IN PRACTICE

How normalised is HIV care in the UK? A survey of current practice and opinion

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Sex Transm Infect 2007;**83**:151–154. doi: 10.1136/sti.2006.023176

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Accepted 8 January 2007
Published Online First 17 January 2007

Objectives: The prognosis for individuals infected with HIV has changed dramatically over the past 10 years, with patients living longer and requiring other specialist services. It is apparent that access of other healthcare professionals to clinical information about a patient's HIV care differs between centres in the UK. Lack of awareness of an individual's HIV status may compromise their clinical care.
Aim: To establish current practice and identify the views of clinicians caring for patients infected with HIV.
Methods: Lead consultants in all genitourinary medicine departments in the UK were invited to complete a questionnaire regarding use of combined HIV and hospital notes and ability of general practitioners and other hospital specialists to access information about individual patient's HIV care. Clinician's opinions on the ''normalisation'' of HIV management were also sought.
Results: Combined notes (outpatient and inpatient) were used by 12% (16/130) of respondents. The patient's identifying number was used to request blood tests in 86%. Of the respondents, 42% had encountered difficulties in communication that affected delivery of care for an HIV-positive patient.
Conclusions: Centres using combined notes identified a higher frequency of communication with other doctors and specialties, suggesting a higher standard of care. Physicians involved in HIV care should consider combining patients' HIV and hospital notes for improved clinical care.

The prognosis for individuals infected with HIV has changed dramatically over the past 10 years, giving rise to the hope that many newly diagnosed asymptomatic patients will enjoy a near-normal life expectancy.[1] In addition, attempts have been made to reduce stigma associated with HIV infection, with the aim of ''normalising'' the disease.[2] Within the hospital setting, outpatient notes for patients infected with HIV may be handled in the same manner as notes from patients with other sexually transmitted infections (STIs), whereby a separate patient identification number system is used, by contrast with other specialties.

Some units providing care for patients infected with HIV have moved away from this policy, and many infectious diseases units providing care for patients infected with HIV have ''normalised'' care allowing free access to notes within the hospital setting. This policy raises issues regarding patient confidentiality. Anyone receiving patient information is bound by a duty of confidence, which is a legal obligation derived from case law (Common Law of Confidentiality), Parliamentary Acts[3–6] and is a requirement established within professional codes of conduct.[7 8] These legal and professional documents set out principles to follow in seeking, disclosing and using patient information. It is sometimes uncertain whether NHS confidentiality is applicable to patients infected with HIV.

In the late 2005, we conducted a postal survey of all genitourinary (GU) medicine clinics in order to establish current practice and to describe the views of clinicians caring for patients infected with HIV.

METHODS

A questionnaire was circulated to lead consultants of all GU medicine departments in the UK via British Co-operative Clinical Group representatives. Consultants who worked in more than one department made only one return.

The first part of the questionnaire determined the setting in which outpatients infected with HIV were seen and established the cohort size in each clinic. The second part asked for information about the way investigations were requested. This part also sought to establish to what extent results and other clinical information were available to other healthcare workers involved in individual patient care, both within hospital and in general practice. The third part was concerned with information available to other healthcare workers when patients infected with HIV were admitted to hospital with an acute medical deterioration. The last section requested information about communication between GU medicine and departments of obstetrics caring for pregnant women who are infected with HIV. Clinicians were asked about any communication difficulties that potentially affected patient care and for their opinions on ''normalisation'' of HIV management.

Data were analysed on SPSS V.14.0. The association between clinical demographics and the use of combined notes was tested using the χ^2 squared test.

RESULTS

Of the questionnaires sent out to 183 GU medicine clinics, 131 (72%) responded (71% in England, 75% in Scotland and 100% in Northern Ireland). Not all questions were answered by all respondents.

Clinical demographics

The majority of respondents (79/131, 60%) were based in district general hospitals. A further 26% (34/131) were based in teaching hospitals with the remainder in a primary care setting or health centre; 44% were single-handed consultants.

The majority of patients infected with HIV were seen in GU medicine clinics; 3/131 of centres had dedicated HIV outpatient clinics. In 19/131 (15%) clinics, patients were seen in infectious diseases (ID) outpatient clinics, either combined with GU

Abbreviations: GP, general practitioner; GU, genitourinary; ID, infectious diseases; STI, sexually transmitted infection

medicine clinics (16/19) or in the ID clinic. These ID clinics were based mainly in teaching hospitals (53%). Of the respondents, 69% recorded that annual clinic attendance rates were <200 patients infected with HIV per annum.

In 88% (114/130) of centres, outpatient HIV notes were separate from patients' hospital notes. Only 11% (14/130) of centres used combined notes. Combined notes were used by two (1%) clinics for patients with HIV seen in an ID clinic, but not if outpatient care was provided in a GU medicine setting.

Centres which used combined notes were more likely to be based in a teaching hospital than those using separate notes (χ^2 test; 56% vs 22%; χ^2 value = 8.6; $p<0.01$) and to have >200 patients per year (χ^2 test; 63% vs 25%; χ^2 value = 15.5; $p<0.001$). In all, 4/16 clinics using combined notes were based in ID outpatients and two in specialist HIV outpatient clinics.

Outpatient management of HIV-positive patients

On requesting outpatient investigations, many centres (86%) used only number to request blood tests, rather than identifying a patient by name. The majority of centres used name, with or without number, for all other investigations. Centres using patient's names on all requests tended to be using combined notes, but this was not universal; 38% (6/16) used only the number.

Of the respondents, 47% reported that HIV-related results were ''firewalled'' from other computerised results.

The majority (75%) of centres correspond with general practitioners (GPs) after the initial diagnosis and most (60%) correspond after treatment or management change. Centres using combined notes communicated more frequently with GPs (44% vs 26% after each outpatient appointment). Practice varied widely between centres, with one respondent indicating that they never communicated with the GP.

A minority (14%, 18/130) of centres reported that other specialists had open access to patients' notes. Of these 18 centres, two-thirds were using HIV notes combined with the main hospital notes.

Most centres (82%, 107/130) would provide a written summary if requested and provide information via a telephone conversation. A telephone conversation was the only method by which 8% of respondents' shared clinical information with other specialists.

Other methods of improving information sharing were by filing a copy of all letters to the GP in the patient's main patient record and sending update letters to hospital records if a patient was in contact with other specialities.

Sexually transmitted infection screening

In the majority (69%, 11/16) of centres where HIV notes were combined with hospital notes, information concerning STI screening was written in separate GU medicine notes, but the remainder kept STI records in hospital notes.

Inpatient management of patients infected with HIV

In 83% (108/130) of centres, inpatients with HIV were cared for in the same organisation or trust. Centres vary widely with regard to responsibility for the inpatient care of patients infected with HIV. Nearly half (49%) of all the respondents had a shared-care arrangement between GU medicine and other specialities. Centres relying on specialities other than GU medicine or HIV medicine for inpatient care were less likely to be based within the same organisation (66%, 24/35 vs 91%, 86/95) and more likely (80%, 28/35 vs 66%, 63/95) to see <200 patients per annum.

In 17% of centres, ID physicians cared solely for inpatients. These centres tended to be based in Scotland, northern and northwestern regions. A further 6% of hospitals shared care between ID and GU medicine physicians. In 49% of centres inpatient care was shared between GU medicine/HIV physicians and other specialists, and by GU medicine/HIV specialists alone in 17%.

All centres using combined case notes would send them when a patient was admitted to hospital. A minority (14/114) of centres using separate notes would also send case notes. The remaining centres provided clinical information to the admitting team by way of identifiable summary, 61% (61/100), and/or letter, 75% (75/100). Only one centre would send no information with the patient.

Open access to HIV case notes for acute admissions was available to the duty medical team in only a minority (13/130) of centres, and, in all but one, this was because the HIV notes were combined with the main hospital notes. There was no access to patient notes out of hours in 87/130 centres.

Difficulties in accessing notes ''out of hours'' have been described, even when notes are combined. The majority (13/16) of centres using combined notes store them within the GU medicine department. Of these, 75% indicated that out of hours the hospital medical team was able to access notes, however usually not until the next morning or working day.

Two centres used electronic patient records and two centres that used separate inpatient and outpatient notes, copied each letter to the GP and filed them in the hospital notes; one centre filed copies of all outpatient correspondence which was kept on the inpatient ID ward. In one centre, patients had hand-held summaries.

Antenatal care

In all, 26% (34/130) of centres held joint antenatal clinics with obstetricians for the care of women infected with HIV, this was not necessarily in larger centres. Patients managed by centres using combined notes were more likely to be seen in joint antenatal clinics (56% vs 26%) or to be discussed in a case note review meeting (50% vs 34%). Of those centres without joint clinics, 35% (34/96) had joint case note review meetings with obstetric staff. Almost half (48%, 62/130) of the centres had neither a joint clinic nor case note review of obstetric patients. Several centres reported they had not managed women infected with HIV in pregnancy.

Doctor's opinions on normalisation

Difficulties in communication affecting delivery of care for a patient infected with HIV had been encountered by 42% of respondents. Of those, 67% felt that ''normalisation'' of HIV care would be the best care for HIV management. Centres already using combined notes were most likely to feel that ''normalisation'' of HIV would be the best care for HIV management (100% vs 55%).

DISCUSSION

Two major issues are at variance with each other regarding the care of patients infected with HIV. First, the duty of healthcare workers and the healthcare system to protect the confidentiality of individuals and, second, a wider agenda to ''normalise'' HIV disease as far as possible. It is imperative that these two factors should not lead to suboptimal care of a patient infected with HIV.

This survey suggests that in most centres management of care for patients infected with HIV is far from normalised. Protecting the confidentiality of patients seems to be the main consideration in regard of the process of record keeping. Even in centres where attempts to normalise care are made by combining outpatient HIV notes with hospital notes, many centres use a confidential number to request blood tests.

Normalisation of HIV care has inherent difficulties; confidentiality being a major issue. General legal principles are outlined in the Human Rights Act (1998, Article 8),[3] which respects an individual's right to a private life, and in UK Common Law (of Confidentiality) where consent is required for disclosure of identifiable data, unless there is an over-riding legal provision or public interest involved.

From a medical perspective, it is inferred that healthcare workers have a duty to respect confidentiality of personal information. Both the NHS Code of Practice on confidentiality[7] and GMC guidelines[8] recommend that doctors should ensure patients are aware that personal information about them will be shared within the healthcare team. However, doctors should respect the wishes of any patient who objects to particular information being shared with others providing care, except where this would put others at risk of death or serious harm.

Specific to sexually transmitted infections, the NHS Trusts and Primary Care Trusts (STD) Directions (2000),[5] based on the NHS (Venereal Diseases) Act 1974,[6] further emphasise the importance of confidentiality but do provide for sharing of information between healthcare workers in connection with the "treatment of those persons suffering from such disease or the prevention of the spread thereof."

This level of confidentiality is perceived as being insufficient for some patients infected with HIV. Many respondents commented on their patient's unwillingness to disclose their diagnosis to their GP. HIV remains a socially stigmatising disease[9 10] and disclosure of HIV status remains a major concern for patients. In future, as GPs become more involved in provision of care of patients infected with HIV, this issue needs to be addressed.[11]

Of note, centres using combined notes communicated with GPs more often and had improved communication with medical and surgical on-call teams and with obstetricians. This infers that these patients received a higher standard of care as errors in prescribing or other adverse medical events may be less likely. Units managing larger patient cohorts and, therefore, with most experience, identified the need for safety by using combined notes. Difficulties in communication affecting delivery of care for patients infected with HIV when separate notes were used were encountered by 42% of responding physicians. This is a clinical governance issue for physicians caring for patients infected with HIV. Even when combined notes are used, logistical problems remain in access to notes stored within a GU medicine department, which is frequently located off-site or is locked "out of hours". A first step in improving communication may be the use of alternative methods such as filing all copies of GP letters in a patient's hospital notes or making results available on a centralised computer.

Several respondents indicated that despite no access to outpatient case notes "out of hours," a specialist registrar or consultant in GU medicine/HIV was able to provide clinical information by telephone. Smaller units may be able to recall details of their patients, but this may not be feasible in larger centres. In addition, as patients infected with HIV live longer, they will be seen with non-HIV-related conditions by other hospital specialities and access to HIV clinical records will become increasingly important. Use of (centralised) electronic patient records may improve accessibility, should this facility eventually be available. Such a system is used in North America, by the Veterans Administration healthcare system, for care of both patients infected with HIV and those who are not.

An aspect of care which might not benefit patients infected with HIV is that results of STI screening were recorded in hospital notes in nearly a third of centres which used combined notes, albeit sometimes in a separate section. Disclosure of sexual history and STI diagnoses other than HIV to healthcare workers not necessarily involved with the treatment or contact tracing of such a condition could be seen as a breach of the NHS Trusts and Primary Care Trusts (STDs) Directions (2000) based on the NHS Venereal Diseases Regulations (1974).[5 6]

Part of the role of a GU medicine/HIV physician is to reduce stigma associated with HIV infection. By not "normalising" HIV care, perceived stigma may be perpetuated. This survey suggests that patients with HIV will have improved clinical care if their outpatient notes are combined with hospital notes. Centres where HIV notes are kept separately from hospital notes should consider combining notes for delivery of optimised clinical care.

Key messages

- In all, 42% of GU medicine/HIV specialists in this survey had encountered difficulties in communication affecting delivery of care for a patient infected with HIV
- There appears to be a conflict between protecting patient confidentiality and normalising HIV disease as far as possible
- Very few centres have made attempts to normalise care by combining outpatient HIV notes with hospital notes
- Centres using combined notes had improved communication with GPs, on-call teams and other specialities, which infers a higher standard of care
- Centres where HIV notes are kept separately from hospital notes should consider combining notes for delivery of optimised clinical care

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Funding: The British Association for Sexual Health and HIV funded secretarial support.

Competing interests: Professor RF Miller is co-editor of *Sexually Transmitted Infections*, part of the *BMJ* Publishing Group.

DR, EF, CO'M, RM and RFM initiated the study and wrote each draft of the questionnaire. ER and EF wrote each draft of the paper; EF, CO'M, RFM and DR contributed to the revisions of the paper. PK and Regional Representatives (see below) coordinated distribution and collection of questionnaires within their respective regions.

Anura Alawattegama, Mary Browning, Chris Carne (Chairman), Jackie Cassell, Gail Crowe, David Daniels, Annemiek deRuiter, Wallace Dinsmore, Sarah Edwards, Kevin Fenton, Elizabeth Foley, Mia Huengsberg, Philip Kell, George Kinghorn, Deb Mandal, Raymond Maw (Honorary Secretary), Sandy McMillan, Rob Miller, Eric Monteiro, Andrew Nayagam, Abayomi Opaneye, Sasi Rajamanoharan, Karen Rogstad, David Rowen, Celia Skinner, Helen Ward, Jeremy Willcox.

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