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St Bartholomew's and the Royal London School of Medicine and Dentistry, within Queen Mary and Westfield College, was formed in 1995 on the merger of the former Medical College of St Bartholomew's Hospital and The London Hospital Medical College with Queen Mary. The School is located at Whitechapel, West Smithfield, Charterhouse Square and Mile End.

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Dr. PE Hewitt
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December 20, 1999

Dear Dr. Hewitt,

I enjoyed my meeting with you and Dr. Knight last Tuesday. I know that you agree that it would have been impossible to provide earlier comments of any value without becoming more acquainted with the latest details of the debate about notifying both recipients of the blood of nvCJD patients and donors who have given blood to those who have contracted the illness.

As I understand it, the reasoning behind the original decision not to inform recipients or donors in the circumstances described was based on the premise that not doing so could in no way impinge on their interests. This was because of the uncertainty surrounding the mode of transmission and the lack of a screening or diagnostic test to diagnose infection.

The issue of the lack of any effective intervention has also been mooted as a justification for non-notification. I would discount this as relevant to any new policy about notification. Many terminally ill people both need and want to know information about their diagnosis and prognosis, despite the absence of effective treatment. They require such information because of decisions about their lives or deaths which they may wish to make on its basis. It is impossible with any certainty for clinicians effectively to judge who these individuals are or what kind of information they require, even when they are actively treating them. Indeed, there are obvious difficulties in assuming that when some patients reject information which they may find distressing, they can be said to be making an informed choice about their rejection. It certainly cannot just be assumed that recipients or donors who are linked to nvCJD will not wish to be informed of this fact - if anyting can be said to practically turn on the provision of such information.

Therefore, the key moral issue is whether or not there is a) evidence - or the appearance of evidence - that there is a link between nvCJD and blood and b) an effective diagnostic test. Personal decisions of the kind which I have described might be related to either. Let us take each in turn.

1. Scientific evidence of transmission by blood.

If I understood you and Dr. Knight, there is now very little sound evidence that nvCJD can be transmitted by blood. The problem is that the National Blood Authority has adopted a policy about the non-use of the blood of the recipients of potentially infected blood which entails that they must be informed that they are ineligible to give it. The Department has also insisted that as the medium of potential transmission, white cells be removed from blood for transfusion. Both decisions suggest - and will certainly do so to the public - that there is evidence of transmissibility. Therefore, recipients or donors who are told that their blood cannot be used must be informed of the circumstances surrounding this decision. On the one hand, if they are given no explanation then they will rightly demand it. On the other hand, if they are told nothing and allowed give blood which is then simply destroyed, they would be doing so under false pretences. This is both immoral and illegal. If any thing should now be clear in the practice of health care in Britain, it is that deception is not an option for good clinical practice or public policy.

2. The emergence of a screen or diagnostic test to diagnose infection.

At our meeting, we discussed the potential diagnostic efficacy of Professor Collinge's tonsil biopsy. Since then, I have taken other advice on this and on the probability of the development in the United States of an effective diagnostic blood test over the next year. As regards the former, while opinion is obviously divided, there does appear to be some consensus that Professor Collinge's test will have some predictive value for individuals who choose to have it. Concerning the latter, the entire point of the development of a blood assessment is to generate an easier, and possibly more accurate, means to the same end. Further, there is no reason to believe that competent individuals who choose to have such tests would be unable to understand them or any doubts or qualifications which professionally exist about their predictive value - provided that details were properly and sensitively explained and the individuals were appropriately counselled.

This must mean that individuals do have a diagnostic choice - albeit a complex one - which they may wish to make upon being informed of a possible blood link to nvCJD. They do have potential personal interests in knowing their nvCJD status, however their professional advisors/counsellors may wish to qualify the nature and certainty of this status. Therefore, it would be wrong to deny them access to knowledge about their blood link to the disease if this is known by the National Blood Service.

Please note that in arguing as much, I am again not underestimating the importance of providing this information in an appropriate and skilled manner. Equally, it is clear that as more and more policy discussions about the potential implications of hvCJD are made public, the importance of a programme of public education cannot be overestimated. This should be about its nature, prognosis, the probability of its spread, its potential resource implications and so on. For example, we may now be close to a public announcement about surgical instruments and nvCJD which should be carefully planned and executed against the background of a much broader educational programme. These educational issues cannot be divorced from any moral assessment of the specific problem of what should be said to recipients or donors of blood which may have been infectious. It goes without saying that they have their own profound resource implications.

If I can be of any further help in this matter then do let me know. I realise the pressure under which you and your colleagues are working and want to help you in any way that I can.

Best wishes.

Yours sincerely

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Len Doyal
Professor of Medical Ethics