Equality of Opportunity Committee

EOC(3)-14-09 : Paper 1 : 3 November 2009

INTRODUCTION

BMA Cymru Wales is pleased to provide evidence to the Health, Well-being and Local Government Committee on stroke services in Wales.

The British Medical Association represents doctors from all branches of medicine all over the UK. It has a total membership of over 138,000 including more than 3,000 members overseas and over 19,000 medical student members.

The BMA is the largest voluntary professional association of doctors in the UK, who speak for doctors at home and abroad. It is also an independent trade union. BMA Cymru Wales represents some 6,000 members in Wales from every branch of the medical profession.

Discrimination against people living with HIV in healthcare settings and in other settings by healthcare professionals

Some of the information provided in this paper can also be found in the Medical Foundation for AIDS & Sexual Health booklets 'HIV in Primary Care', and 'HIV for non-HIV specialists'. MedFASH is a registered charity supported by the British Medical Association and is dedicated to the pursuit of excellence in the healthcare of people affected by HIV, sexually transmitted infections and related conditions.

MEDICAL NOTES

"We feel that it is important that the Committee consider the process of HIV diagnosis and clinical management and the implications of this for non-specialist healthcare professionals. "

HIV (Human Immunodeficiency Virus) is a virus that weakens the body's immune system. HIV, in the absence of treatment, almost always progresses to AIDS (Acquired Immune Deficiency Syndrome).

The United Kingdom continues to experience a relatively low prevalence of HIV, and treatment outcomes are some of the best in the world. However, the number of people with HIV infection continues to rise. There is no cure and no vaccine, although current treatments are life-saving.

In the first few weeks after infection with HIV there may be a flu-like illness (primary HIV infection). Thereafter, the infected individual may be well for some years, although the virus is actively replicating. From the time of infection, it usually takes a number of years for the virus to significantly jeopardise immunity.

The problems caused by HIV infection are sometimes subtle and insidious, and patients may recover and be well for some time before encountering another problem.

Detection and Diagnosis

HIV testing is voluntary and confidential. There are a number of tests and clinical markers of HIV infection:

The standard test is the HIV antibody test, this method gives no indication of disease progression and a subsequent blood test is needed.

The HIV antigen test looks for evidence of HIV itself (as opposed to the antibody).

The CD4 count is also a useful test for HIV; it measures the CD4 lymphocyte cells and is a useful indicator of the state of the immune system for those infected with HIV.

Finally the viral load is a measure of the amount of HIV in the blood. The higher the value the more active the virus and hence the disease process.

The clinical diagnosis of HIV-related conditions is not always easy. Many of the problems associated with HIV are commonly seen in people without HIV - for example, seborrhoeic dermatitis, shingles, folliculitis or a glandular fever-like illness e.g. a sore throat or fever.

That said, in primary care GPs are familiar with the concept of considering rare and serious conditions when patients present with what appears as extremely common symptoms - and are trained to do so.

Treatment

Antiretroviral therapy (ART) limits HIV replication. It has had an enormous impact on morbidity and mortality from HIV disease. Because HIV readily mutates as it replicates, resistance to single anti-HIV drugs develops very readily. This means that currently three or more drugs are used in combinations, and that adherence to drug regimens is essential. After ART has started, the combination of drugs may be changed according to any side effects experienced. These will often be minor but can include more serious conditions such as hyperlipidaemia, diabetes and lipodystrophy (a syndrome characterised by redistribution of body fat). However, new drugs and strategies are continually being developed.

Prevention

The BMA is aware of our responsibility, as a professional organisation and as individual clinicians, to contribute to prevent HIV infection and onward transmission: i.e. in talking to patients, promoting safe sex, ensuring that pregnant women receive antenatal screening for HIV, discouraging and treating for drug use, and by providing post-exposure prophylaxis (PEP).

There is a place for HIV prevention in the daily activities of the primary care team. Practice policies and systems can help to ensure that the patient with HIV receives high quality care and that staff are informed and adequately prepared to provide this.

Experts agree that there is little hope of a vaccine being rolled out in the near future. Although new hope was cast recently after scientists trialled a new vaccine in Thailand on 16,000 people which cut HIV infection rate by 31% - this is highly significant but is by no means the end of the road. In the meantime, with effective treatments available for HIV the majority of people diagnosed in the UK now have a very good prognosis and long life expectancy.

IN FIGURES

SOURCE: Health Protection Agency. HIV in the United Kingdom: 2008 report

PRIMARY CARE CASE STUDY

BMA CYMRU WALES

PRIMARY CARE

Whilst much of the treatment of HIV infection is specialised, general practice and primary care have important roles in helping infected patients. GPs and primary care teams can play important part in the prevention, diagnosis and management of HIV infection, and in the care of the dying patient.

HIV is increasingly managed as a chronic disease, with many more patients surviving for longer periods. This is shifting the emphasis of care towards partnership between specialist centres and primary care.

There is evidence to suggest that a significant proportion of people who present late with HIV infection have been in contact with doctors in preceding years with symptoms which, in retrospect, were related to HIV. So, often, people who are unaware that they have HIV are attending primary care.

In 2004 the Medical Foundation for AIDs and Sexual Health (MedFASH, a charity supported by the British Medical Association) produced a booklet entitled 'HIV in Primary Care' which is an essential guide to HIV for GPs, practice nurses and other members of the primary healthcare team. The booklet gives guidance on diagnosis and treatment of HIV, it also tackles the wider issues - such as how to improve HIV detection in GP practices and to approach the subject with patients or to relay HIV-positive results .

Early detection is extremely important. The stakes are very high for these patients - HIV diagnosis at the primary infection stage may be life-saving. There are two general circumstances which provide valuable opportunities to diagnose HIV infection in primary care:

clinical diagnosis when the patient presents with symptoms / medical conditions suggestive of HIV.

offering an HIV test to an asymptomatic patient because they are / may be at risk of infection.

MedFASH advise primary care practitioners to follow the procedure below when they encounter a patient with any of the conditions that may be HIV related

SYMPTOMS ASSOCIATED WITH LONGSTANDING HIV INFECTION:

- **Respiratory conditions**. Including - pneumonia; TB and atypical mycobacterial disease; chest infections
- **Neurological and visual conditions**. Including - cryptococcal meningitis and infections of the retina;
- **Tumours**. Including – lymphoma; cervical carcinoma; Kaposi's sarcoma (KS)
- **Constitutional symptoms**. Including – fever; weight loss; sweats; lymphadenopathy
- **Skin conditions**. Including - fungal infections; viral infections e.g. shingles; molluscum contagiosum e.g. warts and herpes; bacterial infections e.g. impetigo.
- **Conditions affecting the mouth**. Including - oral candidiasis (thrush); aphthous ulceration; oral hairy leukoplakia; Kaposi's sarcoma; gingivitis; dental abscesses.

In 2003 MedFASH published recommended standards for NHS HIV services, endorsed by the Department of Health and the British HIV Association. These were developed for England but are relevant for all parts of the UK.

Using the patient pathway as a framework, the standards address the role of both specialist and mainstream providers, highlighting the importance of managed service networks for consistent and equitable care delivery. The standards identify GPs and primary healthcare

teams as playing an important part in the prevention and management of HIV, including diagnosis.

CONFIDENTIALITY

Doctors are required to follow the general principles of confidentiality for any medical condition as laid down by the GMC in its guidance 'Confidentiality: protecting and providing information' which states:

"'Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care".' ,

DISCRIMINATION

The right to the highest attainable standard of physical and mental health is a fundamental human right. In the BMA's view, human rights are of central importance to the practice of medicine, underscoring its fundamental commitment to human wellbeing.

UNAIDS defines HIV-related stigma and discrimination as: "... a 'process of devaluation' of people either living with or associated with HIV and AIDS ... Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status."

Discrimination of people diagnosed with HIV/Aids by any healthcare professional is unacceptable. The BMA believes that all patients are entitled to good standards of practice and care from their doctors, regardless of the nature of their disease or condition.

Historically - fear, stigmatization and discrimination have, in no small way, hindered efforts at stemming the HIV epidemic globally. Discrimination of any form in health and social care settings has a negative impact on health outcomes and on quality of life - discrimination also affects the rate on onward transmission of diseases such as HIV. With its potentially devastating consequences on care-seeking behaviour, stigma represents a major "cost" for both individuals and public health. Both experienced and perceived stigma and discrimination are associated with reduced utilisation of prevention services.

In the UK, advances in medicine and the 'normalisation' of how the HIV virus is treated have challenged much of the stigma previously found in healthcare settings. Today, clinicians approach all patients using the same universal cross-contamination prevention measures, across the board. In this way, clinicians approach every patient in the same 'cautionary' way. This is basic clinical practice and is essential for adequate diagnosis, treatment and care for a variety of illnesses and conditions. It also protects healthcare workers and other patients.

The Terrence Higgins Trust and others report that on a UK basis HIV-related discrimination still occurs in healthcare settings, although we have failed to find comprehensive figures which give an indication of the prevalence of this in Wales. In the absence of such data it is difficult to assess (a) the extent of the problem and (b) what action is required as a result. We appreciate that it may be difficult to provide precise figures since patients who have a positive HIV diagnosis may be reluctant to be identified or to report concerns. Nevertheless, it is difficult to fully address any problems on the basis of anecdotal evidence; we therefore feel that the Committee should consider undertaking a scoping study to ascertain the prevalence of incidents of discrimination against people living with HIV in healthcare settings specifically within Wales.

Some clinicians have been accused of discriminatory behaviour because they are perceived to refer HIV patients to specialists, secondary care, or to dedicated centres unnecessarily. We would argue that this tendency for referral results from a lack of training or knowledge about the HIV disease and that therefore these clinicians may have a lack of confidence in treating the HIV illness generally - even if the patient presents with common complaints - rather than because of prejudiced or discriminatory held beliefs. It is important to remember that for a range of conditions, clinicians often refer patients to colleagues for a second, or specialised, opinion - advanced training and awareness is however the key to overcoming tendencies to refer.

It is also important to remember that HIV decreases the body's immune system; precautionary measures which may seem over-the-top are often to protect patients who are more vulnerable to infection - as much as they are for the protection of the healthcare worker. The same universal precautionary measures are used in the treatment of other blood borne viruses such as TB and hepatitis.

At all times, confidentiality, communication, continuity, sensitivity and a non-judgemental, non-discriminatory attitude are crucial components of the care of those who are or may be infected with HIV. Ultimately, refusal to treat HIV patients is a disciplinary offence.

For those people whose jobs do not involving any direct contact with blood, the risk of HIV transmission from a patient to a healthcare worker is extremely small. For those who do work with blood, or sharp contaminated equipment for example, universal standards of infection control should be adopted.

Developing a practice that is trained and alive to patient concerns about confidentiality and fears of discrimination is likely to support:

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.

Of course many healthcare workers themselves are HIV positive. The General Medical Council's policy is to support disclosure with confidentiality and acceptance, allowing HIV positive doctors to continue their professional practice. These rights are protected in British

law, as are the rights of HIV patients, through the Disability Discrimination Act 2005. But the reality of ensuring that employers and colleagues do not discriminate against HIV positive doctors remains a challenge in medical practice. The General Medical Council considers HIV infection to be a serious communicable disease because it can be transmitted from human to human and results in a serious life threatening illness. HIV positive doctors must, therefore, follow the council's guidance, which say that doctors must seek appropriate help and advice from a consultant specialising in occupational health, infectious diseases, or public health. They must not rely on their own assessment of risk. Clinicians with HIV must change their professional practice to avoid "exposure prone procedures"

Worldwide, three reports exist of transmission from HIV positive doctors to patients. These three reports were made before the introduction of universal precautions or the changes to professional practice that HIV positive doctors now make. Transmission from HIV positive patients to doctors has been reported in 106 cases worldwide, with five in the UK.

HIV-related discrimination is often caused by lack of knowledge about the disease and can stem from misconceptions about onward transmission. Discrimination taking place within healthcare settings or by healthcare professionals is no exception.

GUIDANCE / PUBLICATIONS / MedFASH

The BMA supports the principles and values of medical professionalism as defined for doctors in the General Medical Councils guidance Good Medical Practice 2006: Decisions about access to medical care, which states:

You must treat your patients with respect whatever their life choices and beliefs.

You must not unfairly discriminate against them by allowing your personal views to affect adversely your professional relationship with them or the treatment you provide or arrange.

You should challenge colleagues if their behaviour does not comply with this guidance.

In addition, there are various sources of guidance available for healthcare workers on treating patients with HIV:

Health Protection Agency, HIV and AIDS: information and guidance in the occupational setting, revised July 2003 (www.hpa.org.uk)

The Medical Foundation for AIDS & Sexual Health World Health Organisation, Universal Precautions, Including Injection Safety (www.who.int)

Department of Health, HIV post-exposure prophylaxis: Guidance from the UK Chief Medical Officers Expert Advisory Group on AIDS, 2004 (www.advisorybodies.doh.gov.uk/eaga/PDFS/prophylaxisguidancefeb04.pdf)

Department of Health, Guidance for clinical health care workers: protection against infection with blood-borne viruses,1998 (http://www.dh.gov.uk/assetRoot/04/01/44/74/040/4474.pdf)

The Medical Foundation for AIDS & Sexual Health (MedFASH) is a charity which works with policy-makers and health professionals, to promote excellence in the prevention and management of HIV and other sexually transmitted infections. MedFASH is supported by the BMA and undertakes a range of projects and work in partnership with others, in order to influence policy and offer advice to doctors and other health professionals. Current and recent activities include:

Developing recommended standards for NHS HIV services and facilitating the further development of managed service networks for HIV, in support of key objectives in the government's National Strategy for Sexual Health and HIV for England.

Developing recommended standards for sexual health services and facilitating the development of sexual health networks.

Managing a national review of GUM services

Developing materials to support health professionals, most recently HIV in primary care, an essential guide for GPs, practice nurses and other members of the primary healthcare team

Providing authoritative responses and briefings to government and other policy-makers on current policy issues.

In June 2007 the BMA and the Commonwealth Medical Trust published 'The Right to Health - a Toolkit for Medical Professionals' which is designed to provide practical, realistic guidance for health professionals on the meaning and implications of the right to health. It is aimed at an international audience of health care workers and is designed to be rooted in everyday practice.

The most effective way for the majority of health professionals to fulfil their obligations under the right to health is to ensure that they provide the highest possible standard of care and treatment in a way that respects the fundamental dignity of each of their patients.

TRAINING and EDUCATION

The need for targeted education and training is very much a global concern. Even in the UK where treatment outcomes for HIV patients are among the best in the world there is a need for education to be targeted at both professionals and at the wider public.

The National AIDS Trust's ARE YOU HIV PREJUDICED? Campaign has been designed to challenge HIV-related stigma and discrimination. Two education packs have been produced as part of this campaign, one aimed at tackling discrimination in the workplace, and one aimed at the primary health care setting (e.g. GPs, dentists). Both of these packs provide people working in the relevant setting with information, ideas, and good practice guides to tackle discrimination and comply with the legal framework.

We would support the roll out of a wider public awareness campaign on HIV, aimed at enhancing general understanding of the illness and dispelling any misconceptions.

In addition we recognise that there is a need to undertake a similar campaign aimed specifically at healthcare professionals. We would suggest that the primary objectives of any such training aimed at healthcare workers be two-fold:

To address the lack of awareness among healthcare professionals of what stigma/discrimination is and the that effect it can have;

To increase understanding of HIV transmission.

This should also include more detailed information about the clinical management of HIV in primary care settings - which goes well beyond detection and referral - we would, or course, be happy to support such a programme using any of the tools at our disposal.

It goes without saying that all members of the healthcare team and those working within the healthcare settings (e.g. doctors, nurses, clerks, receptionists) should be included, and specifically targetetd, by such a campaign.

Within any training or awareness programme there is an opportunity to promote the importance of providing patient-centred care and improve existing communication techniques across the health care workforce.

An approach for the way forward?

The Journal of the International Aids Society recently produced a paper on combating HIV stigma in healthcare settings. It concluded that, interventions to combat HIV related stigma in healthcare settings must focus on three areas - the individual, environmental and policy levels:

THE INDIVIDUAL LEVEL - At the individual level, increasing awareness among health workers of what stigma is and the benefits of reducing it is critical. Raising awareness about stigma and allowing for critical reflection on the negative consequences of stigma for patients, such as reduced quality of care and patients' unwillingness to disclose their HIV status and adhere to treatment regimens, are important first steps in any stigma-reduction programme. A better understanding of what stigma is, how it manifests and what the negative consequences are can help reduce stigma and discrimination and improve patient-provider interactions.

Health workers' fears and misconceptions about HIV transmission must also be addressed. Fear of acquiring HIV through everyday contact leads people to take unnecessary, often stigmatising actions. Thus programmes need to provide health workers with complete information about how HIV is and is not transmitted and how practicing universal precautions can allay their fears. In addition to basic HIV epidemiology, health workers must be able to understand the occupational risk of HIV infection relative to other infectious diseases that are more highly transmissible and commonly found in health care settings.

Understanding the association of HIV and AIDS with assumed immoral and improper behaviours is essential to confronting perceptions that promote stigmatizing attitudes toward individuals living with HIV. Programmes need to address the shame and blame directed at people with HIV by providing health providers with a safe space to reflect on the underlying values that lead to the shame and blame. It is important for health care workers to disassociate persons living with HIV from the behaviours considered improper or immoral that is often associated with HIV infection.

THE ENVIRONMENTAL LEVEL - In the physical environment, programmes need to ensure that health workers have the information, supplies and equipment necessary to practice universal precautions and prevent occupational transmission of HIV. This includes gloves for invasive procedures, sharps containers, adequate water and soap or disinfectant for handwashing, and post-exposure prophylaxis in case of work-related, potential exposure to HIV. Posting relevant policies, handwashing procedures or other critical information in key areas in the health care setting enables health workers to maintain better quality of patient care.

THE POLICY LEVEL - The lack of specific policies or clear guidance related to the care of patients with HIV reinforces discriminatory behaviour among health workers. Health facilities need to enact policies that protect the safety and health of patients, as well as health workers, to prevent discrimination against people living with HIV. Such policies are most successful when developed in a participatory manner, clearly communicated to staff, and routinely monitored after implementation.

Several studies have shown that stigma reduction activities in hospitals have led to positive changes in health providers' knowledge, attitudes and behaviours, and better quality of care for HIV-positive patients. These activities can include:

1) Implementation of a brief survey to document the need for action to reduce stigma and guide the design of the intervention

2) Establishment of a steering committee to plan the intervention

3) A flexibly scheduled participatory training programme for healthcare staff (from cleaners to clerks to nurses to doctors), which focused on increasing knowledge and awareness of HIV, universal precautions, and fear-based and value-based stigma, including what stigma looks like in the health care setting

4) Participatory drafting and negotiation by all staff of a policy to foster staff safety and a stigma-free atmosphere

5) Provision of materials and supplies to facilitate the practice of universal precautions.