Rapid response to:

Reducing error, improving safety

BMJ 2000; 321 doi: https://doi.org/10.1136/bmj.321.7259.505 (Published 19 August 2000)Cite this as: BMJ 2000;321:505

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Rapid Response:

Tainted Blood

Dear Sir,

I read with interest the letter you co-wrote to the BMJ letter's page (19th - 26th Aug 2000) in response to the issue featuring medical error. I saw your professional title and wondered if it was possible I had stumbled across that rare breed, a haematologist with a conscience.

I am the co-ordinator of Haemophilia North, a voluntary group set up to support haemophiliacs infected with HIV and hepatitis viruses and give them a voice. My partner is co-infected HIV and hepatitis B and C. My partner's brother died of Aids in 1986.

The following passage from your letter remains in my mind.

"Behind each adverse event there is a patient, a doctor, and a doctor-patient relationship. A patient must be told when things have gone wrong. Every effort must be made to minimise the after effects, including financial recompense where necessary. Most patients wish to know in detail what happened and what is being done to reduce the possibility of a recurrence. And members of healthcare teams need mechanisms to come to terms with their fallibility. It is hoped that clinical governance will make a difference."

I would be grateful if you could shed some light as to why the above has still not happened with regard to the contamination of haemophiliacs through NHS blood products. This issue was described in the House Of Lords this year as the biggest medical treatment disaster in the history of the NHS, yet no public inquiry! I do not hear haematologists standing up and supporting their patients in the fight for a public inquiry, indeed there is a wall of silence!

Haemophiliacs in England, Scotland, and Wales, as in Southern Ireland and Canada want their day of justice, indeed as doctors are well aware part of the psychological healing process is coming to terms with the truth about what has occurred. Haemophiliacs are unable to move on with what is left of their lives until this happens in an official capacity such as a public inquiry.

It has been left up to haemophiliacs and their families to dig for that truth largely unsupported. The following should leave you in no doubt as to what we are having to confront and we ask why haven't the so-called professionals told us the truth. Haemophiliacs not only have to deal with professionals withholding information but also with professionals inappropriately transferring their anger onto patients because their patients have stumbled onto the truth.

The Facts:

1. We are of course aware that the Department Of Health and haematologists blatantly ignored WHO guidelines in the 1970s and used imported American factor concentrates, that is a country with a low incidence of hepatitis imported blood products from a country with a much higher incidence of hepatitis, plasma collected from high-risk populations within a higher risk country.
2. We are aware that the Department Of Health and haematologists ignored the literature and research available at the time which studied and documented the greatly increased risks of using blood obtained from paid, skid-row donors such as those shown on the 1975 "World In Action" documentary "Blood Money".
3. We are aware that plasma collected for Factor VIII and other blood products was obtained in large quantities from the captive "high-risk" donors of prisons such as Arkansas, Louisiana and Arizona. Indeed we are fighting now for justice with the families of some of those prisoners who went on to die of hepatitis C. Some prisoners even had the wrong blood cells put back into their bodies during plasmapheresis, equipment sometimes used on more than one patient increasing the spread of viruses.
4. We are of course aware that plasma was obtained from "high-risk" donors in third world countries in Africa, ("high-risk" for viruses such as HIV and hepatitis), Central America etc, the poor and sick exploited by unscrupulous blood-brokers who were rewarded with influential positions on the World Federation O f Haemophilia such as vice-chairman.
5. We are aware that human blood was relabelled as animal blood to avoid customs, and blood from cadavers was relabelled as having come from live donors.
6. We are NOW aware of the reason why a hepatitis waiver was included in an HIV ex-gratia payment, an attempt to silence haemophiliacs and prevent future litigation should a haemophiliac survive Aids.
7. We are aware that many haemophiliacs were misinformed both by the Department Of Health and haematologists with regard to the hepatitis C virus in

1991 being told “it was nothing to worry about" and “less of a problem than hepatitis A or B," despite hundreds of articles /research papers, books, stating a very different picture.

8. We are aware that many haemophiliacs were not even tested for the hepatitis C virus until 1994 despite accurate tests being available at a much earlier date.
9. We are aware that haemophiliacs are frequently told by haematologists that the “benefits of treatment outweighed the risks." In Newcastle alone out of 105 patients tested for HIV, 95 tested positive, 77 are now dead, 95% of those surviving haemophiliacs have hepatitis C usually in addition to hepatitis B. Very successful treatment!!!
10. We are aware that the Department Of Health and many haematologists assume all haemophiliacs and their families are stupid and haven’t got the intelligence to fathom out why so many haemophiliacs were infected with HIV and hepatitis C and are now dead. This assumption is incorrect!

I write to you and your colleagues to ask what support will your group offer haemophiliacs to highlight the issues raised, bringing them to the attention of a wider audience as we are doing, and what support will your group give to help us fight for a public inquiry.

Thank-you for taking the time to read this. I look forward to your reply.

Yours sincerely

Carol Grayson, (Co-ordinator Of Haemophilia North).

GRO-C

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Competing interests: No competing interests
24 October 2000
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