CHAPTER 6

REFLECTIONS ON THE RESEARCH PROCESS

"Everything that limits us we have to put aside" (Richard Bach, Jonathan Livingstone Seagull, 1970)

Conclusion

In my study I set out to answer the question "how has the global politics of blood impacted on the UK haemophilia community?" During the research process I felt apprehensive that I was covering a wide area of study however I feel that this was necessary in order to interpret the answers I received in the questionnaires. I needed to understand the point of view of the Government, the medical profession and other organisations and I explored this through my textual analysis of the SSR. This systematic interpretation of material provided the link between Government health policies (viewed within the wider global context) and how these policies and medical practise had actually affected the day to day lives of haemophiliacs. I believe that had I just used questionnaires the study would have highlighted key themes in the haemophilia community but would not necessarily have shown the connection between the behaviour of the policymakers and the survival strategies adopted by participants in my study. Similarly a textual analysis of the SSR on its own would have concentrated on blood policy but would not have shown the wider consequences of that policy on many individuals. I acknowledge that because of my personal situation my research cannot be entirely free of bias, I hope however that much of the additional evidence presented in the appendices supports my findings. I also found at times that my years of writing in the

style of a grassroots campaigner made it difficult to adopt the writing style of an academic researcher. I discussed this in person with an anthropologist who felt that there was a move now in academia to accept "different" voices which he felt also had a right to be heard.

I believe that my analysis of the SSR reveals that much more could have been done by the Government and medical profession to protect haemophiliacs from the risk of contamination with HIV and hepatitis viruses at almost every stage. Once they became aware that haemophiliacs were infected they disempowered patients by withholding information, denying them informed choice in relation to treatment, carrying out unethical research and in some cases failing to treat their medical conditions. The impact of Government and medical policies on the haemophilia community had far-reaching consequences and for many years power lay almost entirely in the hands of the professionals. In order to cope with HIV/HCV haemophiliacs have had to develop new coping mechanisms to survive or in many cases face their mortality. These adaptations have occurred over a number of years and have involved changes in self-identity with the emergence of a community united by contaminated blood and all its symbolism within society. An analysis of the questionnaires shows a transition in the community from a passive state to a more active state. Haemophiliacs and their families have fought back against the institutions by educating and empowering themselves, accessing information, standing up for their human rights and challenging the balance of power through political, social, and legal channels.

I believe that I too have gone through a process of change both as a researcher and a human being. I have learned that my own personal life experience and that of the UK

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haemophilia community can be used in a positive way to help others. I also feel that there is still research work needs to be carried out in this country looking at the circumstances of haemophilia widows and bereaved children, and the psychological, social and financial effects of losing a loved one to HIV/HCV. The "Life Stories" oral history project mentioned previously will soon be starting work in this area, I will be contributing to the project rather than instigating this particular research.

I feel there is also a need for further study into the global blood trade and the effect on donors and recipients in developing countries where illegal blood collection is still a problem in relation to the spread of disease. I think it is important to work with infected communities in other countries where there are also human rights abuses against those infected with HIV/HCV. I hope to carry out a study on the haemophilia community in China through a placement devised through joint co-operation with VSO and the Aizhixing Institute in Beijing where I wish to collect case histories of blood donors and recipients to investigate the effect of the illegal blood trade in China. Much of the general evidence and knowledge acquired during this study can be adapted for this purpose.

It is also my intention to present this study to the Government in the presence of my MP Jim Cousins, carrying out this research has also been a further exercise in empowerment for me. The Haemophilia Society has offered to publish an edition of this dissertation once completed and it is my hope that this study will lead to a greater understanding and respect in society for those living with HIV, hepatitis C, and other blood borne viruses.

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List of Abbreviations

| AIDS | Acquired immune deficiency syndrome |
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| ALT | Alanine transaminase |
| BPL | Blood Products Laboratory (now known as Bio Products Laboratory) |
| DNA | Deoxyribonucleic acid |
| FDA | Food and Drug Administration |
| GP | General practitioner |
| HCD | Haemophilia Centre Directors |
| HCV | Hepatitis C virus |
| HIV | Human immunodeficiency virus |
| NANBH | Non A Non B Hepatitis |
| NBTS | National Blood Transfusion Service |
| NHS | National Health Service |
| РТН | Post-transfusion hepatitis |
| PFL | Plasma Fractionation Laboratory |
| RHA | Regional health authorities |
| RIBA | Recombinant immunoblot assay |
| RTC | Regional transfusion centres |
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APPENDICES A

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| Fiona Murray- Notes For Panorama | A20 |
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| Hepatitis Waiver (1991) (HIV Settlement). | A21 |
| Letter From Kelly Duda To Stephen Grimes QC (12, Nov, 2003) | A22 |
| Letter From Linda Miller To Tony Blair (March 22 nd 2001) | A23 |

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