

Kent Haemophilia Centre
Comprehensive Care Centre
Kent and Canterbury Hospital
Ethelbert Road
Canterbury
CT1 3NG

Tel: 01227 783157
Fax: 01227 783158

MW/SP

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Charles Lister

Dear Charles

HAEMOPHILIA – hepatitis C testing

You will understand that the issues around hepatitis C testing are both complex and sensitive. Furthermore, these events occurred well over ten years ago so in response to your queries all I can do is try and recollect the series of events that occurred around that time. I have also been through the papers of the UKHCDO Annual General Meetings, the workings of the UKHCDO Chronic Liver Disease Group and any such national advice that emanated from UKHCDO. I did not start to attend the UKHCDO Comprehensive Care Centre meetings until 1995 and it might therefore be worthwhile seeking the advice of Frank Hill (Chairman of UKHCDO) to make sure that there is nothing in the minutes of the CCC meetings that would be relevant to your query.

Against that background, one must also note – as ever – that it is clear that the practice of individual haemophilia centres varied widely in the way in which they responded to hepatitis C, both in terms of testing patients and informing them of the result. In part, this was probably the result of any formal guidance in relation to these areas in national guidelines.

We must also bear in mind that it has always been part of the culture of haemophilia centres to regularly screen the blood of their heavily treated patients for the possible presence of viruses. This is an understandable reaction that has grown out of the practice of using coagulation factor concentrates since the early 1970s and the subsequent realisation that they could transmit viruses. In most centres therefore, it has been standard practice to carry out say twice yearly a 'viral screen' and against that background it doubtless seemed natural to haemophilia centres to start testing for hepatitis C when the test became available, which to the best of my recollection was around 1990.

Although haemophilia centres had been intimately involved with the HIV crisis in the early 1980s, and had become used to the concept of counselling patients prior to HIV testing it was not felt that such a process was necessarily required when the hepatitis C assay became available. This was partly because of the difference in outlook between HIV and hepatitis and also the difference in stigma between finding out that you were positive for HIV as opposed to hepatitis. There were also no particular problems with insurance in carrying out hepatitis testing of the kind that had become only too familiar when patients submitted to an HIV test.

Of course, today's culture of getting informed consent from a patient was of much lower profile ten or fifteen years ago and I am sure that many centres just did not consider that it would be necessary to advise their patients that they were carrying out hepatitis C testing. Against the background of the comments made above, many centres would have assumed that it was their responsibility to carry out hepatitis C testing (in addition to the

other viral screens they were already carrying out) and assumed that the patient would support this. On the other hand, I know of a number of centres that did inform their patients.

I have found copies of formal guidelines issued by the UKHCDO Chronic Liver Disease Group in July 1990, February 1993 and December 1994. None of these documents mentions the importance of telling patients that they were being screened for hepatitis. The February 1993 document stresses the relevance of offering HCV testing to sexual partners, which implies presumably that the guidelines recommended that patients should be told of their result. The December 1994 guidelines are more specific, stating 'the patient should be kept fully informed of the results of all laboratory tests, including HCV antibody status'.

I have also come across a bulletin on hepatitis issued by the Haemophilia Society in November 1994. This makes no mention of pre-test counselling.

All in all therefore, there was no national policy to recommend to centres that they should counsel their patients before HCV testing. It seems likely that some centres did inform their patients, whereas others clearly did not.

In my experience, I am not aware of any centres that had a policy of withholding results from their patients. It is true that it was not always possible to understand the full implications of a positive HCV antibody result because in theory this could mean either that the patient was infected or had been infected and had subsequently cleared the virus. Without a PCR test being available, there was no way of telling the difference between these two theoretical possibilities. Be that as it may, I can find no evidence that this would have been behind a policy of withholding information from patients and – as I say – nor am I aware that any centre did anything else other than tell their patients of the results, even though the result itself might have been complicated to explain.

As far as the allegation about withholding information about HCV positive results putting sexual partners at risk, I have already noted that the February 1993 UKHCDO Liver Disease Working Group guidelines clearly state that 'anti-HCV Ab testing should be offered to all sexual partners of HCV antibody positive patients'. This was certainly the practice of other centres, with whose work I am familiar, and I am sure that UKHCDO would therefore refute this allegation.

In summary, I am sure that UKHCDO would refute these allegations more or less totally whilst accepting that all was not carried – in retrospect – as well as one might have wished for. The philosophy in haemophilia centres has always been to regularly carry out viral screening, for reasons outlined above, and it therefore seemed natural to add hepatitis C to this list when the test became available. There seems to have been no national dialogue at all at the time about the relevance of obtaining informed patient consent for the performance of these tests – this would have broken with the traditional approach. I am not aware of results being withheld from patients and indeed I remember many conversations with colleagues when we discussed how difficult it was at times to convey to a patient what a positive HCV antibody result might mean. Nor would I support the idea that the health of partners was put at risk by withholding information as there is evidence that it was national policy to offer sexual testing, against a background of an extremely low incidence of HCV transmission through sexual activity.

I hope these comments are helpful.

Yours sincerely

Dr M Winter
Haemophilia Centre Director