Infectious health care workers: should patients be told?

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This thoughtful reflection on a valuable questionnaire survey of patients’ attitudes regarding being told that their dentist had been infected with hepatitis B is of very direct relevance to HIV, as the authors show. The measured tone and analytical approach are a welcome change from the stridency that has characterised some of the debate elsewhere. I am very conscious that more time and effort has gone into drafting and redrafting, amending, revising and refining policy in this area (in the UK at least) than in any other area of HIV control, with the probable exception of blood transfusion. Yet this is the setting that has the lowest risk among all established routes. Why has it been so hard to establish a satisfactory policy and practice to deal with this situation?

Many factors, of course, apply. However, much seems to stem from a prevailing view, fostered by recent political administrations, that health care can be delivered in a risk-free way. This has also been linked with a “blame culture”, where adverse outcomes are seen as someone’s fault, and where the professions (and the “establishment”) are regarded with distrust. It has been fuelled by levels of concern about risk for HIV (and other blood-borne pathogens to a lesser extent) that have stemmed more from media “stories” about perceived risk than careful risk assessment.

Hence Blatchford et al comment that public anxiety about HIV relative to hepatitis B was a factor in assessing how the incident was handled, implying that HIV was of greater concern - even though the risk of transmission is some two orders of magnitude less. Interestingly, they also comment that, because the risk of death with HIV is higher than for hepatitis B, this balances the overall risk. I am not sure of the validity of this argument, though it is certainly a widely held view.

It is notable that in the mid-1980s, the perceived risks of HIV outweighed those of hepatitis B in respect of the low uptake of plasma-derived hepatitis B vaccine among health care workers, even though there were over 50 deaths from occupationally acquired hepatitis B among health professionals in the USA in one year and none from HIV.

Another interesting factor in the public, and especially the media - and hence political - concern about the issue of HIV-infected health care workers, was the issue of the confidentiality of the health care worker. This is necessarily in hazard from any look back procedure, from either direct or deductive disclosure. Confidentiality is generally and properly regarded as a right among patients (though the media have been all too willing to breach it where HIV has been concerned). However, where the patient is a health care worker, it has been regarded as a right that is all too readily dispensed with. The terms “secrecy” and “cover-up” were all too often substituted to influence opinion in the media coverage of the issue. This was linked to the fact that health care professionals were seen as having drawn up the policies, and were therefore judged to be protecting their own interests.

This was very evident when sections of the press elected to “out” a number of health care workers who had been following the existing policies, because the press regarded the risk as unacceptable, despite the careful scientific deliberation in drawing up the current policies. This led the government of the day to draw up new guidance based on a very different level of risk assessment and, above all, to introduce procedures that would almost inevitably have breached the confidentiality of the health care worker. While these were in place (thankfully briefly), there was an almost complete cessation of individuals coming forward with risk for or known HIV, even to those clinicians who had publicly rejected the new guidance. Those who had previously come forward said they would not have done so if the new guidance had been in place, because it gave them, and those close to them, no protection against press intrusion into their privacy.
Thus measures that were designed to protect the public against a very low risk, had the perverse effect of reducing the willingness of health professionals to self-declare their risk, because their own rights had not been adequately safeguarded. Yet self-declaration of risk is a critical component in the effectiveness of these policies, so the policy would have, if anything, increased any risk. Subsequent guidance has largely rectified this balance. Blatchford et al recognised the need to balance these issues, though they do not articulate fully the rationale in terms of the benefits to public health and private rights. It is notable that their survey of those contacted about an incident shows that many respondents wished to know the identity of the health care worker.

**Careful assessment**

The authors comment that the view has been expressed that patients have a right to know that a health care worker has an infectious risk and that this overrides the need for secrecy. However, there needs to be a careful assessment as to what criteria and what level of risk justify such a policy, both in respect of the rights of the health care worker and in terms of the public health consequences. Sadly, these are rarely resolved in the handling of incidents, especially if the media become aware of the issue. My personal experience has been that public health officials frequently tend towards a risk-averse approach that disregards or diminishes the rights of the individual health care worker. Having witnessed the excessive and unjustifiable intrusions into the personal life of individuals, their family and friends, this is of very real concern, both in terms of human rights and in terms of unintended adverse consequences to public health. I have been struck by the much greater willingness of professionals to protect their patients where their own rights are properly regarded.

One section of a previous policy said that breaching confidentiality was justified to allay public anxiety, even apparently where that anxiety was unjustified (and often fuelled by media misinformation). It has always seemed to me ironic that the very professionals who are expected by the public to observe and safeguard confidentiality are afforded less right to this in respect of their own health matters. Furthermore, those professionals whose work puts them at most risk from blood-borne infections from their patients are in effect regarded as having lesser health rights if the potential transmission goes the other way.

In assessing the possible purposes of look back procedures by the Association for Practitioners in Infection Control (APIC) criteria, Blatchford et al consider that gaining epidemiological data on the risk of transmission is “for research”. This is moot. Arguably, by gaining such information - if it can be done without unacceptable hazard to the individual, or even with the individual's agreement and collaboration - we are benefiting the public and personal health of all concerned in future incidents, enabling such exercises in the future to be more carefully focused on instances where there is a greater justification. Thus research is not just a way of satisfying curiosity but a means of assisting in policy development in a way that maximises public health benefit while minimising personal harm. The authors are, however, right to insist that the Helsinki declaration applies; this would be as a basis for ensuring that an appropriate balancing of risks and benefits applies to each instance, including the possibility of not doing the study in those specific instances where human rights would be breached. The key research subject in this case is the health care worker.

The development of policy and process in the area of blood-borne infections has obviously evolved alongside the emerging knowledge in these areas, including increasingly awareness of the natural history of these infections and their increasing treatability. Thus the current assessment offered by the authors on the Wilson and Jungner criteria would have been answered very differently in the mid-1980s for HIV. An indication of the difficulties where crucial information is still emerging can be best seen by analysing these issues now with respect to hepatitis C, where the answers are still lacking in many respects and yet where similar issues of principle apply.

**More anxious**

The other main aspect of this valuable paper is the systematic gathering of information about the perceptions of the patients who were contacted in the look back procedure. While most patients were content to have been informed by letter, a significant minority would have preferred contact in person. In any event, their responses show that the content and tone of the letter was of great importance. The letter used in this instance apparently fell short of their expectations. A significant proportion (56%) were made more anxious by the letter. The Manchester case that is referred to turned on the route and content of the letter informing individuals, and was initiated because of the high level of anxiety it engendered in some recipients. The court concluded that the patients should have been told in person, as in the previous Exeter case. However, the court’s decision was reversed on appeal.
The authors comment that patients wanted more information than professionals had been inclined to offer. It is indeed reasonable to conclude that more information (given in an appropriate way) will give more reassurance. It is interesting to wonder why professionals are more inclined to “protect” patients by giving less, despite a greater trend currently towards patient autonomy and less professional paternalism. Professionals are likely to have been skewed in their perceptions of the risk of increasing anxiety and hence harm, by their experience of those who had been harmed in the past, who would have come to their attention, not those who were reassured. The study provides some important data that can reassure professionals that increased anxiety need affect only a small proportion. This anxiety can evidently be ameliorated further by the content and tone of the notification. This can surely inform future practice based on the needs of the whole population being notified, and not excessively influenced by those who suffer adversely.

In the present climate of health care in the UK, there will be continued scrutiny of the extent to which the health of professionals may affect their ability to care for their patients without adding further risks to those that are intrinsic to the delivery of health care itself. Health professionals are fallible and have the same range of human problems, health or otherwise, as anyone else. Failure to practise at a sufficient level of competence can to some extent be covered by the current and increasing move towards tighter regulation. The difficulty is the extent to which, by the nature of their professional role, there is a duty to warn patients of risks that may flow from their personal or health circumstances, even where this reduces their rights as individuals.

These matters evidently affect not only the risk of the impact of blood-borne infections but also the impact of, for example, depression, substance misuse, fatigue or lack of insight. How far does the public have the right to be notified of these matters and how much must be presumed to be part of the intrinsic consequence of having their health care delivered by human beings?

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References