HIV testing in dementia: clinical, ethical and patient safety implications

This article presents patient safety issues along with the professional and ethical challenges in relation to UK guidelines on HIV testing in patients who are incapacitated as a result of dementia. Current protocols are designed to protect the patient, but may have undesirable consequences for patients, carers and doctors.

Modern medicine has to face ethical and patient safety issues in relation to undertaking appropriate tests and communicating the results to patients who are unable to fully understand the implications of these tests or results. Clinical accountability, confidentiality and being open to patients and carers are fundamental principles to improve openness and honesty. Being open is part of improving patient care, quality and patient safety, which is integrated in communicating with patients and the public (National Patient Safety Agency, 2005). In addition there are issues concerning who should give consent for the tests, who can undertake the tests, plus who should be made aware of the results and where the results should be recorded. This article discusses a patient who presented such dilemmas.

Case history

A 66-year-old widower was admitted in February 2006 to the Ayr Hospital, Scotland with a significant decline in cognitive function. He had become increasingly forgetful over the previous 12 months; from being fully independent, including looking after his own garden and cycling around the town, he had become increasingly unable to cope at home. He had several falls during the month before admission. He started behaving strangely, such as getting into the bath fully clothed, turning the oven on and off for no apparent reason and wandering into neighbours' gardens in the middle of the night. He had also become doubly incontinent. He had a past medical history of Crohn's disease and on admission was taking mesalazine 800 mg twice daily. He was a smoker and social drinker. He did not have any history of working abroad.

Clinical examination revealed generalized hyper-reflexia, mild ataxia and evidence of right-sided neglect. Jaw jerk and palmo-mental reflexes were present. He had fluent aphasia and difficulty with aspects of executive dysfunction consistent with a progressive aphasic syndrome. On mini-mental state examination he scored 15/30 (he was not orientated in time, place or person and failed the serial 7 test).

Investigations demonstrated that there was no lymphopenia or raised serum gammaglobulin. However, serum vitamin B_{12} and folate levels were low. Rheumatoid factor, tissue transglutaminase antibody and antinuclear antibody were negative. Magnetic resonance brain imaging demonstrated generalized atrophy and a diffuse increase in signal return from the white matter, most prominently from the centrum semi-ovale and periventricular regions. A focal parenchymal lesion was noted in the posterior-lateral aspect of the left thalamus. Electroencephalography demonstrated frontal slow wave activity but no specific abnormalities suggesting Creutzfeldt–Jakob disease. CSF analysis demonstrated paired oligoclonal bands and a polyclonal increase in CSF gamma globulin.

The initial provisional diagnosis was progressive degenerative dementia (probable frontotemporal dementia) but the cause was not established. In the absence of any other clinical or haematological features and the patient's inability to give consent, human immunodeficiency virus (HIV) testing was not undertaken.

A few months later the man was referred from a rehabilitation ward with a lower respiratory tract infection. He had a seizure thought to be secondary to hypoxia while in the accident and emergency department, and at the time of venepuncture there was a needlestick injury to one of the nursing staff. The injury was cleaned and irrigated as per local infection control guidelines. As the possibility of HIV was mentioned in the transfer letter, the patient's HIV status was checked. He tested positive and the nurse was given post-exposure prophylaxis.

Consent for HIV testing

Conventionally HIV testing should be undertaken after pre-test counselling. This should include a full explanation of the implications of the test and the patient needs to be capable of giving informed consent according to the Mental Health Act 1983 (Rogstad et

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al, 2006). In this case the patient had advanced dementia and was incapable of giving valid consent. Discussion with patients who have dementia is often impossible as misinterpretations may occur in communication between the parties involved (Vroman et al, 1994).

The United Kingdom National Guidelines on HIV Testing (Rogstad et al, 2006) do not give specific advice on HIV testing in patients who are incapacitated as a result of dementia, although they do cite the General Medical Council guidelines on consent for testing of serious communicable diseases. However, the General Medical Council (GMCtoday, 2006) subsequently announced that the paragraphs relating to non-consensual testing following injuries to health-care workers are superseded by recent legislation, which underlines the precarious nature of this territory for health-care professionals. Before these developments the General Medical Council advice was as follows:

> **'You should not arrange testing against the patient's wishes or without consent other than in exceptional circumstances, for example where you have good reason to think that the patient may have a condition such as HIV for which prophylactic treatment is available. In such cases you may test an existing blood sample, taken for other purposes, but you should consult an experienced colleague first. It is possible that a decision to test an existing blood sample without consent could be challenged in the courts, or be the subject of a complaint to your employer or the GMC. You must therefore be prepared to justify your decision.' (General Medical Council, 1998)**

In other words, while there may not have been a risk of General Medical Council sanction for testing an existing blood sample for HIV, the legal position with regards to testing for HIV was unclear.

In contrast, the General Medical Council guideline on consent states the following:

> **'In England and Wales, decision-making in these circumstances is governed by the Mental Capacity Act 2005 and in Scotland by the Adults with Incapacity (Scotland) Act 2000. The legislation sets out the criteria and procedures to be followed to make decisions, including decisions about medical interventions, when patients lack capacity to make these decisions for themselves. It also grants legal authority to certain people to make decisions on behalf of a patient who lacks capacity (Human Tissue Authority, 2006). In Northern Ireland, there is currently no relevant primary legislation and decision-making for patients without capacity is governed by the common law, which requires decisions to be made in a patient's best interests.' (General Medical Council, 2008)**

Crucially patients can be tested in theses circumstances only if it is in their 'best interests', which would require a high standard of circumstantial medical evidence for unexplained symptoms to be attributable to HIV so as to require diagnosis and treatment (White, 2007).

When it comes to the circumstance of needlestick injury to a health-care worker and the question of testing the HIV status of a patient, there is a potential conflict between the rights of the patient and the rights of the health-care worker (for example, not to be harmed by the unpleasant side effects of post-exposure prophylaxis when this is not required), whereby the rights of the patient necessarily prevail over the rights of the health-care worker (Szeremeta et al, 2001).

Proxy consent

The Adults with Incapacity (Scotland) Act 2000 allows proxy consent or withholding of consent by a formally appointed welfare attorney for treatment of the granter (i.e. the patient), who agreed to the arrangement before losing capacity. The position is similar in England and Wales under the Mental Capacity Act 2005. In Scotland, if the appointed welfare attorney refuses consent where the relevant powers apply, then a blood sample may not be taken but the decision to take a blood sample could be challenged.

Apart from these circumstances, the medical practitioner primarily responsible for the medical treatment of the adult obtains authority to treat by completing and signing the certificate of incapacity. However, precisely what may be included under the definition of treatment has been the subject of debate. In other contexts, for example, taking a blood sample for diagnostic purposes is understood as treatment (Human Tissue Authority, 2006).

According to the Code of Practice (paragraphs 2.32–2.36) for Part 5 of the Adults with Incapacity (Scotland) Act 2000, treatment 'includes any procedure or treatment designed to safeguard or promote physical or mental health'. Under principle 1 of the Act, anything included under this definition of treatment must be in the best interests of the adult with incapacity, even if a blood sample that was previously taken from the patient is available for testing.

Presuming the adult with incapacity does not have a formally appointed proxy, and a test for HIV would be in the patient's best interests, the question arises as to whether to consult the next of kin before a test is undertaken. Although consulting close family members or carers is a matter of good professional practice, unless they have been authorized to act as a welfare attorney by the Public Guardian in Scotland (in England and Wales this could be a lasting power of attorney, or an appointment as a deputy by the Court of Protection), they are unable to give or withhold consent on behalf of the incapacitated patient, and again the legal standard is whether or not the blood test would be in the patient's best interests (Johnston and Liddle, 2007). The Department of Health (2001) guidance on consent with older people comments as follows:

> **'…those close to the incapacitated person should always be involved in decision-making, unless the older person has earlier made it clear that they don't want such involvement. Although, legally, the health professional responsible for the person's care is responsible for deciding whether or not particular treatment is in that person's best interests, ideally decisions will reflect an agreement between professional carers and those close to the older person.'**

Moreover, absence of capacity is not in itself reason to exclude the patient from the decision-making process. The above document comments further (p. 10–11):

> **'…people who lack capacity to consent or refuse a particular treatment option may still express willingness or unwillingness to co-operate with what is being offered. Such preferences should always be taken into account when deciding whether the proposed care or treatment is genuinely in the patient's best interests. The only interests which you should take into account when deciding if particular treatment is appropriate are the older person's best interests. It is not lawful to balance these interests against the interests of their family, or the interests of health professionals.' (Department of Health, 2001)**

It is sometimes possible to obtain consent from some patients with dementia. The principles set out in the Mental Capacity Act 2005 include a presumption of capacity (principle 2), 'and a requirement that all practicable steps should be taken to help a person to make a decision (principle 3)'. Also the Department of Health guidance on consent with older people comments:

> **'…you should never automatically assume that a person lacks capacity simply because they have dementia. A patient's capacity should always be assumed until proved otherwise.' (Department of Health, 2001)**

Confidentiality

Another aspect to consider is the disclosure of information in these circumstances. The earlier General Medical Council guidance on consent for testing of serious communicable diseases expressed this as follows:

> **'If you decide to test without consent you must inform the patient of your decision at the earliest opportunity. In such cases confidentiality is paramount. Only the patient and those who have been exposed to infection may be told about the test and its results. In these exceptional circumstances neither the fact that the test has been undertaken nor its results should be entered into the patient's personal medical record without the patient's consent.' (General Medical Council, 1998)**

This suggests that in the authors' case the results of any test should not have been entered into the patient's personal medical records and therefore the GP should also not be notified. This could, however, conflict with the best interests of the patient if denied the opportunity of antiretroviral therapy for his disease (which is of proven benefit). In addition, if and when the patient develops other complications such as infections like pneumonia, the treating physician would find it much more difficult to diagnose and treat the underlying problem (e.g. *Pneumocystis jiroveci* pneumonia).

Theoritically purists would suggest that health-care workers should always be aware of universal standard precautions when dealing with patients to avoid risks of needlestick injuries. However, there are suggestions that health-care workers lack confidence in standard precautions and clinicians are often more cautious with high risk patients and in patients with known positive HIV status so as to avoid possible needlestick injury (Temple-Smith et al, 2006).

Further, there is the issue of whether or not to disclose the results to the next of kin who has given permission to test for HIV. This obligation goes beyond the good practice discussed earlier of involving those who are close to the incapacitated person in the decision-making process. If the next of kin had been granted power of attorney by the Public Guardian for the welfare of the adult lacking capacity, then he or she must be consulted in the same way that a patient with capacity would be consulted since future decision making in matters relating to consent would depend on being in possession of the same information that the patient would otherwise require if competent.

HIV testing in the work-up of dementia

In the initial work-up with any patient with dementia, the clinician tries to find causes of dementia which are treatable, reversible or where treatment is available to slow or halt the progression of dementia. HIV-associated dementia is a potentially treatable condition. Highly active antiretroviral therapy (HAART) has been shown to improve dementia, halt progression and improve general wellbeing, which would clearly be of major importance for the patient's best interests. Therefore are we coming to a stage when clinicians should offer an HIV test to a larger proportion (if not to all) patients with dementia?

The Royal College of Psychiatry (2006) guidelines on blood tests for Alzheimer's disease suggest that the clinician can opt for an HIV test in the initial work-up, but as with the General Medical Council guidelines on serious communicable diseases, these may now be superseded. In the National Institute for Health and Clinical Excellence (2006) clinical guideline on dementia, the advice under investigation of suspected dementia is: ‘Do not routinely test for syphilis serology or HIV unless there are risk factors or the clinical picture dictates’. There is also an argument that HIV exceptionalism must end at some point and that HIV testing should be normalized. However, we are still some way from achieving that at the present moment (De Cock and Johnson, 1998; Brewster, 2007).

Surrogate testing for HIV

As a surrogate test for HIV, CD4 testing has been found to be non-specific and poorly sensitive. However, a CD4: CD8 ratio is probably the best test available (although it also has its shortcomings, including the ethical grounds). Examination of CSF and neuroimaging are said to be suggestive but not specific. Neuropsychological testing for HIV includes trail making B, digit symbol, grooved pegboard and computerized reaction times tests. These tests are useful for the diagnosis of dementia in a patient previously known to be HIV positive rather than being specific for HIV-associated dementia (Davis et al, 2002).

Conclusions

At the time that the authors’ patient tested positive for HIV infection the advice was more clear cut than it is at present. The situation is now much more uncertain, and if the patient had tested negative the legal implications may have been different. The key issue is whether or not it is in the best interests of the patient to be tested for HIV when this is for the benefit of an injured health-care worker. Beyond the necessity of establishing the patient’s best interests, there are the legal aspects both of taking a blood sample and also of the subsequent testing of an existing sample. Furthermore, there are complexities relating to the proxy consent of a welfare attorney and also the confidentiality and communication of test results.

Given that the law does not legitimize treatment undertaken without consent that is for the benefit of a third party, a decision to take a blood sample from an incapacitated adult for reasons other than the patient’s best interests is not presently indicated. **BJHM**

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KEY POINTS

- This article explicates professional and clinical complexity in relation to testing patients with dementia for the presence of the human immunodeficiency virus (HIV).
- Current guidelines for the testing of HIV status in patients lacking capacity are designed to protect the patient, but may have undesirable consequences for patients, carers and health professionals.
- The law does not legitimize treatment undertaken without consent that is for the benefit of a third party, so a decision to take a blood sample from an incapacitated adult for reasons other than the patient’s best interests is not presently indicated.