HIV-related deaths in the HAART era

The main project of the year was a review of deaths among adults with HIV infection, recognising that survival has improved dramatically since the introduction of highly active anti-retroviral therapy (HAART). A total of 133 clinical centres took part, of which 40 reported no recent deaths and 90 submitted data on 387 patients who had died between October 2004 and September 2005.

The survey element of this project revealed issues about the usefulness of local death reviews, the importance of good communication, and how clinicians get information when patients die outside hospital or at tertiary referral centres. Even before the data was analysed, two clinicians wrote to BHIVA saying that their experience of taking part had led them to raise concerns locally about poor access to information and records of recently deceased patients.

Immediate causes of death and scenarios accounting for death among the 387 analysed patients are shown in Figures 1–3. Key findings from the casenote review were that:

- Overall, 32% of deaths were considered not directly related to HIV infection, although this can be difficult to determine. Main causes of death in this category were cardiovascular disease, non-HIV related cancers, and chronic liver disease attributed to alcohol and/or hepatitis B or C.

- Late diagnosis of HIV infection accounted for 24% of all deaths and 35% of HIV-related deaths. This is likely to be a minimum estimate, because some deaths attributed to untreatable HIV complications involved conditions which HAART can prevent and because audit respondents might not know of deaths occurring without the involvement of HIV specialist services.

- Deaths due to catastrophic events in patients on HAART including acute drug adverse reactions were reassuringly rare.

“...This has immediately revealed huge data gaps and a lack of communication between the various centres.”

Clinician’s comment on taking part in mortality audit

Figure 1: Immediate cause of death
These included three cases of lactic acidosis and one of fulminant liver failure, which was attributed to isoniazid.

- Only 11 (3%) of patients reportedly died because they ran out of treatment options with multi-drug resistant (MDR) HIV. This is also reassuring as it suggests that currently available treatments can offer durable control of HIV for most individuals.
- Recent arrival in the UK was not a significant factor in mortality – only 12 patients were known to have arrived within 6 months of death.
- There was some evidence that HIV-related deaths are not always correctly certified as such.

Based on these findings, BHIVA is pursuing two recommendations aimed at reducing late diagnosis deaths:

- BHIVA requests its members to discuss these findings at local grand rounds, to communicate the impact of late HIV diagnosis to non-HIV clinicians and jointly consider how to facilitate rapid diagnosis and transfer of patients to specialised HIV care.
- BHIVA asks EAGA and the Department of Health to consider how to promote more routine HIV testing in generic services as well as specialist HIV/GU/sexual health settings.

**Key outcomes**

During the year the committee has discussed possible key indicators for regular audit and re-audit, which might include:

- Proportion of patients with CD4 count under 200 cells/µl when diagnosed with HIV – this is an indicator of late diagnosis of HIV, which BHIVA audits have repeatedly identified as a major area of concern, including the mortality study reported above.
- Proportion of patients who have ever had a CD4 count under 200 cells/µl who are on HAART – as an indicator of treatment acceptability and timely uptake in accordance with BHIVA guidelines.

- Proportion of patients achieving HIV viral load undetectability within 6 months of starting HAART – this is a key treatment effectiveness outcome.
- Proportion of patients starting HAART who have been tested for HIV resistance – last year's re-audit showed a worryingly low level of pre-treatment resistance testing, despite guideline recommendations. This is of concern as use of drugs to which the patient is already partially resistant can lead to treatment failure, emergence of more extensive drug resistance and hence the need for complex and expensive third- and fourth-line regimens.
- Proportion of patients starting HAART whose hepatitis B status has been determined within the preceding year or is known to be immune – as an indicator of management of co-infection. Some of these indicators can be monitored via data that are routinely collected by national surveillance agencies. The subcommittee will consider how to incorporate the others into its future work.
Managing cardiovascular risk

The mortality audit was accompanied by a survey on the management of cardiovascular disease (CVD) risk factors. This was timely in view of concerns about possible adverse CVD effects of HAART and about non-HIV-related illness among people with HIV. In total, 137 centres responded to the survey and the results were generally positive in terms of reported use of appropriate clinical guidelines and routine assessment of CVD risk. However, some findings merit closer attention:

- Only 37% of respondents said they had good access to smoking cessation services for HIV patients. This is alarming as people with HIV have high rates of smoking and should be a priority for cessation services in view of their risks both of CVD and respiratory diseases.
- Similarly, only 13% of respondents reported good access to exercise classes for managing CVD risk among HIV patients.
- Most respondents did not specify total cholesterol or fasting triglyceride thresholds at which they intervene in HIV patients, preferring to base the decision on an overall assessment of CVD risk. However, one respondent selected a fasting triglyceride threshold of over 12 mmol/l, and nine selected 8–12 mmol/l. These are high levels which may suggest under-intervention.
- Hardly any respondents measure HIV patients’ waist circumference, which is unsurprising as guidelines do not recommend this. However, there is increasing evidence from outside the HIV sector that waist measurement may be a better marker of CVD risk-associated obesity than body mass index. It is not clear whether this might be relevant to HIV management in future.
- 47% of respondents answered “Yes” when asked if they were contemplating any change to their clinical practice as a result of completing the questionnaire. This suggests that the survey focused people’s thoughts on CVD risk management even before the results were presented at the BHIVA annual conference in April 2006.

Disseminating audit results

Publication and feedback is an essential part of the clinical audit cycle, to enable participating centres and others to reflect on findings and change practice where necessary. The committee sends each audit participating centre a confidential summary of its own results with aggregated data for comparison, as well as presenting national results at its conferences and on the BHIVA Clinical Audit Faculty website at www.bhiva-clinical-audit.org.uk

The committee also seeks to publish its major findings in appropriate peer-reviewed journals. Reports of recent studies are in preparation, and articles published to date are as follows:


In addition, a report of the 2003–4 survey on management of hepatitis B and C co-infection has been accepted for publication in the *International Journal of HIV and STDs*.

Web-based audit

Following a pilot survey, the committee has decided to move to web-based survey software for future audit projects. The new system offers considerable advantages over paper questionnaires – clinicians who took part in the pilot preferred it. This system also enables quicker and easier questionnaire design and saves printing, scanning and data-entry.
Protocol change

After consultation, the subcommittee changed its protocols with effect from the 2005–6 audit programme, to allow stratification by characteristics of clinical centre such as size/caseload and region. Any variation in patient data by these characteristics must be interpreted cautiously. For example, in the mortality audit late diagnosis accounted for a higher proportion of deaths at smaller clinical centres than at larger ones but this is not evidence of different standards of care. A plausible explanation is that people with undiagnosed HIV present at their nearest hospital, whereas diagnosed patients with complications are often referred on to larger specialist HIV centres.

Influencing policy development

A large part of the work of the subcommittee has been concerned with assessing how clinicians view BHIVA’s clinical guidelines and to what extent these are followed in practice. This information feeds into the process of updating and revising each set of guidelines. In addition, the committee has now established a regular mechanism for presenting its findings to the UK Chief Medical Officers’ Expert Advisory Group on AIDS.

About the National Clinical Audit Subcommittee

The subcommittee has completed several successful audit projects since it was established in 2001, and its position was consolidated in 2004 with the confirmation of 3-year funding from the Department of Health. The subcommittee’s terms of reference are subject to revision as part of a wider review of BHIVA’s governance, but its broad aims include agreeing and implementing a rolling programme of national clinical audit of the care of persons infected with HIV, with particular reference to BHIVA’s clinical guidelines, and other clinically important topics where an audit shows deficiencies in care, and advising on necessary change and re-audit as appropriate.

Work programme

In this busy year, the subcommittee is also running a survey on monitoring of recently diagnosed HIV patients and has set up a cohort audit with prospective data gathering on patients starting HAART from naive during April–September 2006. Outcome data on these patients will be collected in spring 2007, after which results will be analysed and presented. A survey on clinical networks and a snapshot audit of current inpatients is in planning for autumn 2007.

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