), but may be normal. PCP can lead to a pneumothorax. PCP may also have a more insidious onset and the diagnosis can easily be mistaken for interstitial lung disease.

Cryptococcal meningitis. This typically presents with headache, with or without classical signs of meningism. Occasionally, rapid progression occurs, and the patient may present in a coma, or with seizures.

Cerebral toxoplasmosis. This may present with headache, fever, lethargy and confusion, progressing to fits and coma. All adults presenting with a new seizure or space-occupying lesion should be offered an HIV test.

Recurrent presentations related to alcohol, homelessness and recreational drug use (including injecting and use of 'club drugs'), may indicate HIV risk and these individuals should be offered a test.

Individuals with psychiatric presentations may have a delirium due to an opportunistic infection and testing should be considered. Mental health issues may result in high risk behaviour as well and an HIV test should be offered.

case study**Prompt diagnosis of PCP**

Mr A is a 25-year-old previously well male who works in a bank. He presented with shortness of breath which had been affecting his usual activities at the gym. It had been getting worse over the past few weeks but in the last few days he had noticed a fever and dry cough. He had asthma as a child and wondered if it had returned. On examination he had some dry flaky red skin in the nasolabial folds and his chest was clear with no wheeze heard. A chest X-ray was unremarkable but his O₂ saturations at rest were only 92 per cent and he seemed very breathless on return from having a chest X-ray. He was markedly hypoxic when arterial blood gas was done - out of proportion with the clinical signs.

The diagnosis of PCP was made in view of his hypoxia, fever, insidious onset of symptoms. The seborrhoeic dermatitis on the face was a clue for underlying HIV. Prompt consideration of PCP in the differential diagnosis and treatment with high dose co-trimoxazole and steroids along with HIV testing and specialist input led to a full recovery. On full history-taking he revealed that he had had unprotected sex with men.

Learning points

- Severe PCP still carries a significant mortality and should not be missed.
- Prompt diagnosis of PCP can lead to a full recovery.
- Young people do not generally have severe hypoxia without a cause.

case study**Presentation may not be HIV-related**

Mr B is a 28-year-old man from Estonia who presented to the ED on a busy Saturday evening with acute back pain. He had felt his back 'give' whilst lifting a heavy sofa. On examination he was diagnosed with mild musculoskeletal injury and was prescribed ibuprofen. The doctor then noticed some small raised purple lesions on his face, which the patient said had been present for several months. On further questioning, the patient said that he had been feeling very run down over the past six months, and had lost about

10kg in weight. He had put this down to stress as he was living in a hostel and was separating from his wife. He had also been worrying about his children in Estonia, where his wife had recently been diagnosed with TB. The doctor then examined him more carefully. He had oral thrush and cervical lymphadenopathy.

Learning points

- The presence of conditions that are possibly HIV-related can be used to initiate discussions about HIV testing.

case study

HIV testing process in ED

Mr C is a 26-year-old man, living in a large Eastern European city, who presented to an ED complaining of severe right loin pain.

History, examination and investigations, including U+E, FBC were all consistent with renal colic. On presentation the nurse inserting his intravenous drip offered him an HIV test as part of the unit's screening policy. He accepted. His girlfriend also requested one and was given a card to facilitate her attendance at the local sexual health clinic. His test was reactive and he was contacted by the sexual health clinic's specialist nurses

and recalled for further testing. His only reported risk was unprotected sex with white European women.

Learning points

- In an area with a diagnosed HIV prevalence of more than 2/1000 anyone having blood samples taken should be offered an HIV test.
- Testing programmes in the Emergency Department, Medical Admissions areas and primary care, should all have clear care pathways with their local sexual health and/or infectious diseases services.

3.2 Primary HIV infection – an important diagnostic challenge

Primary HIV infection

Although the opportunity to diagnose primary HIV infection is limited by the short duration of the symptoms and their non-specific nature, making the diagnosis is extremely important because:

- the next opportunity for diagnosis may be at a late stage, with significant disease progression, and the prognosis for the patient will be worse
- early detection may protect other people from becoming infected both at the time of seroconversion as the patient is likely to be very infectious then, and subsequently if they remain unaware of their HIV status
- emerging data suggest that early treatment is beneficial to the individual^{22,23}

Some hints and tips on primary HIV infection

- A useful rule of thumb is that if you are considering infectious mononucleosis then you should also consider primary HIV infection.
- Take a history and conduct an examination to look for evidence of primary HIV infection.
- Symptoms and signs can be non-specific, but include fever, sore throat, malaise or lethargy, arthralgia and myalgia, headache, neck stiffness, meningism and cervical lymphadenopathy.
- Symptoms and signs that are more specific to primary HIV infection include rash affecting the trunk, and orogenital or perianal ulceration. Diarrhoeal illness or aseptic meningitis may occur.
- The CD4 count may drop acutely at this stage of HIV infection, and so acute conditions associated with immunosuppression may occur (eg opportunistic infections such as PCP)
- Raise the subject with the patient, eg *'Illnesses like this are usually caused by viruses – the infectious mononucleosis or flu virus. Some other viruses can also be a cause, such as HIV and we would routinely check everyone for HIV'*.

case study

Primary HIV infection resembles infectious mononucleosis

Mr D, a 32-year-old nurse, developed a flu-like illness and stayed home from work. He had a sore throat, myalgia, diarrhoea, sweats and fever. He was not improving after four days so went to see his general practitioner (GP) for a sick note. The GP felt he had 'glandular fever' (a British term for infectious mononucleosis) and signed him off work for a week due to his occupation. The day he attended the GP he noticed a faint rash on his chest which was attributed to a viral illness. Blood was taken but did not confirm infectious mononucleosis. He remained unwell and after looking up his symptoms on the internet he decided to attend an STI

clinic for a sexual health screen. The HIV point of care test was negative but, as he had had unprotected sex with a new male partner in the preceding six weeks and had symptoms of seroconversion, HIV serology was sent to the laboratory for a 4th generation test. The p24 antigen was positive. His HIV viral load was 5.4 million copies/ml and CD4 count was 459 cells/ μ L. He improved over the next few weeks and returned to work having informed occupational health.

Learning point

- Anyone presenting with infectious mononucleosis-like illness should be offered a test for HIV.

Rash of Primary HIV Infection

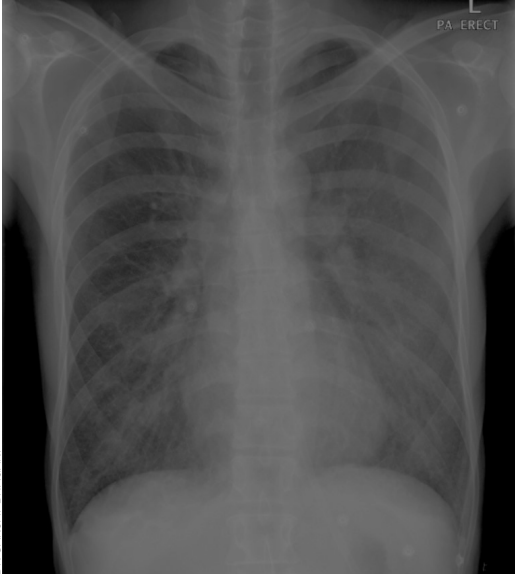


DR NICK BECHING

3.3 Respiratory medicine

From the early stage of HIV infection, patients are vulnerable to pathogens of the respiratory tract.

Chest X-ray of severe PCP in a patient presenting late with HIV



DR. SANJAY BHAGANI

HIV-related presentations

Pneumocystis pneumonia (PCP)

With CD4 counts below 200 cells/ μ L, pneumonia due to *Pneumocystis jirovecii* (previously known as *Pneumocystis carinii* and still commonly abbreviated to PCP) is common. It is a life-threatening infection and has a significant mortality rate. Symptoms are typically insidious in onset. PCP may be the first HIV-related clinical problem the undiagnosed patient develops and the earlier the infection is identified and treated the lower the mortality. PCP may present to the Emergency Department rather than respiratory clinic (see Section 3.1, page 33), although this varies throughout Europe, depending on healthcare models.

Symptoms

- persistent dry cough
- increasing shortness of breath or decreased exercise tolerance: 'I first noticed it when I ran for a bus, but now I feel short of breath just sitting'
- difficulty in taking a full breath
- fever
- diarrhoea

Assessment

The chest is often clear on auscultation, although an increased respiratory rate is often present. Fine crackles may be heard. Patients with PCP characteristically desaturate on exercise. PCP can be confused with asthma, more common atypical chest infections and even anxiety. Patients with severe disease may present with significant hypoxia. The chest X-ray typically has perihilar ground glass shadowing that spares the costophrenic angles.

Mycobacterial infections

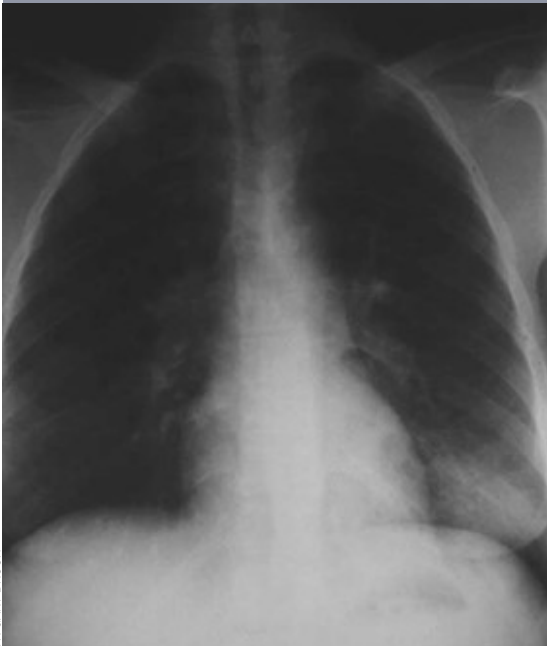
Mycobacterium tuberculosis. TB is an important and common disease in HIV-infected patients, especially those from countries which also have a high TB prevalence. Atypical mycobacterial disease (*Mycobacterium avium-intracellulare* or MAI/MAC) is less common, and is associated with late stage HIV infection.

In early HIV infection, TB typically presents in a pattern characteristic of TB in the non-HIV-infected, with upper lung zone infiltrates, often with cavities. The sputum tends to be smear positive. Cavities are a less common presentation of TB in the patient with a low CD4 cell count. These patients are more likely to present with either diffuse disease that may be miliary or with predominantly middle and lower lung zone infiltrates that can be mistaken for a bacterial pneumonia. Rates of smear negative disease are higher in individuals with a low CD4 count.

Symptoms

The patient may have a cough, fever, sweats, shortness of breath, weight loss and haemoptysis.

Left lower lobe tuberculosis in an HIV infected individual



DR GARY BROOK

Extrapulmonary tuberculosis. The prevalence of extrapulmonary tuberculosis is increased in HIV-infected patients. Low CD4 counts are associated with an increased frequency of extrapulmonary tuberculosis and atypical chest X-ray findings, reflecting an inability of the impaired immune response to contain infection. Patients with extrapulmonary tuberculosis present with signs and symptoms specific to the involved site, such as lymphadenopathy, headache, meningism, pyuria, abscess formation, back pain and abdominal pain. These findings in HIV-infected patients can present a diagnostic challenge. Whenever possible, diagnostic specimens should be examined for acid-fast bacilli (AFB) and cultured for mycobacteria.

HIV-related conditions that may present in a respiratory clinic

- Recurrent bacterial pneumonia
- TB and atypical mycobacterial infections
- Sinusitis
- Lymphocytic interstitial pneumonitis (LIP)
- Non-specific interstitial pneumonitis (NSIP)
- Fungal pneumonias (PCP, *Candida*, *Cryptococcus*, *Aspergillus*)
- Viral pneumonitis (CMV, HSV)
- Kaposi's sarcoma
- Lymphoma
- Lung cancer

***Mycobacterium avium-intracellulare* (MAI)** – also called ***Mycobacterium avium complex* (MAC)**. This may cause systemic symptoms including fever and diarrhoea: chest symptoms may or may not be present. Abnormal liver function tests (ie elevated alkaline phosphatase) and anaemia may be found.

Assessment

Usual assessment for TB (chest X-ray, sputum analysis). European Union guidelines for managing TB²⁴ recommend that all patients with TB are risk assessed for HIV.

'Ordinary' chest infections

The commonest organisms causing lung infections in the general population, eg *Streptococcus pneumoniae* and *Haemophilus influenzae*, are also a major cause of chest

infections in immunocompromised patients. They present with symptoms and signs similar to those seen in HIV-negative patients. Bacterial pneumonia may have atypical features on chest X-ray in HIV-positive patients. Individuals with a clinical presentation of community-acquired pneumonia should be offered an HIV test.

case study

A persistent cough

A 53-year-old office worker, Mr E, noticed a persistent cough for 18 months associated with some wheeze and shortness of breath. He attended his GP who referred him to the local respiratory clinic. He was a non-smoker with no occupational risk factors or pets at home. He had a past medical history of hypercholesterolaemia for which he was taking a statin. A CT scan showed a soft tissue density in the left lower lobe and some ground glass change in both lungs. He had a bronchoscopy and developed an acute reaction with pulmonary infiltrates so he was admitted to hospital. The biopsy of the lung mass revealed Epstein Barr Virus associated

lymphoproliferative disorder and an HIV test was then done which was positive. His CD4 count was 9 cells/ μ L and HIV viral load was 150,000 copies/ml. The bronchoalveolar lavage was positive for PCP. Antiretrovirals and PCP treatment were commenced; however, he deteriorated from a respiratory point of view and was intubated and ventilated and required a prolonged intensive treatment unit and ward-based hospital stay. The lung mass resolved with suppressive HIV treatment.

Learning point

- Chronic respiratory symptoms may be HIV related, doing the HIV test early in the work-up prevents late diagnosis and morbidity.

case study

A recurrence of TB

A 47-year-old migrant worker presented to the Respiratory Medicine Department with a presumed relapse of tuberculosis. He reported a history of having pulmonary TB diagnosed two months earlier in the Ukraine, where he was visiting his family and friends, and reported taking multiple pills for one month before running out of them. Since he felt better he thought it was gone. He continued to lose weight and a few weeks later he developed fever and a productive cough. His chest X-ray showed perihilar shadowing and bronchoscopy revealed PCP, while mycobacteria were not seen nor cultured in the sample from a broncho-alveolar lavage. He was offered an HIV test that was positive. His CD4+ count was 30. His PCP treatment was started followed by antiretroviral medication. Five

weeks later his fever recurred and his previously cleared chest X-ray showed some new biapical consolidation and a CT of his chest showed apical cavities. A repeat bronchoscopy sample and plain sputum sample grew *Mycobacterium xenopi*. Antimycobacterial treatment was commenced with good effect.

Learning points

- Diagnosis of TB requires early routine HIV testing.
- In severely immunocompromised patients, multiple opportunistic infections may occur at the same time.
- After commencement of antiretroviral therapy, immune reconstitution syndrome may manifest other dormant opportunistic infections, such as atypical mycobacterial disease.

case study

Chest infection

Mr F, aged 36, was referred to the local Emergency Department by his GP. He gave a 10-day history of increasing dyspnoea and non-productive cough, unresponsive to oral amoxicillin. He described having had several weeks of fever with sweats and had lost 5kg in weight. On examination he was cyanosed with fine crackles in both lung bases on auscultation. A chest X-ray showed bilateral diffuse infiltrates, O₂ saturation was 90 per cent on room air, PaO₂ (on air) =7.9 kPa, WBC = 12.3 (90 per cent neutrophils).

The initial diagnosis was severe community-acquired pneumonia and the patient was admitted to hospital by the general medical team, given supplemental oxygen by face mask, and parenteral cefuroxime and clarithromycin.

On the senior doctor review the next morning he was re-assessed. He remained hypoxic and re-examination revealed oral hairy leukoplakia and marked oral candidiasis. Underlying immunosuppression was suspected. Treatment was changed to high dose intravenous co-trimoxazole with adjuvant steroid therapy. At bronchoscopy a few days later, cysts of *Pneumocystis jirovecii* were identified in lavage fluid – confirming a diagnosis of *Pneumocystis*

pneumonia (PCP).

After discussion with the medical team the patient agreed to an HIV test. He reported that he had had receptive unprotected anal intercourse with several male partners following the breakdown of a long-term relationship some six years previously. The HIV test was positive and a CD4 count was 120 cells/ μ L. The patient was referred to the HIV specialist team and, following completion of treatment for PCP, began combination antiretroviral therapy.

Learning points

- Consider PCP in patients with recent insidious onset exertional dyspnoea or where atypical or severe respiratory infection is possible.
- Test all severe pneumonias to avoid delay in correct therapy, ie steroids, co-trimoxazole.
- People diagnosed with HIV-related problems should be referred urgently for specialist evaluation, preferably within 24 hours.
- Once the patient consents make sure that the discharge summary sent to the GP includes reason for admission, the HIV diagnosis, medication details and arrangements for HIV follow-up clinic.

3.4 Neurology

HIV-related presentations

Neurological involvement is common in those infected with HIV.

Some neurological manifestations result from a direct encephalitic effect of HIV and others from the local effects of neoplastic and infectious lesions. Focal lesions are most commonly due to *Toxoplasma gondii*, cytomegalovirus, herpes simplex virus, lymphomas, or HIV virus itself. Meningitis is most commonly caused by *Cryptococcus neoformans* and more rarely due to tuberculosis or bacterial infections. Seroconversion illness may present as viral meningitis as well.

Neuropathies

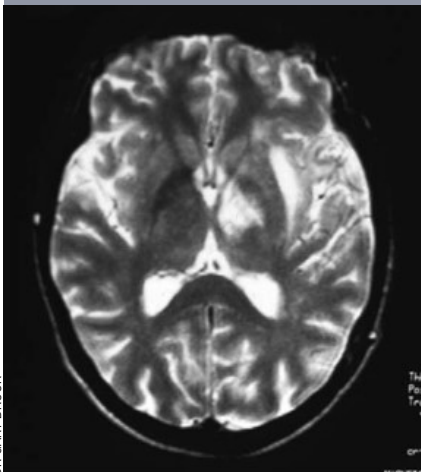
Peripheral neuropathies are common in HIV-infected patients and may be a result of:

- HIV
- opportunistic infection
- a complication of medication (mainly associated with didanosine and stavudine, and less commonly with lamivudine. As the former two are now infrequently prescribed this may only come to light on taking a drug history.)
- nutritional deficiency (eg B12 or folate deficiency).

Patients may also present with:

- Guillain-Barré syndrome or transverse myelitis.

MRI scan of progressive multifocal leucoencephalopathy



DR GARY BROOK

HIV encephalopathy

HIV encephalopathy, also known as HIV or AIDS-related dementia, is one of the most common and clinically important CNS complications of late HIV infection. While its pathogenesis remains unclear it is generally thought to be caused by HIV itself, rather than another opportunistic infection and the primary treatment is antiretroviral therapy.

Neurosyphilis

In Europe, there has been a resurgence of syphilis. Men who have sex with men have been disproportionately affected and around half of these men were HIV-positive²⁵. Therefore, there should be a high index of suspicion of HIV with any presentation of syphilis.

Symptomatic early neurosyphilis usually occurs within the first 12 months of infection. Symptoms include meningitis, cranial and optic nerve abnormalities, uveitis and stroke.

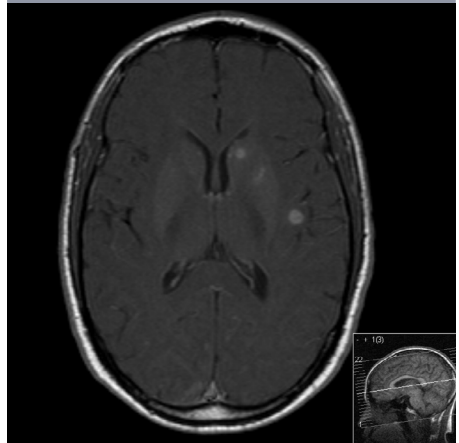
Clinical features of HIV-related neurological conditions

- Toxoplasmosis presents with focal neurology evolving over a few days.
- Cryptococcal meningitis presents with headaches and cranial nerve abnormalities. Meningeal symptoms may be absent. Occasionally the patient may present to the Emergency Department in a coma.
- Cytomegalovirus (CMV) encephalitis presents with confusion, lethargy, cranial nerve palsies and nystagmus; it occurs with advanced immunosuppression.
- HIV encephalopathy presents with cognitive and motor impairment.
- Progressive multifocal leucoencephalopathy (PML) presents with weakness, headaches, speech impairment, altered vision and weight loss. It is caused by the human polyomavirus (JC virus).
- Primary cerebral lymphoma (also known as primary CNS lymphoma) is a cause of cerebral lesions in patients with advanced HIV disease. The most common signs and symptoms are confusion, lethargy, and personality changes or focal deficits, eg hemiparesis, hemisensory loss, ataxia, and aphasia.

HIV-related conditions that may present in a neurology clinic

- CNS infections
- Toxoplasmosis
- Cryptococcus
- Aseptic meningitis/encephalitis
- Cerebral abscess
- CMV
- Space-occupying lesions
- Guillain-Barré syndrome
- Dementia
- Transverse myelitis
- Peripheral neuropathy
- Progressive multifocal leucoencephalopathy (PML, JC virus)
- Primary CNS lymphoma
- Vacuolar myelopathy
- Neurosyphilis

Contrast enhancing intracerebral lesions – cerebral toxoplasmosis



DR SANJAY BHAGANI

case study

Viral meningitis that failed to get better

Ms Z, a 20-year-old female student, presented to the Infectious Diseases Department with a one-week history of progressive headaches, photophobia and fevers. Neurological examination was unremarkable apart from neck stiffness. Lumbar puncture was performed, revealing raised lymphocytes (56 per μL) and protein (0.95 g/L). Three weeks prior to the admission, she spent two weeks on vacation in an Italian beach resort. Lyme disease, tick borne encephalitis, West Nile virus and other endemic infections were negative. Her fevers and headaches persisted for two more weeks. An HIV test was offered although the patient was perceived low risk and had denied any high risk behaviour. A 4th

generation test was reactive and confirmatory testing was positive. Her CD4+ count was 350. Antiretroviral treatment was started and symptoms rapidly resolved.

Learning points

- Meningitis may be a manifestation of primary HIV infection. In all cases of aseptic meningitis where no clear cause is identified, an HIV test should be offered routinely.
- Women in general tend to be diagnosed with more advanced HIV disease than men, as they are not perceived as a high risk group.
- Denial of high risk behaviour does not exclude occasional high risk behaviour.

case study

Too young for stroke

Mr Y, a 35-year-old professional, was admitted to a neurology ward with sudden onset left sided hemiparesis and expressive and receptive dysphasia. His friend reported that he had been having headaches and difficulty concentrating over the previous week. An MRI scan had shown three small subcortical hyperintensities in the right hemisphere in the capsula interna. Lumbar puncture showed a raised lymphocyte count and protein, with normal glucose. Syphilis serology was positive. An HIV test was positive.

Learning points

- Sudden onset neurological illness and/or focal lesion in the CNS should trigger a routine HIV test.
- Diagnosed sexually transmitted diseases should always trigger a routine HIV test as these conditions often co-exist.
- HIV itself can be associated with brain focal inflammation and vasculitis.
- HIV testing without consent may be done in circumstances where patients' best interests are taken into account and documented. Local guidelines should be followed.

case study

Peripheral sensory neuropathy

Mr G, a 56-year-old, recently divorced, Swiss business man presented to his family physician with a several month history of cotton wool sensation on the bottom of both feet. He was normotensive and normoglycaemic. He seldom drank, was a non-smoker and travelled extensively for work. Examination was consistent with a mild bilateral peripheral sensory neuropathy. After initial investigations (including normal B12) he was referred for further investigations. Examination confirmed the previous findings, and initial investigations were unremarkable apart from a significantly elevated serum globulin. After three visits and no cause being identified he was referred to the vascular surgeons for assessment, who felt there was no underlying arterial cause. Whilst awaiting a further appointment he attended a sexual

health clinic for a sexual health screen and was diagnosed with HIV; his CD4 cell count was 269 cells/ μ L. His regular female partner with whom he was having unprotected sex was found to be HIV-negative, including after the window period.

Learning points

- Peripheral sensory neuropathy occurs frequently in people with HIV infection, both on and off ART. The prevalence of HIV in those presenting with peripheral neuropathy is estimated at 4 per cent²⁶ (and is currently being evaluated in a larger group in the European HIDES II study). It falls within the indicator condition category which means an HIV test should be offered.
- Elevated globulin levels are common in HIV infection and if seen in the absence of another underlying cause should prompt the offer of an HIV test.

3.5 Dermatology

Kaposi's Sarcoma



DR GARY BROOK

HIV-related presentations²⁷

Skin conditions occur in more than 90 per cent of people with HIV during the course of their infection²⁸. Some people have an exacerbation of a pre-existing condition, such as psoriasis. This often occurs when the patient becomes increasingly immunocompromised. Others may have new skin problems, most of which are also commonly found in the general population, although some, such as Kaposi's sarcoma, are strongly suggestive of underlying HIV infection.

HIV-related conditions that may present in a dermatology clinic

- Seroconversion
 - Rash
 - Alopecia
- Pruritus
- Exanthems
- Acne (vulgaris/rosacea)
- Psoriasis
- Vasculitis
- Urticaria
- Ichthyosis
- Xerosis
- Alopecia (diffuse and areata)
- Fungal/yeast infections
 - Seborrhoeic dermatitis
 - Candida
 - Tinea (facei, corporis, cruris, pedis, unguium)
 - Pityriasis
 - Onychomycosis
- Viral infections
 - Herpes zoster
 - Herpes simplex
 - Viral warts (HPV)
 - Molluscum contagiosum
 - Epstein Barr Virus (hairy leukoplakia)
- Bacterial infections
 - Staphylococcal, impetigo, folliculitis, cellulitis
 - Mycobacterial lesions
- Infestations (scabies)
- Neoplasia
 - Skin cancer (basal cell carcinoma, squamous cell carcinoma, melanoma)
 - Kaposi's sarcoma
 - Lymphoma
 - All anal and genital carcinoma
- Drug hypersensitivity

Seborrhoeic Dermatitis



DR MA ANSARY / SCIENCE PHOTO LIBRARY

WELLCOME IMAGES

case study

Common skin problems

Mr H was a 21-year-old student. He had returned two weeks previously from a year in Malawi, where he had taught secondary school English. He had had mild psoriasis since age 10, which was well-controlled whilst he was in Africa. Immediately after returning, his skin had flared up becoming significantly worse than previously. He was single, a non-smoker, and drank 20 units of alcohol a week. He was referred by his family doctor to the dermatology clinic. The registrar treated him for psoriasis with topical corticosteroids and vitamin D analogues and arranged review in two weeks.

On review his rash was worse and he was pyrexial with enlarged cervical glands. Another doctor examined him and recognised that the rash was morbilliform and not typical of a psoriasis exacerbation. The doctor asked Mr H about his sexual history. He said that he had had a girlfriend in Malawi, and that they did not always use condoms. He had never

had any sexually transmitted infections. The doctor took blood for appropriate tests, which confirmed primary HIV infection. Mr H was distraught when he got the results and initially stated that he did not want anyone to be told about his result, including his family doctor. He was referred to the HIV specialist team and, after further discussion of the issues with the counsellor, he felt that it was in his best interests to inform his family doctor.

Learning points

- HIV infection can often exacerbate common skin conditions.
- Although sometimes people with newly-diagnosed HIV are initially reluctant to share their HIV result with their family doctor, it is almost always in the patient's best interest to establish normal communication with the GP.
- Any patient diagnosed with HIV should be immediately referred to an HIV specialist for further management¹⁰.

3.6 Gastroenterology and hepatology

HIV-related presentations

Diarrhoea

Acute or chronic diarrhoea can be a feature of HIV at any stage of the infection. Diarrhoea is most commonly due to an infection and much more rarely due to HIV enteropathy or malignancies such as Kaposi's sarcoma, lymphoma or bowel cancer. Symptoms of colitis or small-bowel watery diarrhoea are common, and often very distressing.

In one national audit of new HIV diagnoses the most common indicator condition for patients newly diagnosed with HIV, the most common indicator condition they presented with at the time of diagnosis, or had presented for care for, in the preceding 12 months was diarrhoea²⁹.

CMV can cause a colitis which can present with bloody diarrhoea and fever. Diagnosis is made on biopsy. Unlike CMV retinitis this can occur in individuals with a high CD4 count.

Lymphogranuloma venereum (LGV) is a sexually transmitted infection (certain subtypes of chlamydia) which can present with diarrhoea or constipation, rectal pain and discharge, tenesmus, and PR bleeding. It

Causes of diarrhoea in people with HIV

Bacterial

- *Campylobacter* and *Salmonella* species are more likely to produce bacteraemia in people with HIV. Consider HIV testing in anyone with salmonella bacteraemia
- Enteroaggregative *Escherichia coli* (eAggEc) and other *E coli*
- *Clostridium difficile*
- Shigella

Protozoal

- *Cryptosporidium* species (AIDS-defining when persistent)
- *Giardia lamblia*
- *Isospora belli*
- *Entamoeba histolytica*
- *Microsporidium* species (only in

severely immunocompromised)

Mycobacterial

- *Mycobacterium avium-intracellulare* (MAI) (only in severely immunocompromised)

Viral

- Adenovirus
- CMV (only in severely immunocompromised)

Non-infectious

- Kaposi's sarcoma
- Lymphoma
- Cytopathic effects of HIV – chronic diarrhoea of unknown cause, weight loss of unknown cause

is primarily seen in HIV-positive men who have sex with men. If suspected a full sexual health screen should be performed.

Oesophageal candidiasis

This is seen in patients with a low CD4 count. It presents with dysphagia, odynophagia, retrosternal pain, nausea and vomiting. Oropharyngeal candidiasis is nearly always present, and can form the basis for a presumptive diagnosis of oesophageal candidiasis if the patient is HIV-positive and has difficulty swallowing. All patients with these symptoms should have an HIV test.

Cholangitis

Patients with HIV can also present with cholangitis secondary to opportunistic infections such as CMV, cryptosporidiosis or microsporidial infection (usually in those who are severely immunocompromised).

Viral hepatitis

Co-infection of HIV with viral hepatitis is not unusual and the infections share the same modes of transmission. Co-infected patients have an increased risk of liver fibrosis and progression to cirrhosis and hepatocellular carcinoma.

All patients with hepatitis B or C should be tested for HIV, as knowing about the dual diagnosis alters the way both conditions are managed.

Vaccination should be offered to those who are hepatitis A and B negative. There are various treatment considerations when treating HIV and hepatitis B or C including new treatments, drug-drug interactions and avoidance of precipitating resistance. All patients with HIV and viral hepatitis co-infection should be managed by specialists with expertise in this area.

HIV-related conditions that may present in a gastroenterology & hepatology clinic

- Chronic diarrhoea
- Oesophageal candidiasis
- Cholangitis
- Weight loss of unknown cause
- Proctitis - often secondary to lymphogranuloma venereum (LGV)
- Viral hepatitis A B C D E

case study

Hepatitis C co-infection

A 35-year-old man, Mr K, was referred by his GP to the gastroenterology clinic. He had been complaining of tiredness and general malaise for several months and the only abnormality the GP had found was mildly elevated liver enzymes. He acknowledged having used intravenous drugs a few times as a teenager and was tested for hepatitis C and HIV infection. Hepatitis C antibody was detectable, his liver function tests were mildly abnormal and his subsequent liver biopsy revealed early fibrosis. He was referred for treatment of his hepatitis C.

His HIV test was also positive with a CD4 count of 550 cells/ μ L and an HIV viral load of

2,000 copies/ml. He was referred to the specialist HIV unit to be assessed for ART.

He was also offered advice about reducing his alcohol intake and reducing the risk of transmitting HIV and hepatitis C to future partners. Patients who have hepatitis C and HIV are more likely to transmit hepatitis C sexually.

Learning points

- Hepatitis C co-infection should be actively sought and treated to prevent progression to cirrhosis and hepatocellular carcinoma.
- Co-infected patients should be referred to the HIV specialist team as soon as possible for assessment for ART.
- Hepatitis C is curable.

case study

Anorexia that was not nervosa

A 20-year-old female was admitted to the gastroenterology unit in the Czech Republic for nutritional support due to significant weight loss of 14kg over the last six months (her weight had decreased to 47kg from previous 61kg). She was being treated by her psychiatrist for an eating disorder, anxiety and depression. She complained of fatigue, complete loss of appetite and loose stools 3 to 5 times a day. The stools were charted and laxative abuse was ruled out while she was being investigated as an inpatient. Cryptosporidia eggs were found in the stool and her HIV test was positive with a CD4+ count of 9. Antiretroviral treatment was started rapidly. Despite this, her

diarrhoea became worse resulting in severe malabsorption, and intractable gastrointestinal bleeding. The patient died in intensive care five weeks later. All of her reported sexual contacts were offered HIV testing and tested negative.

Learning points

- Anxiety and weight loss in a young woman due to HIV could be misdiagnosed as an eating disorder.
- In some cases, HIV infection may progress very rapidly to AIDS.
- An HIV test should be a part of routine screening in any cases of significant weight loss, chronic diarrhoea, and fatigue.

3.7 Oncology

HIV-related presentations

Three malignancies are closely associated with HIV infection and their diagnosis classifies an HIV-infected patient as having developed AIDS. These are cervical cancer, Kaposi's sarcoma and non-Hodgkin's lymphoma.

In addition, an increasing number of other cancers are now recognised as being more common in those with HIV than in the general population.

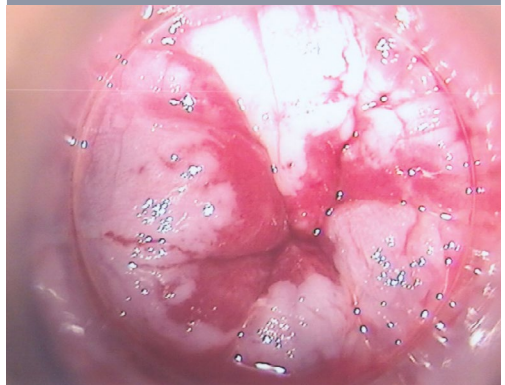
As both Hodgkin's and non-Hodgkin's lymphomas are associated with HIV infection, it is recommended that all individuals with lymphoma should be tested for HIV¹⁷.

Primary central nervous system lymphoma is more common in HIV-infected patients than in the general population, although it is a feature of late-stage disease.

HIV-related conditions that may present in an oncology clinic

- AIDS-defining cancer
 - Cervical cancer (HPV-related)
 - Non-Hodgkin's lymphoma
 - Kaposi's sarcoma (human herpes virus 8-related)
- HPV-related
 - Anal cancer and anal intraepithelial neoplasia
 - Vulval and vaginal intraepithelial neoplasia
 - Head and neck cancer
- Hodgkin's lymphoma (Epstein Barr Virus-related)
- Lung cancer
- Liver cancer (Viral Hepatitis B C)
- Colorectal cancer
- Melanoma
- Renal cancer
- Seminoma
- Castleman's Disease (human herpes virus 8-related)

Anal pre-cancer (AIN 2/3)

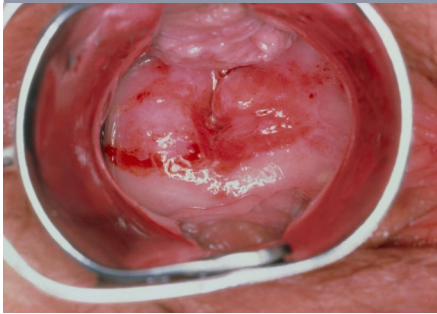


DR MAYURA NATHAN

3.8 Obstetrics and gynaecology

In the last decades, European countries have implemented to a various degree a universal antenatal screening policy for HIV. All pregnant women in Europe should be routinely recommended and offered an HIV test during pregnancy^{15,30}.

Cervical cancer



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In 2013, fewer than 1 per cent of incident HIV infections were due to mother-to-child transmission, demonstrating the effectiveness of antenatal diagnosis and treatment⁴.

The UK National Guidelines for HIV Testing 2008³¹ recommend universal HIV testing for all women attending termination of pregnancy services. This is based on evidence from unlinked anonymous seroprevalence surveys conducted in inner London termination clinics that there is a consistently higher prevalence of HIV infection in women terminating their pregnancies compared with those giving birth³². Other European countries may show similar patterns.

HIV-related presentations

Women with HIV, especially those with a low CD4 count, are more at risk from human papilloma virus (HPV)-related disease, including cervical intraepithelial neoplasia (CIN), cervical cancer, vaginal intraepithelial neoplasia (VIN) and genital warts. HIV testing should be performed in all women with cervical cancer and in those with CIN 2 or 3 or VIN.

Incidental findings

HIV testing should also be considered in women with severe recurrent vaginal candidiasis, genital herpes and pelvic inflammatory disease (PID), particularly if the presentations are chronic or florid or if they have other HIV risk factors. Smear abnormalities suggestive of HPV infection should also prompt consideration of an HIV test.

Any diagnosis of a sexually transmitted infection is considered as an indicator condition and should prompt the offer of an HIV test.

Almost all fertility clinics are now offering HIV testing as routine to patients.

Florid Genital Warts



DR C O'MAHONY

3.9 Haematology

Haematological abnormalities are common in those with HIV and are often the first presentation in undiagnosed patients. Impaired haematopoiesis, immune-mediated cytopenias (anaemia, thrombocytopenia, neutropenia and lymphopenia), B-cell dysregulation and altered coagulation mechanisms have all been described. Lymphoma is also more common in HIV (see Section 3.7). These abnormalities may occur as a result of HIV infection itself, as sequelae of HIV-related infections or malignancies, or as a consequence of drugs used to treat HIV and associated complications and immune dysregulation. Changes on a routine blood count may therefore suggest possible HIV infection and testing should always be routinely offered in individuals presenting with unexplained cytopenia.

Although blood products are now screened throughout Europe, in some parts of Europe and in other parts of the world, contaminated blood products may have previously resulted in HIV infection; therefore individuals with haemophilia and other clotting disorders should be offered an HIV test on first presentation.

Anaemia is a common finding in patients with HIV, particularly in individuals with more advanced disease, and is the strongest predictor of mortality in untreated patients. Anaemia may arise due to infiltration of the marrow because of malignancy or infection (such as *Mycobacterium avium-intracellulare* and parvovirus). Other causes include haematinic deficiency, including vitamin B12 and folate in cases of HIV related malabsorption and iron deficiency (from chronic blood loss in patients with colitis, Kaposi's sarcoma and peptic ulcer disease).

Thrombocytopenia is frequently associated with HIV infection. Possible aetiologies include immune-mediated destruction (idiopathic or due to mimicry of HIV directed antibodies), splenic pooling and marrow

suppression, especially in patients with hepatitis C co-infection. Thrombotic thrombocytopenic purpura (TTP) is seen in patients with HIV (typically in the treatment naive and occasionally in those on ART). This typically presents with the pentad of thrombocytopenia, microangiopathic haemolytic anaemia, neurological symptoms, renal failure and fever. It is associated with a high mortality and is a medical emergency. All presentations of TTP should prompt an urgent HIV test.

Neutropenia and **lymphopenia** are common in those with HIV infection. Low lymphocyte counts often reflect a low CD4 count and this should prompt HIV testing. There is a high incidence of neutropenia and lymphopenia in those with more profound immunodeficiency.

HIV-related conditions that may present in a haematology clinic

- Lymphoma
- Anaemia
- Thrombocytopenia
- Leukopenia/neutropenia
- Venous thromboembolic disease
- Thrombotic thrombocytopenic purpura

3.10 Ophthalmology

HIV-related conditions that may present in an ophthalmology clinic

Viral

- Herpes zoster ophthalmicus/retinitis
- Herpes simplex keratitis
- CMV retinitis
- Herpes simplex virus

Protozoal

- *Toxoplasma gondii*

Fungal

- Microsporidial keratoconjunctivitis
- *Candida endophthalmitis*

Other

- Syphilis
- Kaposi's sarcoma
- Lymphoma

HIV

- Retinal haemorrhages
- Cotton wool spots
- Optic neuropathy
- Retinal arterial occlusion

HIV-related presentations

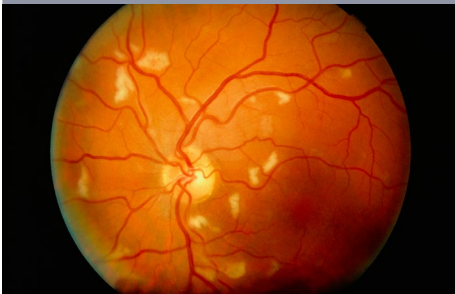
Unexplained or atypical retinopathies or uveitis may indicate underlying HIV infection. HIV itself commonly causes retinal haemorrhage and cotton wool spots and rarely optic neuropathy. Kaposi's sarcoma may spread to involve the conjunctivae, eyelids and orbit in patients who are severely immunocompromised.

Vision can also be compromised by infections with CMV, varicella zoster virus (VZV), herpes simplex virus, syphilis, herpes zoster virus and *Toxoplasma gondii*.

CMV retinitis can cause blindness if untreated. It is usually seen in severely immunocompromised patients with a CD4 count of less than 100 cells/ μ L. CMV retinitis may be the first presentation for people with HIV.

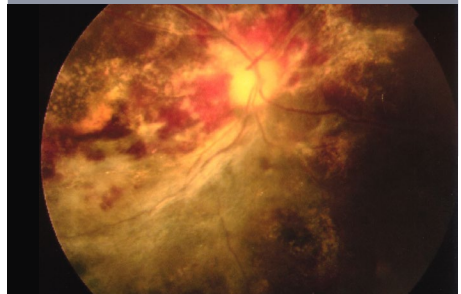
VZV retinitis can cause significant peripheral outer retinal necrosis (PORN) and visual impairment.

HIV retinitis



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CMV Retinitis



DR NICK BECHING

3.11 Ear, nose and throat

HIV-related presentations

HIV can cause many conditions of the ear, nose and throat. Individuals with undiagnosed HIV may present to an ear, nose and throat (ENT) clinic and it may be the first opportunity to offer them an HIV test.

HIV should be considered in patients with persistent cervical lymphadenopathy, which may be due to HIV itself or secondary to infections (especially TB) and tumours (especially lymphoma).

Infection or inflammation of the sinuses is a common problem among people with HIV and its severity increases in people with lower CD4 cell counts.

HIV-related conditions that may present in an ENT clinic

- Head and neck cancer
- Chronic parotiditis
- Oropharyngeal candidiasis
- Aphthous ulceration
- Recurrent/severe herpes simplex infection
- Oral hairy leukoplakia
- Gingivitis, dental abscess
- Kaposi's sarcoma (palate)
- Sinusitis
- Lymphadenopathy
- Salivary gland enlargement

Oral hairy leukoplakia



WELLCOME IMAGES

case study

Oral lesions and recurrent parotitis

A 27-year-old male presented to a rapid access ENT clinic with recurring bilateral parotid swelling without fever. On examination, no salivary duct obstruction was seen and other investigations were also unremarkable. An HIV test was not considered. The swelling resolved spontaneously after four weeks on symptomatic treatment. Three weeks later he presented again with ulcerous lesions on the left side of his nose, and on the soft and hard palate. At the same time, his cervical lymph nodes were swollen. A swab from the lesion was PCR positive for varicella zoster virus. The lesions healed on acyclovir treatment. On a follow-up visit he

was offered HIV testing by one of the more junior doctors and the test was positive. His CD4+ count was 290. Antiretroviral treatment was started rapidly. The lesions never recurred.

Learning points

- Parotid swelling may be directly HIV related or secondary to opportunistic infections, including TB.
- Zoster either recurring, generalised or in unusual locations indicates immunosuppression and should prompt an offer of HIV testing.
- A review of the patient's history and actively asking about other health problems may reveal the need for an HIV test.

3.12 Mental health

Risk factors for HIV infection are common in those with mental health problems. Migrants from areas of high heterosexual spread, men who have sex with men and those with a history of injecting drug use are all at elevated risk of HIV infection. Some migrants are at increased risk of severe mental health problems and, possibly, common mental health problems and many people with a history of injecting drug use have mental health problems. The direct links between mental health problems and sexual risk behaviour are complex and depend on the condition and individual circumstance. Mental health problems can lead to an increase in unsafe sexual behaviours or, conversely, reduced libido and/or social isolation can reduce sexual activity.

There is a lack of good epidemiological studies of HIV infection in those with mental health problems but most studies point, unsurprisingly, to elevated prevalence.

It is important to consider HIV as part of the differential diagnosis in cognitive impairment. HIV infects the brain and can itself cause cognitive impairment ranging from mild impairment to severe HIV-associated dementia. HIV-related immunodeficiency puts individuals at risk of opportunistic brain infections and some neoplasms. (See Section 3.4 on neurological disorders for further information).

Psychosis and severe mood disorder even in the absence of (obvious) cognitive impairment are more common in those with HIV infection, although the mechanisms are unclear. Some antiretrovirals can themselves cause psychiatric syndromes and/or cognitive impairment.

Anxiety and depression are more common in those with HIV infection. In some cases this is the result of individuals knowing their status, but in other cases the link seems to be indirect. For instance, depression is more common in men without a partner and risky sexual behaviour may be used as a means of temporarily regulating mood. This suggests that mood disorders are likely to be common in those with undiagnosed HIV infection.

case study

Mr W was an Eritrean migrant in his late twenties. He was admitted into a general psychiatric ward with first episode psychosis. He gave a history of substance misuse, but not of injecting. He denied same sex sexual activity. He gave a history of hepatitis B infection, confirmed on serology, which he attributed to non-sterile medical procedures in Eritrea. He was offered an HIV test which he accepted and the result was positive. The patient reacted well to the result with careful counselling. After further tests he was started on ART and, after links were made with the medical practitioners at the centre where he was housed he was discharged with follow-up arrangements in place.

Learning points

- All individuals coming from an area of high

HIV prevalence should be offered routine HIV testing.

- Offering a test was straightforward, the patient was able to give informed consent and the positive result did not adversely affect his mental state. The risk of an adverse reaction to a positive result can be reduced by careful post-test counselling as with any other patient.
- Whether the HIV infection was a factor in his psychotic episode is unknown, but detecting the infection and treating it effectively was important in preventing onward transmission; and relatively early detection and treatment reduced the risk of early death.
- Discharge planning for migrants should be done together with the relevant health providers that work with migrants.

3.13 Other presentations where HIV testing should be routinely offered

Pyrexia of unknown origin

Pyrexia of unknown origin (PUO) covers a broad range of possible diagnoses.

PUO in inpatients who have not been previously diagnosed with HIV should therefore prompt consideration of HIV infection and inclusion of HIV testing in their investigations. PUO in the context of a potential tropical infectious disease should also prompt consideration of HIV in patients who have been abroad recently and who present with symptoms. This could be primary HIV infection (see also Section 3.2).

In patients with advanced HIV infection prolonged febrile episodes are frequent. The causes are mainly the result of opportunistic infections (eg MAI, PCP) or malignancies and rarely due to HIV itself.

case study

Primary HIV infection

Miss J was a 30-year-old university lecturer who presented at the Emergency Department with a five-day history of fever, headache, sore throat and a sore mouth. She said she was worried that she might have malaria, as she had returned from a safari holiday in Namibia about 10 days previously, although she had taken antimalarials as prescribed whilst away. On examination, Miss J was pyrexial with mouth ulcers. The malaria slide and malarial antigen tests were negative, her

erythrocyte sedimentation rate was raised and she had slight neutropenia. Miss J agreed to have an HIV test. The p24 antigen was positive and the HIV antibody test negative, confirming primary HIV infection. She then stated that she had had unprotected sex with the tour guide whilst on her safari.

Learning point

- Consider primary HIV infection in people with fever returning from overseas travel to areas of high HIV prevalence.

Sexually transmitted infections

The 2014 European Guideline on HIV testing recommends that all patients presenting with symptoms of a sexually transmitted infection (STI), or for a routine STI screen, should be tested for HIV¹⁰.

The behavioural risk factors for most STIs are the same as those for HIV (unprotected vaginal or anal intercourse) and this should prompt an HIV test even in those patients who do not belong to one of the traditional at-risk populations.

3.14 Paediatrics

The overwhelming majority of children with HIV are infected through mother-to-child transmission. By 2013, the European network of HIV-cohorts, EuroCoord (www.eurocoord.net), had registered cumulatively 8229 perinatally HIV-infected individuals from 16 European countries excluding Switzerland, Ukraine and Russia. The cohorts from France, Italy, Spain and the UK contributed 88 per cent³³. However, these figures are estimates as some countries do not have established cohorts and only a few have a national cohort covering all treatment centres³⁴.

The epidemiology of paediatric HIV infection in Western and Eastern Europe differs substantially. In Western Europe, effective measures to prevent primary HIV infection in women, HIV testing and counselling of pregnant women during the first and third trimesters, and access to antiretroviral therapy for effective prevention of mother-to-child transmission of HIV have resulted in a low incidence of new paediatric infections of fewer than 200 per year in 2012. In contrast, the numbers of HIV-infected infants in some Eastern European countries are increasing, mostly due to an increase in HIV-infected pregnant women. However, some new paediatric infections are still reported from Western European countries, particularly associated with people with HIV (diagnosed or not) immigrating³⁵ from highly endemic countries.

Children may be diagnosed with HIV because they present with symptoms or because they are tested after their parents or siblings are found to be HIV-infected. Although mother-to-child transmission of HIV in Western Europe is now generally a very rare event, new infant infections may still occur especially in the context of a mother who fails to engage with medical services. Infants are at particular risk of severe HIV disease and up to 20 per cent will develop an AIDS diagnosis or die within the first year of life if they do not receive appropriate treatment³⁶. Infants most often present with PCP, CMV disease, HIV encephalopathy, and/or failure to thrive.

After the first year of life older children may present with recurrent infections (of the ear, chest or skin, for example) or more severe manifestations of common childhood infections (eg severe chicken pox). Certain infections such as severe pneumonia or TB

Paediatric herpes zoster with superinfection



are particularly associated with HIV infection. Whenever they occur in a child, HIV testing is recommended. Another common presentation of HIV in children is chronic painless swelling of the parotid glands, as well as chronic enlargement of the cervical glands and recurrent upper respiratory tract infections. This is often accompanied by lymphoid interstitial pneumonitis (LIP) where there is infiltration of the lungs with nodules of inflammatory lymphocytes. It is usually asymptomatic, but has a characteristic appearance on chest X-ray which can be difficult to distinguish from miliary tuberculosis. Children of any age with more advanced immunodeficiency may present with AIDS diagnoses similar to those seen in adults.

With access to treatment and adequate adherence support, infants and children respond very well to ART with the prospect of long-term survival into adult life. Children in Western European paediatric cohorts are now progressing to adolescence and transitioning to adult services. The

majority of them are well and managed as outpatients. Current challenges facing clinical teams involve complex issues of adherence, transition to adult care and sexual health in this adolescent group. In many countries, most HIV-infected children are managed in specialist centres attached to teaching hospitals in close collaboration with antenatal and obstetric services to optimise psychosocial, preventive, diagnostic and treatment strategies. The European Network for the Treatment of AIDS (PENTA) provides paediatric treatment guidelines³⁷ which are endorsed by multiple national HIV associations.

Paediatric parotid swelling



DR LEON LEVIN

Consider HIV in children if a parent is diagnosed

If an adult is diagnosed with HIV then they must always be asked if they have children. All children of HIV-infected parents who are potentially at risk of HIV infection should have an HIV test, the result of which should be documented in medical records. In infants this is urgent. In older children who are well it is less so; however, the process can be complex. If parents decline testing or it is not clear which method of testing should be used, the family should be referred to a local paediatric team with experience in counselling and testing in this context. Children and young people may be infected with HIV and never have presented with symptoms even up to 20 years of age. Therefore, whatever a child or young person's age, if a family member has been diagnosed with HIV then they should always be recommended to test.

case study

Late diagnosis in a child

Mrs O had lived in the UK for 10 years, and was originally from Uganda. She brought her 14-year-old niece, B, to the General Practitioner (GP) as she was worried about some painful spots on her leg. The GP diagnosed herpes zoster affecting L2-4 dermatomes and the lesions resolved after treatment with acyclovir.

On review, Mrs O informed the GP that B had arrived in the UK six months previously to live with her, as her own mother had recently died of tuberculosis. Her father had died of cancer four years previously, and her baby brother had died of pneumonia seven years ago at three months of age.

The GP recommended that given B's recent herpes zoster and her family history, she should have an HIV test. Initially Mrs O

refused testing as she was worried about testing B and could not believe that she could be possibly infected when she was so well. The GP referred them to local paediatric HIV services. After involvement of the multidisciplinary team, Mrs O consented and B underwent testing, having also given informed consent. Her result was positive and she was started on treatment.

Learning points

- Some children with HIV only present with symptoms in the second decade of life.
- Always take a family history; this may identify risk factors for HIV in a child with or without significant symptoms.
- If difficulties arise when a child requires HIV testing, referral should be made to local paediatric HIV services.

case study

HIV infection during pregnancy

Ms S had a negative HIV test in pregnancy when she first visited antenatal care services at 12 weeks of gestation. By the time her baby, A, was 14 weeks old he had been treated twice by her family doctor for oral thrush which had persisted. Two days ago A was admitted to the Paediatric Intensive Care Unit (PICU) with severe pneumonia. He was now very ill and on a ventilator. The PICU doctor informed Ms S that A had a very severe kind of pneumonia called PCP, which usually only occurs in infants with immune deficiency. The doctor advised that his immune system needed to be tested and that this would involve an HIV test. Ms S explained that she had had a negative HIV test in pregnancy so she did not think that A could have HIV. The doctor explained that if a mother becomes infected with HIV during pregnancy or whilst breastfeeding then she has a high chance of passing it to her baby, as during primary HIV infection there is a very high level of the virus in the blood which could infect the

baby during birth, and in the breast milk which may pass to the baby during feeding. Ms S then told the doctor that A's father was from Zimbabwe and that he had returned from a three-month visit there when she was seven months pregnant. She agreed to the HIV test and the result showed an HIV infection in the infant.

Learning points

- Even though a mother has had a negative HIV test at the first visit at antenatal care she could have acquired HIV in pregnancy and her infant could have HIV.
- Women with ongoing risk for HIV should have repeat tests during pregnancy so they can access antiretroviral therapy to reduce the risk of mother-to-child transmission of HIV.
- Pregnant and lactating women should be advised to have protected sex to prevent transmission of sexually transmitted infections which may cause disease in mother and foetus/baby (eg HIV, syphilis, gonorrhoea, chlamydia).

Section 4

Pre-test discussion

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Pre-test discussion

Pre-test discussion

The term 'pre-test discussion' is now considered to be more appropriate than 'pre-test counselling'¹⁵ which was previously used and implied the need for in-depth counselling by a specially-trained healthcare worker.

For the clinician, the main reason for a pre-test discussion is to obtain the patient's informed consent to be tested for HIV. However, for the patient it may also be an opportunity to consider the possible outcomes and their consequences in the broader context of their own lives. The time a discussion may take is variable. With a moderately well informed, lower risk person the discussion may take just a minute or two, but with a person from a marginalised group with a high risk of HIV infection there are many factors which can impact upon their decision to take an HIV test. These are discussed more fully in Section 6.

There are several key pieces of information which should be given to a patient to ensure they can give informed consent. These can be delivered in printed form; and the patient can then be asked if they have any questions and if they consent to a test. It is often worthwhile to repeat what is written regarding how they will receive their results.

The following is a breakdown of the essential areas that need to be covered in a pre-test discussion, whether verbally or in written form.

Discuss the benefits of performing an HIV test

As when proposing any clinical investigation, it is important to inform the patient of the rationale for testing. They should be informed of the advantages of early detection and access to effective treatment and support services; prevention of transmission to sexual partners should be emphasised. In the vast majority of cases this will be sufficient.

However, there are various reasons why some patients may be particularly apprehensive about taking an HIV test; it may be a lack of up-to-date knowledge regarding the effectiveness of treatment but can also include fear related to stigma, discrimination, loss of employment, or the detrimental impact of a positive test result on immigration procedures, insurance and mortgages, so clarity and reassurance (as appropriate) about confidentiality is important. Some patients, particularly those who are asymptomatic, may believe they are better off not knowing; such concerns should be listened to, addressed and balanced against the significant advantages of knowing one's status if positive.

Some patients may find the use of the term 'positive' to be confusing and it has been known for patients to equate 'positive' with 'good news', and to assume therefore that they do not have HIV. This should be clarified, ideally via printed information they can retain. This is particularly true for those for whom language is a barrier to effective communication ie non-native speakers, for whom printed information should be provided in their first language.

Make arrangements for giving the test result

This will vary depending on the circumstance under which the testing occurs; it may be by phone, planned follow-up or during an inpatient admission. The patient contact details should be confirmed, including the preferred method of contact, and permission, or not, to leave a message. It is also important to ask and record whether the patient has agreed for the result to be shared with their primary care physicians. A time frame should be given, including what steps the patient should take if they do not receive a result.

In the case of testing in the Emergency Department when the result may be given by someone else, or another team (for example someone from the local sexual health clinic) the patient should be so advised.

Written consent

Written consent is not required for an HIV test in most countries. The 2014 *European Guideline on HIV testing* states that: 'Verbal communication is usually sufficient for obtaining informed consent. Obtaining written consent is a barrier to HIV testing and testing rates increase if testing requires only oral consent.'¹⁰

How to offer an HIV test

Some clinicians may find it difficult to raise the issue of HIV testing with a patient. All evidence to date, however, suggests that for the vast majority of patients the offer of an HIV test is acceptable in a wide variety of clinical settings. Even among those patients who decline a test, the majority still find it acceptable and decline for a variety of other reasons³⁸.

Here are some suggested approaches to broaching the subject.

- If investigating an indicator condition – *'We routinely perform a number of tests to find the cause of your condition/symptoms. These include a test for HIV'*
- If infectious mononucleosis type syndrome - *'These symptoms are usually caused by viral infections. We can't test for all of these but we*

can test for some of the most common ones, including HIV, Epstein Barr Virus etc.'

- In primary care/acute medical admissions in a high prevalence area – *'We are doing several blood tests, and these routinely include a test for HIV'*

Offering and recommending testing to patients from groups at higher risk of HIV infection and who are attending healthcare services for reasons which are ostensibly or, in fact, unrelated to HIV can be more difficult as the patient may not be expecting to hear this. They may also have more anxiety about HIV testing, if they have not previously tested, or feel they may be at particular risk.

Consider the case of a man from Malawi presenting to the Emergency Department with a broken ankle; HIV testing may be the last thing he wants to think about or considers relevant to his needs at the time. Nonetheless, where there are good epidemiological reasons for recommending testing to patients from higher risk groups, the subject could be raised as follows:

Omission of sexual history taking should not prevent HIV testing

- If a clinician believes that HIV may be part of a differential diagnosis, HIV testing should be recommended whether or not a sexual history is taken.

'I realise this might not be the first thing on your mind, but have you considered an HIV test? I ask

because we know there is a high rate of HIV among people from certain countries and we now offer everyone from those regions a test. If you have never had a test, would you like me to arrange one for you today?'

It is important to recognise the more relaxed and comfortable the healthcare worker is in offering the test, the more likely the patient is to find the offer acceptable.

Patients who decline a test

Sometimes a patient will decline a test and the reasons for this should be explored as they may have incorrect information about HIV transmission, the improvements in HIV therapy or the consequences of testing, such as concerns about confidentiality or insurance.

For patients who are at higher risk of HIV infection but decline testing in your setting, it may be better to recommend referral to a specialist service (sexually transmitted infection or infectious diseases clinic, or non-governmental organisation) where they can discuss their concerns more fully and where additional support is available. There should be a process whereby their subsequent attendance can be verified and followed up; the patient should be made aware of this. Counsellors from

the sexual health clinic may also be able to offer you advice or to see patients with you.

Where patients do not speak the local language, good clinical practice would advise not to use family members or friends of the patient as interpreters when discussing HIV testing as this may breach confidentiality, so use a telephone interpreting service or consider rescheduling an appointment with an interpreter from a recognised service. Patients often prefer the more anonymous telephone service, especially if their expatriate community is small or localised.

It is important to bear in mind that, as with any investigation, patients have a right to decline and are not obliged to give a reason. They should not be pressured or coerced into testing against their own judgement. If this happens, it is important to document this in the notes, along with any reasons the patient gives for declining the test, and that they have been given sufficient information (eg benefits of early diagnosis, effectiveness of ART etc.).

Consideration should be given to repeating the offer in the future if the opportunity affords itself.

Section 5

Post-test discussion

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Post-test discussion

Post-test discussion

Giving a patient the result of an HIV test should be no more or less difficult than giving any other test result, especially when the result is negative. Giving a positive result will require your skills in breaking bad news to patients, and most clinicians will have given test results which were life-altering and which may have upset the patient at some point in their career.

Whatever the result of the HIV test, clear procedures should be in place for giving results, as is the case with other tests. It is considered good practice to agree with the patient how the result will be given when the test is taken and this is particularly important for outpatient and emergency care settings. Co-ordinating results management and governance with the local sexual health clinic can make this process more robust. Patients should always be asked to confirm or update their contact details.

Some sexual health clinic clinics give negative HIV test results by phone or by text message to reduce the number of follow-up appointments and if this is acceptable to the patient, your service may wish to include this option.

However, for certain groups of patients it is strongly recommended that any HIV test results are given in person. These are:

- ward-based patients
- those more likely to have an HIV-positive result
- those with mental health issues
- those for whom language is a barrier to effective communication
- young people under 16 years
- those who may be anxious or highly vulnerable
- those who are homeless as it can be difficult to contact them in the usual ways so arranging to give results in person is helpful.

If the pre-test discussion highlighted specific patient concerns or potential vulnerability it is important to document these clearly, as it may not be you who delivers the result. This may include the need for early referral to support services within the hospital or to voluntary and community-based organisations.

Post-test discussion for individuals who test HIV-negative

If you have initiated an HIV test on clinical grounds, for example in order to exclude HIV from the differential diagnosis, giving a negative result should be straightforward and it is likely that you will need only to refer to your original grounds for testing to give it. However, if you have concerns that the patient's behaviour is putting them at risk of HIV, you could offer simple health promotion advice. If you feel they require more specialist input, you could refer them to the local sexual health service.

The patient should understand the significance of the window period and be made aware that a repeat test may be needed if a potential exposure has occurred within that time. Although the standard (fourth generation) blood test for HIV will detect the great majority of infections at four weeks after exposure, it is currently recommended that the test be repeated at eight weeks following an event assessed as carrying a high risk of infection. Ensure that the patient understands that they may need a repeat test before HIV infection can be ruled out and that they should continue with safer sex practices to prevent onward transmission as, if they are infected, this early stage is one of the most infectious stages of the disease. Once again, referral to the sexual health clinic may be the most appropriate course of action, and you should provide the patient with information about local services so they can access them at the appropriate time.

Some HIV test results may be inconclusive and are usually reported as 'equivocal'. This is generally because the first laboratory test was reactive (often weakly) and subsequent confirmatory testing was negative. The majority of these patients will not have HIV infection but it is essential they be advised correctly and retested, with a subsequent sample sent to a reference laboratory for more detailed testing. Somewhat confusingly some laboratories may also report the above situation as 'reactive', the same terminology which is used for the first positive test an HIV-infected person undergoes, pending a 'positive' confirmatory test result on a second sample. All patients with a reactive result must undergo a second confirmatory test before being given a definitive HIV diagnosis.

Post-test discussion for individuals who test HIV-positive

Although no patient welcomes a life-altering diagnosis, the situation for people with HIV in Europe is much more optimistic than it was 20 or even 10 years ago. If patients are provided with clear information about the availability and effectiveness of antiretroviral therapy, and made aware of



For HIV tests
see page 27

the possibility that they can continue working, have sexual relationships, conceive safely and have children with minimal risk of passing on HIV, many of their immediate fears will be alleviated. There are many agencies that support people and families affected with HIV. As not everyone will access these immediately, it can be helpful to have written information to hand such as a patient leaflet with websites and contact numbers.

If the result is positive, here are some things to consider before the patient attends.

Preparing to give a positive result

You are likely to have time to seek advice if necessary as the lab may contact you to request a repeat sample, or if you ensure you check the result before reviewing the patient. If this is the first time you are giving a positive HIV test result it may be possible to arrange for someone from the HIV specialist unit such as a counsellor to attend the consultation to assist you. Remember:

- you already have skills in discussing difficult issues with patients
- the patient agreed to do their test on your recommendation and will be expecting you to give them the result.

Referral arrangements

The 2014 *European Guideline on HIV Testing* recommends that following a positive HIV diagnosis, a newly diagnosed individual should be immediately referred to an appropriate specialist HIV treatment centre for further management and care¹⁰. If you are giving a positive HIV test result in any secondary care setting you should ensure you have details of the nearest HIV specialist service so that an appointment can be made when the patient attends for their result. This will facilitate their successful transfer to care. In some services it is possible to make an appointment on the patient's behalf, which you can give them and they can then alter if necessary. Having a counsellor or nurse from the HIV specialist service present at this point can be very helpful, or arranging for the patient to be taken there.

It is also helpful to refer or signpost the patient to a local HIV community or peer support organisation which may be able to help them come to terms with their diagnosis.

When the patient attends

Give the result soon after the patient is in the room and is seated. Delaying disclosure can heighten anxiety. Some patients are expecting a positive result and may be quite calm. Some may have already come to terms with being positive, but a calm exterior can mask a sense of shock. Remember if the patient is attending for another reason/condition the result of the HIV test may not be uppermost in their mind. You could say 'I

have the result of your HIV test and it is positive. We need to do a confirmatory test but this means you have HIV infection'. Avoid using terms such as 'sorry', 'regret', or 'I have to tell you'.

Tell the patient that their HIV care will be managed by the specialist team who will undertake a full assessment and be able to answer questions about prognosis, treatment options and reducing the risks of onward transmission, so you do not need to be fully conversant with the complexities of these matters. Remember to re-emphasise that the patient is better off knowing that they have HIV as they can now take positive steps to ensure they remain/become healthy. Having a member of the sexual health team, for example a counsellor, present at this point can be very helpful or, if the clinic is close by, pre-arranging to walk the patient over to the sexually transmitted infection clinic at the end of your consultation.

The *2014 European Guideline on HIV Testing*¹⁰ also refers to providing detailed post-test discussion and partner notification. Once again, this is more likely to be relevant to HIV testing in primary care settings or sexual health services, but it is certainly the case that some people diagnosed in secondary care will need in-depth and ongoing counselling to help them cope following an HIV diagnosis. Referral to specialist counselling services or HIV support groups is appropriate and details of these will usually be available from sexual health clinics/HIV services. However, it is essential the patient is advised not to have sexual intercourse until they have had access to advice and information about disclosure, transmission, safer sex and partner notification. If they disclose they have had unprotected sexual intercourse within the past 72 hours they should advise that partner to attend a sexual health clinic urgently for consideration of PEP.

When the consultation is coming to an end:

- give the patient the details of any referral arrangements or appointments that you have arranged
- remind the patient that their future HIV care should be with the HIV specialist, whether or not you need to see them again
- confirm or update contact details and agree method of contact. You should liaise with the local HIV services to ensure the patient is in their recall system. The patient should be made aware they may be contacted by the HIV team if they do not attend.

It is possible that patients with HIV will be anxious about how their HIV status is to be kept in their records. If they raise this you should clearly outline the benefits of this to their ongoing care, making it clear it will be recorded and re-emphasising the confidentiality of the clinical record.

Benefits of involving the primary care physician

It is important to emphasise the benefits of involving the primary care physician because the primary care physician:

- may be expected to provide general medical care to those diagnosed with HIV and disclosure will grant access to some care that may not be otherwise available, eg vaccines, correct cervical screening schedule
- is usually the first contact for out-of-hours and emergency care
- will need to be aware of any ART prescribed so that adverse drug interactions can be avoided when other drugs are prescribed
- is in close contact with local social, counselling and support services and can therefore refer for appropriate support if required
- can diagnose, treat or refer HIV-related problems which could be overlooked if he/she is unaware of the diagnosis
- can support and test if necessary the whole family, but will not tell other members of the family unless the patient requests it and will not do this without discussion.

The importance of informing and involving the primary care physician

Tell the patient that it is standard practice for specialists to inform a patient's primary care physician of the results of any test or procedure performed in hospital, and that you will 'let the primary care physician know about all your test results so that he/she can help in your future care'. Some patients may initially be reluctant to have their primary care physician made aware of their positive HIV status, so you should highlight the advantages of sharing results with the primary care physician. If a patient is not registered with a primary care physician they should be encouraged to register and be given information on how to do this. The patient does, however, have the right to decline to give consent for their primary care physician to be informed of their HIV status.

Non-attendance for HIV test result

Sometimes patients do not return to collect their HIV test result. There may be simple logistical reasons, they may assume if there was a problem they would be contacted, or it may be because they are worried the result is positive and the

impact this may have. There is usually a significant benefit for the patient in knowing the test result, both for those testing positive and those testing negative. The benefits to the patient of receiving a positive test result are clear, but there are also important benefits for those who test negative, eg relief of anxiety and increased motivation to use HIV preventative measures when in high risk or sero-discordant sexual relationships (where one partner is HIV positive and the other HIV negative). It is good practice to have procedures in place to maximise follow-up for people who do not return for the results of any investigation carried out in a secondary care setting. HIV test results are no different and patient contact details should be recorded and options for contact discussed. Due to the sensitive

nature of an HIV diagnosis and its attendant social implications, it is important to record during the pre-test discussion whether the patient has agreed that the result may be shared with their primary care physician so that appropriate follow-up can occur.

Providing written confirmation of results

Some patients may require a written confirmation of a negative HIV test result, for example for the purposes of employment, or for travel to a country with strict controls on admitting people with HIV. Also, patients who are diagnosed HIV-positive may request written confirmation of their HIV status – a ‘letter of diagnosis’ is usually required when applying for certain benefits, for example.

If there are sound lines of communication between primary and secondary care then such confirmations are better provided by the patient’s primary care physician, but if you are asked to do this it is good practice to have a procedure in place for such an eventuality. This involves:

- asking to see a form of photographic identification such as a passport or driving licence both at the time the test is taken and when the result is given
- documenting the patient’s request and the form of identification both in the notes and in the letter provided
- providing a letter signed by the doctor – a copy of the patient’s laboratory test result is not appropriate
- addressing the letter to a specific individual in the organisation requesting confirmation, not in general terms such as ‘to whom it may concern’.

Section 6

Barriers to HIV testing



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Barriers to HIV testing

The reasons why people may not agree to test for HIV when they might accept investigations for other equally (or in fact more) serious medical conditions are many and complex. This section is intended to give the non-specialist clinician an insight into these reasons and provide some background to what might inform a patient's decision to test, or not to test, for HIV. In so doing, it looks at common barriers for patients and clinicians to HIV testing.

Patient concerns about HIV testing

Confidentiality

Although the 'exceptionalism' associated with HIV, and HIV testing in particular, is now being challenged, many people still worry about confidentiality and fear the consequences of others finding out if they test positive. As HIV remains a highly stigmatising diagnosis in Europe these fears are often not unfounded.

Concerns about the confidentiality of HIV test results can be a barrier to seeking HIV testing or agreeing to be tested. These concerns may also inhibit people from talking openly about personal issues, so it is important for clinicians who offer HIV testing to be willing to explore them and reassure patients about local measures to protect confidentiality. If clinicians take a non-judgemental and empathetic approach to different lifestyles this can help in allaying the patient's fears. Ensuring that services understand and respect patient concerns about confidentiality and fears of discrimination will support and encourage:

- open discussion of, and testing for, HIV with those who may be at risk
- open discussion about safer sexual and injecting practices
- improved quality of care for people with HIV infection.

case study

Fears about confidentiality

Mr and Mrs R are a middle aged couple who live in suburban Rome. They both have HIV and are on treatment. They have two teenage children; the older one is applying for medical school. They are terrified that their children, neighbours and friends might find out about their HIV. Mrs R attends an HIV clinic in central Rome where she has received an anonymous identification code so as not to disclose her name. She keeps her ART in her handbag for fear of her children finding it and asking questions.

She disposes of the packaging away from her home. 'I know if my neighbours found out they would not let their kids stay over at our place, and I am sure I would lose my job. I know that there are supposed to be laws to protect you but you can imagine what would happen – people wouldn't want someone with HIV serving food to their children'.

Learning point

- Some patients will go to enormous lengths to protect their confidentiality.

HIV testing and insurance

It is still believed by some of the general public that having an HIV test (even if the result is negative) will adversely affect life insurance or mortgage applications and this has led to reluctance to test for HIV. This is especially true for countries where healthcare is not provided free of charge and where specific laws are not in place to protect patients' confidentiality in the matter of HIV status. People are therefore afraid that a doctor or patient may have to declare an HIV test regardless of the result on an insurance application.

HIV care providers ought to be aware of the regulations of the country where they practice and be guided by clinical need above all other considerations.

Immigration issues

In most European settings, testing and counselling for HIV are free to everyone regardless of their residence status.

Many people who are seeking asylum in Europe come from high prevalence countries in sub-Saharan Africa and may worry that a positive HIV test could be detrimental in their asylum case, although this is not the case in practice.

Some people from conflict zones may have added HIV risk, having suffered sexual violence or torture. Discussing HIV in these situations must be approached sensitively. It may be helpful to find out if there is a local organisation which can offer advice and counselling for victims of sexual violence or torture.

case study

Immigration and HIV treatment

Dr P, aged 38, from Mozambique, married with two children and in Lisbon studying for his specialty training in oncology was referred for treatment of his hypertension. He presented with widespread seborrhoeic dermatitis and cervical lymphadenopathy. When asked if he had had any medical problems in the past, he denied anything apart from his poorly controlled hypertension.

When an HIV test was suggested, he became very anxious. He said he was very worried about the possibility of HIV, and confided that he would find it very difficult to talk to his wife about it. He also feared that if the government or his employer knew he had HIV, it could have detrimental implications for his

continuing to remain in Portugal. His younger sister had recently died of TB/HIV, shortly after giving birth to her first child in Mozambique.

The doctor involved the HIV specialist team and the counsellor reassured Dr P that he was better off getting his HIV treated and that he was eligible for treatment. He agreed to take the test and it was positive.

Learning points

- HIV prevalence is greater than 15 per cent among adults from some southern African countries.
- Fear of discrimination in immigration and employment can lead to denial about HIV.
- Complex issues should be referred to the HIV specialist team for discussion.

Criminal prosecution of HIV transmission

In recent years there have been a number of prosecutions of HIV-positive individuals for transmission of HIV to a sexual partner in Europe. HIV support organisations fear that any criminal prosecution of HIV transmission increases stigma and marginalisation for people with HIV, and prevents people who may be at risk from seeking testing and care.

Some concerns raised by legal cases have reinforced the standard of care that avoidance of onward transmission is discussed with all individuals who are diagnosed HIV-positive (including disclosure to partners, and use of condoms and clean injecting equipment). Along with this, post-exposure prophylaxis (PEP) for sexual partners and antiretroviral therapy to prevent transmission - 'treatment as prevention' (TasP) - should be explained to patients within their initial HIV clinic visits. There are also favourable data for pre-exposure prophylaxis (PrEP) and this may be relevant to some individuals with sero-discordant partners (ie partners of a different HIV status)^{39,40}, although it is not available in every country.

Stigma

Over the past 30 years HIV and AIDS have traditionally affected marginalised groups in society and been associated with certain behaviours such as unprotected sex, drug use and commercial sex work. In the early years of the epidemic HIV infection led to illness, AIDS and

death in the majority of infected individuals and this perception remains in spite of excellent treatments now available which have made HIV in the developed world a manageable chronic disease. The link between sex or drug use and illness means that people who contract HIV are often thought to have brought it upon themselves as a result of their chosen behaviour. These factors combine to create a stigma around HIV which underpins prejudice, discrimination and even violence towards people infected. Negative attitudes to HIV are widely reinforced in media coverage of the issue and are prevalent in the general population.

Stigma means that some people do not seek HIV testing or may be reluctant to agree to an HIV test, despite knowing they might be at risk. Others do not consider HIV testing because they may not be aware that they could be infected, or they do not think that they belong to a group that is vulnerable to HIV, or they have little information or understanding about HIV transmission.

Despite the general availability of effective treatment in Europe which has led to people with HIV becoming less easily identifiable, many still do not feel able to be open about their status. Few tell employers or colleagues at work, and many do not tell even their closest family and friends. Some people do not feel able to confide in their sexual partners or spouses for fear of rejection or abuse. The isolation and fear of being 'found out' and subsequently rejected or discriminated against, can be enormous, leading to stress and depression. In some communities, the stigma is so great that the HIV-negative members of those communities ostracise and reject the HIV-positive members.

Sometimes these fears are unfounded or exaggerated, and sharing with trusted family members and friends can provide great support. There are also voluntary and community organisations which provide support and services for people with HIV and these have helped many to cope with both the medical and social consequences of a positive HIV diagnosis.

Clinicians' concerns about HIV testing

HIV is a recent phenomenon. What we now understand as AIDS was only described in the medical literature in 1981. Historically, all aspects of HIV diagnosis, treatment and care have been managed within the specialties of dermatology and venereology, genitourinary medicine or infectious diseases. Because of this, the opportunities for generalists and other specialist clinicians to gain experience in diagnosing HIV, offering testing or understanding the concerns of people with HIV have been limited. While this was, in part, a pragmatic response to the way in which HIV and AIDS were represented in the media in the early days of the epidemic which created a stigma around HIV infection, the 'exceptional' approach

to HIV has made clinicians hesitant about recommending HIV testing. This section examines the common barriers that clinicians might encounter to offering HIV testing to patients.

Fear of embarrassing the patient

Some clinicians are reluctant to offer HIV testing to people from groups most at risk from HIV in situations where there are no overt signs of infection, in case they are perceived as making a judgement about that person's sexual orientation, lifestyle or immigration status. Equally, when patients do not have obvious risks of infection this potential for embarrassment has prevented discussion of HIV where there are clinical signs of infection.

A useful rule of thumb is that an embarrassed doctor leads to an embarrassed patient so it is best to be open about the reasons for offering an HIV test. It is often easiest to offer it as a routine test among a raft of others. Or where indicated by symptoms, simply state that when these symptoms are present, the recommendation is that an HIV test be carried out. Saying that this is part of good medical practice can help to reassure the patient that no judgements are being made about any aspect of their personal circumstances.

case study

Late diagnosis

Mr T, a 66-year-old married man, was admitted to hospital with diarrhoea, weight loss, weakness and confusion. Over the preceding six months he had been admitted to hospital on two occasions with similar symptoms and investigated extensively for occult malignancy without a diagnosis being made. No HIV risk assessment was undertaken. On examination he was cachectic, disorientated and febrile, with a small pigmented lesion on his shin. An HIV

test was positive and further investigations showed he had CMV encephalopathy, CMV retinitis and cutaneous Kaposi's sarcoma. His CD4 count was 60 cells/ μ L. Mr T made a full neurological recovery after receiving antiretroviral therapy.

Learning point

- If the symptoms could indicate HIV infection it is important to offer an HIV test even if a risk assessment has not been done.

Lack of time

In many secondary care settings such as outpatient clinics, time can be at a premium and many clinicians fear being drawn into protracted discussions if they suggest an HIV test. Once again, a clear statement of the clinical reasoning for the offer is helpful here, and reassuring the patient about the confidentiality of the service and the lack of repercussions from a negative result can help to reduce anxiety. In exceptional circumstances, if the patient is very anxious you could arrange for the involvement of the sexual health team.

Written information explaining the test is also helpful as it gives the patient and the clinician something to work through and provides a neat framework for the discussion. When written informed consent is required, the pre-test counselling can be integrated into the process and can provide the patient with an overview of the disease and the reasons why the test is carried out.

Lack of specialist HIV counselling skills

Talking about HIV should not be seen as 'special'. Clinicians are used to talking about sensitive issues and HIV should not be thought of differently. Some clinicians think that in-depth counselling is required prior to offering an HIV test. This is no longer the case and a short, focused pre-test discussion similar to that before any test which may result in a potentially life-altering diagnosis for a patient is recommended. Sections 4 and 5 on pre- and post-test discussion provide helpful approaches to discussing HIV with patients.

'The patient won't cope with a dual diagnosis'

Some clinicians worry that a patient will become depressed or suicidal if they find out that they have HIV, particularly if they are presenting with a serious condition and do not think that they are at risk from HIV. Although no patient welcomes a diagnosis of HIV infection, the situation for people with HIV in Europe is that of a treatable chronic disease, and it is important to emphasise that the first condition can only be effectively treated if the HIV is managed concurrently.

case study

Men who have sex with men

Mr P, a 55-year-old man, presented to a sexual health clinic asking for routine screening. He was originally from India, but had lived in Barcelona for most of his adult life. He was asymptomatic and gave a sexual history of a long-term female partner and a couple of casual female partners in the last few years. Men who attend sexual health clinics are routinely asked if they have ever had sex with men. He denied this.

He saw a nurse and had a routine screen for STIs, including an HIV test. The result was positive. When the doctor gave Mr P the positive result at follow-up, he disclosed that he was gay, with a long-term male partner and a few casual male partners over the past few years. He attended for his initial appointment and the

testing of partners was arranged. However, Mr P was very concerned as he was well known in the local community with business interests locally. He decided to access HIV care in a different area, as anonymity was very important to him. This was facilitated for him by the clinic to ensure the appropriate handover of information. Syphilis testing was also positive and the patient was treated for latent secondary syphilis at the centre.

Learning points

- Some men who have sex with men may initially not volunteer or be reluctant to disclose information about their sexual life.
- HIV, like all the other STIs, often travels together with other STIs, such as syphilis in this case.

'The patient doesn't consider themselves at risk'

Knowledge of the facts about HIV among the general population can be quite low. In the UK, the National AIDS Trust has tracked this through a public knowledge and attitudes survey performed at intervals between 2000 and 2014⁴¹.

It is worrying that in 2014 almost one in five people did not know that HIV is transmitted through sex without a condom, and that only 45 per cent of respondents were able to correctly identify all true and all false HIV transmission routes presented to them in the survey. Furthermore, almost a third were unaware that survival after being infected with HIV in the UK is likely to be longer than three years. Such misinformation amongst the general public may mean that individuals presenting for medical care do not consider themselves at risk of HIV, or do not appreciate the benefits of testing, and may therefore not proactively seek testing.

Working with groups most at risk of HIV infection

HIV is most common in certain population groups:

- people who inject drugs
- men who have sex with men
- people from sub-Saharan Africa or who have lived there
- sex workers
- prisoners

Members of all these groups may already feel marginalised or stigmatised in European society. The stigma and discrimination associated with HIV can exacerbate this.

People who inject drugs

Those who have acquired HIV through sharing drug injecting equipment (even if they no longer use drugs) will be aware of being doubly stigmatised; as people who inject drugs they are a socially excluded group, and this may be compounded by a positive HIV status. Those who have not wished to access support, or who have been unable to, may be locked in a cycle of problems as they try to fund their drug use. Dependent drug use may restrict the ability to attend appointments or to take medication regularly. In some cases, HIV may not be a priority in comparison to the daily problems associated with drug dependence.

An integrated approach to care might be needed for this group. Centres that provide treatment for dependencies and opioid substitution therapy should include HIV counselling and care of HIV-infected patients⁴². Moreover, ART can interact with illicit drugs, and cause side effects of which healthcare providers should be aware.

case study

Person who injects drugs

Mr Z, aged 29, presented to a Moscow city hospital with a large groin abscess and evidence of recent injecting. He was thin, febrile and agitated. He was of no fixed abode. It was established that he had recently come from Siberia following family problems and had been injecting drugs for many years. He denied ever having had an HIV test but agreed to undergo testing. The HIV test was positive, with a CD4 count of 220 cells/ μ L and a viral load of 15,000 copies/ml. Hepatitis C antibody was detected on further screening.

Learning points

- HIV and hepatitis C are common in people who inject drugs, especially in people who come from countries which have been slower to adopt safe injecting programmes.
- Hepatitis C co-infection should be actively sought and treated to prevent progression to cirrhosis and hepatocellular carcinoma as rates of co-infection are particularly high among people who inject drugs.
- Co-infected patients should be referred to the HIV specialist team as soon as possible for assessment for ART.

Men who have sex with men

This term is used to describe both men who identify as gay, and also those who have sexual encounters with other men without considering themselves to be homosexual. While gay men may have a sense of belonging and access to gay-oriented culture, other men who have sex with men often see themselves as bisexual or even heterosexual, are sometimes married, and may not be willing to be open about their same-sex encounters.

Certain cultural or religious backgrounds might play an important role in making disclosure of sexual orientation, even with healthcare providers, difficult for some people.

African communities in Europe

There is no single 'African community' in Europe. Churches, mosques and other social gatherings may bring together people from the same country, especially in cities with larger populations of immigrants. Fear and prejudice against HIV may be high in these communities, with resultant stigma and secrecy. Many people from high-prevalence countries will know of family members or friends who are living with, or have died from, HIV. This is particularly true for people from southern Africa as adult HIV prevalence rates are in the order of 15 to 25 per cent in countries like Zimbabwe, Zambia, Botswana and South Africa. In some families HIV may affect both parents and some of the children, creating major family needs.

When offering HIV testing to people from this group, it is essential to present information in a culturally sensitive way. Worries about employment and immigration and asylum issues can compound anxiety about confidentiality and disclosure of HIV status. The more medical aspects of HIV may be difficult for patients for whom language is a barrier to effective communication, or who come from countries such as conflict/post-conflict settings where they may have had limited opportunities for formal education.

Cultural, social and religious views may also affect understanding of, and beliefs about, illness and treatment, so it is important to check patients' understanding of key issues, as many may not remember a great deal of what you have told them during the consultation. Cultural and religious beliefs may also affect how people will cope with a diagnosis of HIV. It is important to explore these beliefs as they may affect future treatment and adherence and to be open and non-judgemental when discussing these issues. It is often helpful to have patient leaflets available which cover key issues about HIV and give contact details of local support groups and HIV services.

case study

Cultural factors affect how a patient deals with their diagnosis

Mrs M was a 45-year-old Nigerian hairdresser/beautician. She was separated from her husband and had lived in Belgium for five years with her three daughters. She presented with a severe bacterial pneumonia due to *Mycoplasma pneumoniae*, requiring hospital admission. On examination the doctor noticed that she had some scarring on her trunk compatible with previous herpes zoster. She made a good recovery from her pneumonia and the doctor suggested HIV testing, to which she agreed. The result was positive and her CD4 count was 190 cells/ μ L. She was referred to the HIV team who initiated ART, carefully explaining the regimen, potential side-effects and the need to adhere rigorously

to her treatment. She was given information about a local support group for women with HIV and an appointment to see the HIV team in outpatients in two weeks' time.

When she was seen in outpatients two months later, the repeat CD4 count was 160 cells/ μ L and her viral load was still high. She admitted she had not been taking treatment because she had 'great faith in God and he is looking after her'. She had confided to a pastor at her church who had prayed with her and was confident that she would get better without treatment.

Learning point

- Some patients' religious and cultural beliefs will affect their understanding of HIV or their attitude to treatment.

Patients with no obvious risk factors

Although statistically more likely to be found in people in the groups mentioned above, HIV can be seen in patients who have no obvious risk factors or who deny any HIV-associated risk behaviour. Some things that happened many years ago may have been forgotten, or the patient may be in denial about them. These could be an isolated episode of injecting drug use, receiving a blood transfusion or other invasive medical procedure in an area of high HIV prevalence or having sexual contact with a person from an area of high HIV prevalence. Others may be genuinely unaware that they have been exposed to HIV.

Such instances do occur and it is important to offer an HIV test where clinically indicated. The issues raised by such cases highlight the need to involve the HIV specialist team who can provide guidance on how to give a positive result sensitively and ensure that partner notification is dealt with appropriately.

case study

Patient with no obvious risk factors

Mrs Q was 58 years old, overweight and alcohol dependent. She had been referred for assessment prior to admission for detoxification from alcohol abuse. Routine blood tests showed abnormal liver function tests, anaemia and neutropenia. Her doctor sent off further tests and was surprised when she was also found to have syphilis, hepatitis B and HIV. She had never injected drugs and had been married for many years. Her husband had been on several golfing

holidays in South Africa where, unbeknownst to her, he had had unprotected sex with commercial sex workers.

Learning points

- Some people have no obvious risk factors for HIV infection.
- People who think that they have no HIV risk factors may need specialist counselling and support to help them cope with a diagnosis.

The patient may suspect that he/she has HIV, but may not volunteer information

Some people, particularly from groups where HIV is prevalent, are very aware of HIV and may have partners, friends or family who are living with HIV. It may be something that they often worry about, but which they are hesitant to mention, especially if they are attending medical services to which they do not consider HIV relevant, eg family planning or gynaecology clinics. Asking probing questions, such as, 'Is there anything particular that you have been worrying about?' or 'Is there anything that you think could be causing this problem?' and reassuring them of the confidentiality of your service may elicit anxieties about HIV.

case study

Patient suspects they might have HIV

Mrs M was a 27-year-old woman attending antenatal clinic for her first pregnancy. She was found to be HIV-positive during routine antenatal screening, and enrolled in a prevention-of-mother-to-child-transmission programme. She suspected that she might have acquired HIV from a previous boyfriend who injected drugs, but refused to tell her husband, because she said he

would blame her and was likely to be violent towards her.

Learning points

- HIV stigma is so great in some communities that HIV-infected people may prefer to conceal their diagnosis from partners and family.
- Specialist HIV services are best placed to deal with the sensitive issues raised.

Section 7

Annexes

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Annexes

Annexe A: Advice on testing without consent

The situations in which you might consider testing a patient for HIV who lacks the capacity to consent are most likely to arise in inpatient situations, for example, where the patient has been admitted to the Intensive Care Unit or via the Emergency Department and is very ill, or in and out of consciousness. Laws covering HIV testing in these situations vary across Europe, and healthcare providers should follow local guidance from professional bodies and ensure that they comply with the local legal framework. What follows is general advice only. In the first instance it is important to determine whether incapacity to consent to testing is temporary, fluctuating or permanent. Where incapacity is temporary, eg the patient is recovering from anaesthesia or under the influence of alcohol or drugs, it may be appropriate to wait until capacity is regained unless there is a compelling reason why this would not be in the patient's best interest. If capacity is fluctuating, eg in dementia, it may be appropriate to use a period of capacity to establish the patient's views on HIV testing and record these for review to establish that their views are consistent and can be relied on. Testing without the patient's consent is justified in rare circumstances, but only if it affects their immediate care and is considered to be in their best interests. In all cases, the healthcare provider must be able to justify their actions and take into consideration national legal and regulatory frameworks.

Testing the unconscious patient without consent⁴³

Where a diagnosis of HIV would lead to a change in management of the patient's condition, the decision should be taken by the senior professional in charge of the patient's care, and after discussion with other teams (such as infectious diseases) as appropriate. Clear documentation of the reason for testing is critical. Arrangements should be made for the patient to be informed of the result, once they are sufficiently alert to be able to understand and remember it. Again, national legal frameworks apply.

Patients without the mental capacity to consent

There may be cases when a patient is unable (eg due to severe depression or cognitive impairment) or unwilling (eg due to mania or psychosis) to give consent, but it is in their best interest to be tested in order to provide optimal medical care. When considering HIV testing

without consent, the clinician must ensure that a clear reason for testing is established, that testing is of specific benefit to the patient's clinical management, and that national legal and regulatory frameworks have been taken into account.

Annexe B: Post-exposure prophylaxis (PEP)

PEP for occupational exposure

PEP for occupational exposure describes the use of antiretroviral therapy to prevent transmission when a person has had a high risk exposure to HIV, eg following a needlestick injury where the source person is known to have HIV. It is important to act quickly as, if PEP is to be given, it should be given as soon as possible after the exposure (within hours) to maximise effectiveness. PEP is generally not recommended beyond 72 hours after exposure.

If the source patient is of unknown HIV status, it is recommended that they are tested urgently for HIV. The use of a rapid testing device (or point of care test) may be useful where obtaining a laboratory test result will be delayed. Informed consent must be obtained from the patient in this case, as for any other HIV test, and the affected healthcare worker should not be involved in this process.

All services should have local policies and referral pathways (including out of hours cover) for the provision of PEP. National guidance should be followed on the drugs to use, and who is eligible for PEP. The medication is usually taken for four weeks.

The unconscious source patient in a needlestick injury

In the event of a needlestick injury or similar accident, it is illegal in some countries (eg the UK) to test an unconscious source patient for HIV for the benefit of another individual, for example to reassure the exposed healthcare worker that they are not at risk of acquiring HIV, or to avoid taking PEP. Follow national laws and guidance of professional bodies.

Post-exposure prophylaxis following sexual exposure (PEPSE)

In the instance of a potential sexual exposure, it may be appropriate to offer PEPSE to the uninfected sexual partner of someone known to have or to be at high risk of HIV infection. PEPSE following potential sexual exposure to HIV is only recommended when the individual presents within 72 hours of exposure, and PEPSE should be given as early as possible within this timeframe. A course of PEPSE lasts four weeks.

The risk of HIV infection following sexual exposure depends on the viral load of the HIV-positive partner, and the nature of the sexual exposure. The risk is very low if an HIV-positive person is stable on HIV treatment with a fully suppressed viral load. Each patient who may be offered PEPSE

therefore needs to be assessed as to the suitability of offering this treatment; local guidelines should be followed as to where this assessment should take place and who should provide PEPSE if it is indicated, but this will often occur in sexual health clinics or equivalent.

PEPSE following sexual assault

PEPSE should also be considered following sexual assault, though, as above, the degree of risk depends on the nature of the sexual assault. A risk assessment may be more difficult as the HIV status of the source individual is often unknown. Follow national guidance.

Annexe C: The patient diagnosed with advanced disease

Diagnosis with advanced disease

Around a quarter of patients diagnosed with HIV will have such advanced disease that antiretroviral therapy may not produce optimal results. Advanced disease is associated with multiple comorbidities from opportunistic infections and cancers causing severe and distressing symptoms. In those patients admitted with life-limiting consequences of HIV at diagnosis, a balance needs to be maintained between active and comfort care. The patient's wishes, supported by their carers if they wish, are paramount in achieving this balance. A multi-professional approach, with involvement of palliative care specialists, may be helpful. Attention to symptom control and psychological support alongside active treatment is recommended.

Recent diagnoses of both HIV and life-limiting infection or cancer can be extremely distressing for patients. There may not be time for them to adjust to either, and evidence suggests it is the HIV diagnosis that proves more challenging. They may wish to keep the HIV diagnosis from their friends and family. There should be systems in place to ensure that the whole healthcare team supports them in this wish. Maintaining confidentiality can cause concern where the patient wishes to be discharged home to die and prefers that the primary care team are not told of the HIV diagnosis. Involvement of a specialist multidisciplinary team with expertise in the area can usually overcome these issues with the patient.

If a patient dies with HIV

Confidentiality should be maintained after death. In the case of death certification, doctors must balance a patient's stated request that their family are not informed against the legal requirement to provide full and honest information. Local laws and guidance should be followed, and advice sought from the local specialist HIV centre.

Section 8

Sources of further information

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Useful organisations and websites

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Sources of further information

Useful organisations and websites

aidsmap

www.aidsmap.com

Extensive information on treatments and the latest research. Database of HIV organisations worldwide (including UK). Leaflets for patients to download and other online information resources in a range of European languages.

European AIDS Clinical Society (EACS)

www.eacsociety.org

Produces the European Guidelines for treatment of HIV-positive adults in Europe. The English version is regularly updated by the guideline panels.

European Centre for Disease Prevention and Control (ECDC)

www.ecdc.europa.eu

European Union (EU) agency which publishes Europe-wide surveillance data and guidance on HIV and other infections for countries in the EU and European Economic Area (EEA).

JUSTRI

www.justri.org

Not-for-profit organisation providing various resources focused on provision of care for people living with HIV and related conditions.

JUSTRISLIDE

www.justrislide.com

A free, online, searchable, downloadable slide library with over 11,000 slide presentations on HIV and allied subjects for personal use and teaching purposes. Register at www.justrislide.com

WHO Regional Office for Europe (WHO/Europe)

www.euro.who.int

Produces public health data, reports and guidelines, including on HIV, and serves the 53 countries of the WHO European Region.

Section 9

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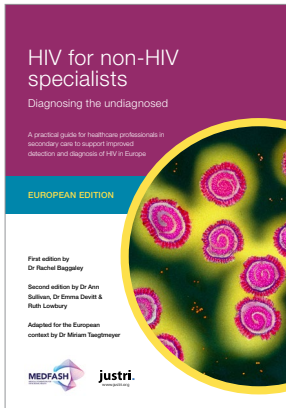
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HIV for non-HIV specialists

Diagnosing the undiagnosed

A practical guide for healthcare professionals in secondary care to support improved detection and diagnosis of HIV in Europe

Thanks to effective treatments, early diagnosis of HIV saves lives and prevents new infections, but a third of people living with HIV in the European Region are still undiagnosed. They may present in a range of medical specialities.

About this booklet

This booklet provides essential information for healthcare professionals in secondary care on:

- the clinical diagnosis of HIV in non-HIV specialist settings, with photographs
- how to offer an HIV test and give results
- barriers to HIV testing for clinicians and patients and strategies for overcoming them
- the background and context of HIV in Europe
- relevant guidelines and sources of further information.

Adapted in this version for a European readership, *HIV for non-HIV specialists* is instructive, practical and easy to use with full colour illustrations.

“I am pleased to endorse this booklet which identifies clinical indicator diseases associated with HIV infection and provides advice about routine testing of your patients and the appropriate management thereafter. I trust it will be a valuable resource for your team.”
Professor Fiona Mulcahy, President, European AIDS Clinical Society.

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