MA GENDER, CULTURE AND DEVELOPMENT

BLOOD FLOWS NOT JUST THROUGH OUR VEINS BUT THROUGH OUR MINDS. HOW HAS THE GLOBAL POLITICS OF BLOOD IMPACTED ON THE UK HAEMOPHILIA COMMUNITY?

By

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ABSTRACT

Many haemophiliacs were infected with HIV and hepatitis viruses during the 1970s and 1980s following treatment with plasma products in NHS hospitals. This dissertation investigates the politics of the global blood trade by examining blood policy documents from the 1960s to the present day and analyses the impact of these policies on the UK haemophilia community. The study critiques the findings of a Government report (Self-Sufficiency In Blood Products In England And Wales: A Chronology From 1973 To 1991, Department Of Health, 2006) which claimed that the benefits of importing US treatment products manufactured from the plasma of remunerated prison and "skid-row" donors outweighed the viral risks to patients. A textual analysis of material originating from the Department Of Health and other organisations examines the Government's failure to achieve self-sufficiency in the manufacture of UK blood products. The anthropological inquiry explores how decisions made by institutions nationally and internationally continue to affect haemophiliacs and their families to this day. The investigation highlights the ethical problems that can arise when blood becomes a commodity and profit is prioritised over safety and how this is interpreted by those at the receiving end of contaminated treatment. Key themes were identified by examining the replies from questionnaires sent out to haemophiliacs and their partners and illustrate the way in which they have adapted to their current situation. The report concludes that research participants have re-evaluated their personal identity and revised their collective response as an infected "subculture" within society to challenge the power of the institutions they deem responsible for the demise of their community. This study

recommends that the Government commissions a full and open independent public inquiry into how patients came to be infected through their NHS treatment.

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
BMJ	British Medical Journal
BPL	Blood Products Laboratory (now known as Bio Products Laboratory
CDC	Centre For Disease Control, Atlanta, United States
DHSS	Department Of Health And Social Security (now the DOH)
DOH	Department Of Health
FDA	Food And Drug Administration
FOI	Freedom Of Information (Act)
GP	General Practitioner
HAA	Australian Antigen Testing
HbsAg	Hepatitis B positive
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
JAMA	Journal American Medical Association
MD	Medical Doctor
NANB	Non A Non B Hepatitis
NHS	National Health Service
PHLS	Public Health Laboratory Service, England
SSR	Self-Sufficiency In Blood Products In England And Wales: A Chronology From 1973 To 1991 (Department Of Health, 2006)
UK	United Kingdom
UKHCDO	United Kingdom Haemophilia Centre Directors Organisation

US	United States
vCJD	variant Creutzfeldt- Jacob Disease
WHO	World Health Organisation

CONTENTS

CHAPTER 1-

CHAPTER 2-

CHAPTER 3-

CHAPTER 4-

CHAPTER 5-

CHAPTER 6-

CHAPTER 1

INTRODUCTION

The times are ominous indeed
When quack to quack cries purge and bleed

(Cobbet, 1793, quoted in Starr, 1998, p. 25)

Blood, Politics, And Identity

Blood has a very powerful symbolism throughout the world. It touches human beings on both a primitive level as a force of life and death and on a higher spiritual level with religious connotations in Christianity, Islam and Judaism. It signifies both power and powerlessness, good and evil, and is deeply rooted in theories of race as shown in "Blood Politics: Race, Culture And Identity In The Cherokee Nation" (Sturm, 2002) and portrayal of gender in, "Blood Magic: The Anthropology Of Menstruation," (Buckley and Gottlieb, 1988). Blood is used as a central theme throughout historical and contemporary literature and also has an important part to play in our understanding of science and medicine. The politics of blood has been part of our day to day life for thousands of years whether related to procreation, war, hunting or disease. James Bradburne (2002, p. 11) states,

> If you believe that blood can transmit diseases you think twice before you risk an exchange of fluids. The way we understand this 'special juice' shapes the way we conduct our lives, choose our partners, structure our institutions, and express our culture. The changing understanding of what blood is, the role it plays, and properties it confers, can bring either prosperity or devastation to countless millions.

Swedish artist, Ivar Arosenius, conveyed his fear of bleeding to death through many of his fairy tale illustrations and his painting of St George and the Dragon. Arosenius, (who died at the age of 30), was born with the inherited blood clotting disorder haemophilia.[1] It can be argued that his lifelong disability led to creativity and that his work embodies elements of his own personal identity as a haemophiliac, (The Telegraph Website, 2006). Haemophiliacs have a special relationship to blood both in substance and symbolism as a result of their condition. In haemophiliacs the clotting of blood is slowed down or impaired in some way. The female is the carrier of the defective gene and if she bears children, a son has a 50% chance of inheriting haemophilia whilst a daughter has a 50% of being a carrier herself. Male children of a man with haemophilia do not inherit this condition. (Haemophilia Society Website, 2005).[2] The only treatment until recently was rest and blood replacement therapy with the missing clotting factor taken from another person's blood and made into "factor concentrates" (plasma products) which are injected into the patient's veins.[3]

Many haemophiliacs including my husband and brother-in-law became infected with HIV and hepatitis C after treatment with human blood products in the 1970s and 1980s in what is referred to by Lord Winston in the House of Lords as "the worst-ever treatment disaster in the history of the NHS" (Morris, 2006, United Kingdom Parliament Website). During this period much of the treatment used on haemophiliacs was imported from America and came from "high-risk" sources including prison plasma donors and sick and impoverished drug addicts and alcoholics selling their blood in most major towns and cities for a few US dollars (Starr, 1999).[4]

My own identity for fifteen years was bound up in being the wife and carer of a haemophiliac and a campaigner on blood safety issues with a former background in nursing patients with HIV and hepatitis viruses. I therefore have my own relationship to blood as a person who administered plasma products by injection and dealt with incidents of bleeding in the workplace and the home environment, in my gendered association through menstruation and as a Christian accepting the blood of Christ in my local church. Following my husband's death from HIV and hepatitis C in 2005 I began an MA in Gender, Culture and Development at Sunderland University. During my course I became rather disappointed that little reference was made to the subject of disability during lectures despite it being one of the great "dividers" in society alongside race, class, gender and sexuality. This omission alongside my interest in global corporations and the politics of the international blood industry led me to choose my dissertation topic. I also wanted to carry out research that would have some practical application on completion of the course.

To what extent can it be said that blood and disability are deeply embedded in a haemophiliac's identity politics? Has the problem of treatment acquired HIV and hepatitis viruses plus the more recent exposure to variant CJD added an additional dimension to identity? Haemophiliac, GRO-A stated that "haemophilia itself became a marker for having AIDS" (Garfield, 1994, p.70) and I wanted to investigate through my study whether haemophiliacs had developed duel overt and covert identities as a result of the sigma of their condition. I was also interested to discover if UK haemophiliacs identified more with representations of hopelessness as in the 1992 Benetton advert featuring an AIDS patient on his deathbed (Bradburne, 2002, p. 222) or had adopted a fighting mode as illustrated in the following portrait of an American haemophiliac:

> HIV turned GRO-A into a fighting man. Like the foot soldiers of centuries gone by, he applies war paint, tattoos his body with the words of his battle cry and rides a warrior chariot into the fray. In GRO-A's case the fighting fields are the front lawns of drug manufacturers and his chariot is an old ambulance he painted red. His war paint is the deep ruby red of fresh blood, and his battle cry accuses the pharmaceutical companies of mass murder after selling tainted blood products that infected him and thousands like him. "I was one of those survivors who didn't appreciate life before (I was diagnosed with HIV). HIV made it easy for me to do the crazy stuff. I'd rather die taken out in front of Bayer than die of AIDS."
>
> (Mackay, Milbouer, 2004, p.76).

My dissertation aims to explore the question "how has the politics of blood impacted on the UK haemophilia community." My study is divided into two main areas of research. The first area of research incorporates textual analysis to critique a Government report covering blood policy documents from the 1973 to 1991 (DOH, 2006) in order to examine the effects on haemophiliacs and their partners. The second area of research involves an anthropological study of the UK haemophilia community through the use of questionnaires to explore haemophilia and partner identity politics and their response to infection with HIV and hepatitis viruses. Prior to carrying out my research I embarked on a comprehensive literature study to identify what had already been written in relation to blood, disability, and disease. Several years ago, Dr Carl Rizza, (Oxford Haemophilia Centre) was asked to comment on the AIDS risk to haemophiliacs through treatment, he answered by stating that the fate of haemophiliacs was "in the lap of the gods" (Starr, 1999, p. 274). I wanted to consider this statement alongside a further question- to what extent did the globalization of blood as a profitable commodity compromise patient safety?

Notes

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[1] There are two different spellings of the word haemophilia. In UK publications the word is spelt as follows- haemophilia. In cases where I quote from a US publication, I use the American spelling- hemophilia

[2] The layperson often has the misconception that if a haemophiliac cuts himself he will bleed to death, however it is internal bleeding into muscles, joints and body cavities that are a major concern to both haemophiliacs and carers of haemophiliacs. Haemophiliacs can bleed after knocking into an object, through exercise such as walking, or can bleed spontaneously. This haemorrhaging can cause excruciating pain as it causes joints or muscles to swell.

[3] The condition of haemophilia has different levels of severity, mild, moderate and severe. In the case of my husband he was classified as a severe haemophiliac which meant that he had less than 1% clotting factor and his blood was deficient in factor VIII. New technology means that factor concentrates used to treat haemophilia are now being replaced by 3rd generation synthetic "recombinant" clotting products which carry no risk of disease.

[4] "High-risk" in this case means a plasma donor deemed to be at "high-risk" of transmitting blood borne viruses such as HIV and hepatitis B and C. Some of the treatment batches given to my husband at the RVI Hospital, Newcastle were traced back to Arkansas State Penitentiary.

CHAPTER 2

LITERATURE REVIEW

Reading without thinking will confuse
Thinking without reading will place you in danger.

(Confucious, quoted in Clements, 1999, p.130)

An Overview Of Haemophilia Literature

After many years of reading publications on haemophilia, and blood and disease in general I have identified a gap in the current literature particularly in relation to material written in the UK where much has been printed reflecting the opinions of doctors and other health care professionals but in comparison relatively little expressing the viewpoint of haemophiliacs. There are many articles which focus on living with haemophilia and the additional problems of coping with HIV and hepatitis viruses but these are often written from a medical point of view with the haemophiliac in the role of a patient reflecting the hegemonic and paternalistic doctor/patient relationship. Haemophiliacs have historically been represented within the medical discourse as disempowered passive recipients of treatment. Until recently, doctors, nurses and social workers had only given tokenistic consideration to empowering the patient.

The issue of allowing haemophiliacs to make an "informed" choice with regard to their treatment has created anxiety for the medical professional since the introduction of factor concentrates in the nineteen seventies. Traditionally haemophilia doctors had steered away from this model of working leaving the treatment outcome to fate rather than good management strategies that incorporate health education and the wishes of the patient. This attitude is reflected in haemophilia literature and I would argue that until the emergence of HIV and hepatitis C and the widespread infection of haemophiliacs with these viruses, many UK haematologists largely avoided becoming active in the global politics of blood and often failed to inform patients of the viral risks associated with their treatment. Haemophiliacs were often not advised of the increased risk of hepatitis infection from imported factor concentrates sourced from "high-risk" donors and manufactured from large plasma pools. The answers I have received from my questionnaires demonstrate the extent to which this withholding of information is still a source of anger for haemophiliacs today.

The paternalistic approach to treatment was a comfortable model for doctors to operate as any empowering model brings with it difficult dilemmas as to how much information to give a patient in terms of assessing risk related to blood products and the possibility of haemophiliacs exercising their right to refuse so called "life-saving" treatment. The doctor/patient power dynamics are demonstrated in the language and behaviour of the medical professional as shown by Daly and Cunningham (2003) when they documented the findings of the *Lindsay Tribunal* public inquiry into the contamination of haemophiliacs in Eire. Doctors took the decision that the benefits of the treatment outweighed the risk of viral infection and yet they often failed to include the patient in the decision making process and omitted to provide haemophiliacs with information on the risks associated with blood therapy to enable each patient to make an "informed" choice.

Exploring Genres/The Discourse On Blood

In the past 30 years there have only been a few books published in the UK specifically on haemophilia although several informative books have been written on the politics of blood and contain chapters which address the contamination of the haemophilia community. There are many research articles on medical issues related to haemophilia but it is important when reading them to consider the possibility of "conflict of interest" in terms of who wrote the article and who funded the research. This has been of major concern to haemophiliacs in the past especially where plasma companies have funded doctors both directly and through research and travel grants. Sheldon Krimsky expands on this point stating that it is often up to the discretion of the author to declare any funding received that might bias the content of a publication. He emphasises the importance of critical analysis when studying documents and questions self-regulation by arguing that "readers, reviewers, and editors should have information on the funding sources and personal financial interests of authors related to the subject matter of the publication," (2001, p.116).

There are many books written specifically on HIV and some more recent literature has emerged on the growing problem of hepatitis C. This is referred to by some doctors as an "iceberg" virus or a hidden disease within a largely untested population with official infection rates representing only a small percentage of the actual cases (BBC News Website, June 9th 1998). The following examples of books show that there are a variety of genres within disease and disability literature from health and medical books portraying signs and symptoms and offering practical advice (Petro Roybal, 2002) to publications focusing on politics, (Barnet, Whiteside, 2002). These publications explore the different issues that emerge from having a disease whether they be medical, political or social and reflect the fact that an holistic approach should be taken by society to accept a person in their entirety. A person with haemophilia often has to manage their disability within a family setting, they may also have a career, are part of a wider community and have their own political ideology. Some literature reflects only a "tunnel-vision" approach to haemophilia concentrating solely on the illness and not on the person as a whole being. Feldschuh (1990) delves further into the subject of globalization investigating the international corporations where blood is business and also the power relations between service providers and those accessing services. Feldschuh provides a theoretical framework with regard to analysing why the blood-banking industry abdicated its responsibility to the public and is useful for this study in examining why contaminated blood was allowed to enter the US blood supply.

Gott (1995) focuses on the theme of artwork created by those infected with HIV. He demonstrates that art can express the politics of identity, tackling disability and discrimination and allowing those infected to project themselves through their own vision of self or to portray themselves as they are seen through the eyes of those around them. An extreme example of this appears in Freeland (2001, p. 4) he states that "performance artist Ron Athey, who is HIV positive, cut the flesh of a fellow performer on stage and then hung blood-soaked paper towels over the audience, creating a panic." Haemophiliacs adopting the role of political campaigners have at times involved a level of theatrical performance as a shock tactic in their protests to governments. There have been a variety of symbolic gestures from the global haemophilia community determined to display collective anger over their contamination with HIV/HCV. In France those infected turned fountains blood red with vegetable dye while in the UK haemophiliacs wore biohazard stickers and hung plasma bags filled with a substitute blood around their necks during demonstrations outside Westminster. At the opening of the new Scottish Executive building the pristine walls were daubed with crimson paint to draw attention to the contamination of a generation of haemophiliacs, referred to by American haemophiliacs as the "haemophilia holocaust"(BBC News Website, Nov 18th 2004).

Another genre within haemophilia literature features publications that emphasise the personal testimonies of infected haemophiliacs or their family members. The haemophilia publications based on "lived experience" are more prevalent in US culture where I have coined the term "disclosure discourse" to describe writings that have emerged to enable those infected to have a voice. Elaine De Prince (1997) adopts this approach providing a narrative from the perspective of a mother chronicling the progressive illness and death of her two sons from HIV/HCV and living with a third infected child. She has empowered individuals living with these viruses who were previously shunned by society to stand up to those oppressing them. De Prince writes as an advocate for people with haemophilia confronting the policies of the plasma companies and taking her campaign to the doorstep of Government. These publications have inspired a global activism amongst haemophiliacs living with HIV and hepatitis C.

The final genre I wish to consider are the novels that feature characters mirroring figures in mainstream society using the format of storytelling with a message reflecting current social issues around the world related to the commodification of blood. Two "blood" novels recently appeared in Asia, one published in Hong Kong, *The Dream Of Ding Village* (Lianke, publication date not stated) an underground publication sold at street-side stalls and *Chronicles of A Blood Merchant* (Hua, 2004) published in the U.S. The fact that Yan Lianke's novel is not sold openly demonstrates the politics of suppression surrounding AIDS in China which I witnessed myself during a recent visit to speak at a Haemophilia/Blood conference in Beijing. The organiser of the conference Dr Wan Yanhai was detained by security services and the conference cancelled as reported in the *Guardian* newspaper (Watts, Nov 26th, 2006). Both novels feature dark tales of infected villagers in rural China who were so impoverished that they sold their blood for a few Yuans and in doing so became chronically anaemic or infected with blood borne viruses through the use of shared plasma collection equipment (Zona Europa Website, date not stated). These publications reflect the real life tainted blood scandals that have recently rocked Henan province and decimated normal village life as an estimated 600,000 people were infected with HIV through non-sterile practices at official and illegal blood collection centres, (BBC News Website, May 30th 2001). Articles on international blood issues and blood novels such as these are important to those within the international haemophilia community that have adopted a campaign role educating the world through e-mail contact and the setting up of "tainted blood" websites (Tainted Blood Info Website, date not stated). Technological advances have empowered haemophiliacs who may be disabled in body but not in mind and who wish to take an active stance on human rights issues in the global political arena.

Key Texts On Disability And Disease

The following section explores the key texts on disability and disease identifying common themes within disability literature. It is useful here to identify a book on general disability before moving on specifically to haemophilia. Henri- Jacques Stiker (1999) examines Western cultural responses to disability from Biblical to modern times and presents a contemporary discourse on disability. The text explores diversity and individualism and generates discussion on attitudes, ethics, and the language and thought surrounding disability. Stiker looks at the historical concept of charity and the giving of aid to those considered "handicapped" within society and also investigates the birth and development of rehabilitation that was not only "curative" and "reintegrating" but needed to address "the social and economic causes and conditions which gave rise to disability" (Stiker, 1999, p.174). This is a useful book to consider when addressing haemophilia identity politics.

The most comprehensive general guide to haemophilia is provided by Dr Peter Jones (2002) which has had regular reprints since the 1970s to include the problem of emerging blood borne viruses in the haemophilia community and update on new forms of treatment. It is considered an important textbook for haemophiliacs and their families as well as professionals. The book provides comprehensive information on the condition itself and on treatment issues, taking the reader on a journey from diagnosis to coping with haemophilia in an educational setting through to adolescence and adulthood. It also looks at practical issues around travel and explores family planning and childbirth for female carriers of the haemophilia gene.

The author is a haematologist by profession and this has both positives in terms of "expert" knowledge but weaknesses in that haematologists have traditionally had close ties to the plasma companies responsible for supplying treatment. It is this aspect that concerns haemophiliacs who feel that the book is medically orientated without addressing how haemophiliacs have responded to the politics surrounding their infection with HIV and hepatitis C and the difficulties of incorporating this into their daily living. For years insufficient effort was made to address the psychological problems that arose from fear over safety of blood products, infection, and the long political struggle for recombinant synthetic treatment as a safer alternative to plasma products.[1] There is anger within the haemophilia community around their contamination that is often not properly addressed in books on haemophilia as the anger can often be focused on individual doctors and is something many would rather ignore.

There are a number of excellent publications that explore the politics of blood. Richard Titmuss (1970) and the latest version of this classic text updated by his daughter Ann Oakley and John Aston (1997) give a comparative analysis of the blood industries in America and Britain. The book written from a sociological perspective considers the ethics of "volunteer" versus "paid" blood donors with regard to plasmapheresis (the process of collecting plasma from donors) as well as looking at supply and demand. This is an important book which sat on the shelves in the offices of many haematologists and warned of the dangers of promoting profit over safety. Titmuss explored the risks associated with US commercial plasma centres that relied on "skid row" donors in poor physical health and "high-risk" prison donors often documented as having a history of drug abuse and unsafe sexual practices.[2] This book is as relevant to-day as it was when first published. The ethical issues and assessment of risk principles can just as easily be transferred to developing countries such as China in the twenty-first century where AIDS activists have expressed concerns that paid donors are still being used despite a legal ban which is now in operation (China Daily Website, Dec 22nd 2005).

Two books by Piet Hagen (1982) and (1993) continue on the theme of ethics exploring blood as "gift" or "merchandise" and focusing on Europe as well as the US Since the books were written the European Union has stressed the need for a ban on the use of paid donors in Europe on the grounds of safety (Irish Health Website, Sept 6th 2001). In 1998 then Secretary Of State For Health Frank Dobson introduced measures to import clotting products for haemophiliacs from paid donors in the US because of the risk of new variant CJD. The UK now imports white cell plasma for large numbers of other NHS patients which is sourced from commercial donors in the US (Guardian Website, Dec 17th 2002). Most NHS patients are unaware of this fact and believe that all UK blood products come from volunteer blood donors.

Douglas Starr (1999) provides the reader with an insight into the history of blood transfusion medicine up to the current globalization of the blood industry and examines the power of blood corporations looking at blood as a very lucrative commodity alongside the concept of collateral damage. His book investigates the impact of HIV and hepatitis viruses on the global haemophilia community and the growth of consumer awareness in relation to safety of blood products. Starr delves into the contentious issue of litigation and the introduction of "blood shield" laws designed to protect the plasma industry. My main criticism of this otherwise excellent book is that there is only limited information on the UK haemophilia population compared to other countries. I contend that this is probably due to the fact that Starr has had to rely heavily on official sources within the UK such as the national Haemophilia Society that has tended to downplay the contamination issue for many years until challenged by the haemophilia community. This is due in part to the Society's reliance on financial support from international plasma companies.

Starr does however utilise the opinions of American haemophiliacs throughout his book as reflected in the following comment made by AIDS activist Michael Rosenberg, "It pains me to say this, because my father was vice-president of the NHF (*National Hemophilia Foundation* in America) but the foundation has become the handmaiden to the industry" (quoted in Starr, 1999, p. 334). Eric Feldman and Ronald Bayer (1999) follow on with the theme of HIV infection in haemophiliacs and blood transfusion recipients giving an additional global political perspective but this book too has scant reference to the UK.

Susan Resnik (1999) offers an ethnographic study of US haemophiliacs which she describes as a "participatory social history." Resnik uses personal testimonies of those infected and the "oral history" approach to research interviewing both patients and service providers. She identified at the time of writing that "there was no written history of the US haemophilia community" (p. 3) and until recently this was same in the UK. In June 2005 the first stage of the *Living Stories* project based at Brighton University and led by Sian Edwards, a Senior Lecturer in HIV was completed with 30 in-depth interviews conducted with HIV positive haemophiliacs now stored in full at the British Library Sound Archive (Living Stories Website, date not stated). As the widow of an infected haemophiliac I will have my own oral history recorded. [3]

Kathy Seward Mackay and Stacy Milbouer (2004) provide both pictorial and personal testimonies from the U.S. haemophilia community infected with HIV/HCV. The book explores both pain and suffering, loss and grief, and also embraces the mobilization of a community in their struggle for empowerment. The theme of hope also emerges as campaigners challenge the blood policies of both the US government and the international plasma companies.

Rosemary Daly and Paul Cunningham (2003) investigate the role of the State and haemophiliacs' fight for justice and recognition of what went wrong in relation to their medical treatment. They explore power and knowledge in terms of doctor and patient as the *Lindsay Tribunal* hears evidence on testing patients for infectious diseases without their knowledge and permission and the withholding of information on the risks of treatment. The reader is given an insight into the mechanisms of control as they translate from government level down to control of the individual and his/her body, dominance of urban space in hospitals and the politics of disease surveillance in the wider community. Daly and Cunningham (2003) reflect on haemophiliac patients as both passive and proactive and the State as enabling and disabling. An earlier publication by Michel Foucault (1980) laid much of the groundwork on the theme of power and control within the medical environment and this study focuses on Foucauldian theory in relation to the haemophilia patient. The works of Foucault are critiqued in Peterson and Bunton (1997) where themes such as the "docile" body, "bio-power" in the health education setting, and "self-autonomy" and "self-governance" are examined which are all relevant to the lived experience of the UK haemophilia community. Linda Mulcahy (2003) contributes to the medical discourse by focusing on medical related conflict and the dynamics of doctor-patient disputes. She investigates moral identities and channels of redress in relation to the management of grievances, medical negligence and iatrogenic injury. Her work is important to consider in terms of this study as it moves away from focusing entirely on financial recompense which is not by itself a satisfactory outcome for many injured parties. Mulcahy also explores the patient's need for "catharsis, personal explanations and apologies" (2003, p. 91).

Virginia Berridge (1996) looks specifically at the AIDS crisis in the UK providing some insight into blood policy development, "national risk" and the response of government to the infection of the haemophiliacs as well as the "repoliticization" of AIDS. Berridge also investigates the role of the medical profession and their reaction to the infection of haemophiliacs. Once again the language of professionals in this text reflects the power dynamics between care-giver and recipient of treatment. The author quotes a former Haemophilia Society worker (unnamed),

> There was a close relationship between people with haemophilia and their doctor - he was almost an uncle and may have known them all their lives. There is much guilt on the part of health-care professionals- they gave their boys HIV. They prescribed the Factor VIII and in many cases injected it.
>
> (Berridge, 1996, p. 234)

Although most haemophiliacs were treated by the same doctors from childhood and the benevolent "uncle" approach may have been appropriate then, as haemophiliacs became adults the dynamics did not change to reflect this and adult haemophiliacs questioning their treatment were often regarded as "naughty boys" by their haematologists as "uncle knows best" what is good for them.

Simon Garfield (1994) elaborates on this theme in a chapter entitled "The Fridge That Day" where he incorporates the viewpoint of doctors and haemophiliacs but tends to use the opinions of haemophiliacs officially associated with the national Haemophilia Society as spokespersons. This is important to acknowledge as divisions have occurred within the haemophilia community between those seen as independent campaigners and those affiliated to the Society which is funded in part by the plasma companies. This book also introduces the reader to the kinds of prejudice haemophiliacs and their families were starting to experience over AIDS in the 1980s. This was a time when,

> the local crematorium kept the body of a haemophiliac back until last, to the end of the day, lest the AIDS virus infect other dead bodies; in one case they burnt an empty coffin and incinerated the body away from the regular furnace. (Garfield, 1994, p. 65)

James Bradburne (2002) explores blood and mythology investigating cultural and religious symbolism and covering areas as diverse as blood borne viruses and the "suffering" body alongside blood in advertising campaigns, buildings and sculptures. The book provides both an historical and contemporary viewpoint looking at rational and irrational beliefs and contains many images of blood within art for example the powerful image of "Der Blutende" (The Bleeding Man) painted by Max Oppenheimer (1885-1954) (Badburne, 2002, p. 31). It also investigates the significance of blood in theories of race, gender and sexuality and this can be linked into past and present issues surrounding blood collection, treatment of haemophiliacs with blood products and the formation of national and international blood policies as well as the politics of blood borne diseases. Bradburne states that,

> The body is perhaps the primary metaphor for a society's perception of itself. The individual and spoken language are what make up the social body, the physical body is a kind of boundary between biology and society, between drives and discourse.

(Bradburne, 2002, p. 205)

The most significant document to be published in recent years in terms of the global politics of blood and the effect on the UK haemophilia community is *Self-Sufficiency In Blood Products In England And Wales: A Chronology From 1973 to 1991* (Department of Health, 2006.) The report, (referred to in this study as the *SSR*) aimed to review key blood policy documents from that era and questioned whether the UK becoming self-sufficient in blood products would have made a difference in relation to haemophiliacs becoming contaminated with blood borne viruses. I provide a comprehensive critique of this report in Chapter 4.

Summary

I will be utilizing some of the key texts discussed in my literature review in relation to my own findings. I will also look at examples of documents omitted from the *SSR* and review previously unpublished material acquired under the Freedom of Information Act (FOI) and accessed through legal channels alongside material within the Government Report. I have been granted permission by a solicitor to utilise these papers as an established campaigner and educator and examine how they fit into the overall global politics of blood analysing the impact government policy has had on the UK haemophilia community and haemophiliacs' attitudes to those who were meant to care for them. I also aim to refer back to those texts written by individuals within the haemophilia community in Eire and America where family and haemophiliac friends received contaminated treatment from the same international plasma companies as UK haemophiliacs and encountered similar problems of prejudice and feelings of disempowerment. These texts will be examined alongside the haemophilia and partner questionnaires I have devised in an effort to identify common themes relating to haemophilia identity politics. I will attempt to establish patterns of treatment of haemophiliacs or lack of treatment (in the widest sense) by linking the evidence included in and excluded from the SSR to the personal life experiences of haemophiliacs as written in their questionnaires responses. I will also study a variety of literature focusing on discrimination and the social stigma of disability as well as the politics of blood and disease.

Notes

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[1] Recombinant synthetic clotting products were deemed to be safer than human derived products but were more expensive. This led to post-code prescribing in some cases when doctors agreed to prescribe in some areas putting safety before finance. Recombinant was phased in from 1998 because of the risk of v CJD from UK plasma with children getting prescribed it first, then adults going by age with the youngest first and older haemophiliacs already infected with HIV/HCV given it last. Haemophiliac Peter Longstaff challenged the system by taking his local Health Authority to the High Court for Judicial Review. His case failed on the grounds that each Health Authority had the power to prioritise spending as they feel necessary. Haemophiliacs in Scotland and Wales were given the safer treatment before those in England. Some haemophiliacs went on treatment strike in protest at their second-class treatment.

[2] Skid-Row- a quarter inhabited by alcoholics and vagrants (Cassell's English Dictionary, 2000, p. 1174).

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[3] I spoke by telephone with Krista Woodley, oral historian on the (Living Stories Website, date not stated) carrying out this research and asked her about her feelings regarding the importance of such a project. She sent me the following quote by e-mail,

> Doctors, social scientists and journalists have written extensively about the social, medical, legal, political and psychological issues surrounding those with haemophilia who were infected with HIV in the early 1980s, but the voices of people with haemophilia and HIV and those most intimately involved, the parents, partners and children, have rarely been heard. The personal testimonies of the people recorded for this project are invaluable in ensuring that a more complete historical picture of this major social, political and medical event is available for our future and to enhance peoples understanding and appreciation of Haemophilia and HIV.
>
> (Woodley, 21st Aug, 2006)

CHAPTER 3

METHODOLOGY

"How we interpret our life experiences is important for our own survival"

(Mckee, 2006, p.34)

The Position Of The Researcher

This chapter focuses on the research process, my personal role as a researcher and outlines the methodology used to aid my study. In any research project it is important for the researcher to declare their own personal position in relation to their area of study and identify any bias which may have influenced their work. I am a white, middleclass, British female. I am the widow of a haemophiliac, an international campaigner on haemophilia rights and blood safety and have a legal case in the US against four American pharmaceutical. I am also a qualified psychiatric nurse with experience of working with virally infected patients. According to Resnik (1999) I belong within my "unit of analysis" (the haemophilia community) and I am part of a community of fate, known to anthropologists as a "communitas." Mehra (2002) argues that understanding the researcher's role in qualitative research and accepting that research is not "value- neutral" can be a process of self-discovery when "systematic and reflective" analysis is employed.

My personal situation has both advantages and disadvantages. The disadvantages are that I have already gained in-depth knowledge of haemophilia issues over a number of years therefore I felt that it was very important to try not to make any predictions or assumptions on the research outcome in advance of my study. I recognise however that my understanding of the haemophilia community will have influenced the way in which I have devised my questionnaires as I was already aware of specific gaps in knowledge and research and my questionnaires were designed to focus on gaining evidence (whatever that might be) in these areas. I also acknowledge that my personal history will have had some influence on my interpretation of text and data. I try to balance this during my textual analysis of the *SSR* by including many of the Government's own previously unseen documents which the Government chose to exclude from their report to contest the official findings. I have utilised medical and legal documents accessed under the Freedom of Information Act in the same way. I am also aware that a lay person reading the Government report would not necessarily be able to identify the fact that there are large gaps where material is missing from the report. It is only due to my personal circumstances that I became aware of this fact and in a position to challenge the findings. I have been able to gain access to many documents previously unseen by the general public including other researchers due to the fact that my husband was a litigant against the State. My role as an activist also helped me acquire US documents from America campaigners accessed under the U.S. Freedom of Information Act.

My background working as a nurse practitioner and educator has given me an awareness of the importance of triangulation in research, namely "the use of overlapping, diverse pieces of evidence and perspectives" (George Mason University Website, 2005) which is an important part of the anthropological approach I have adopted in my study. My overall approach was to use triangulation by examining the documents and views of official organisations, academic research, the thoughts and opinions of the haemophilia community, and my own personal interpretations. Begley (1996) has evaluated the use of triangulation in nursing research and states " 'the triangulation state of mind', the conscious employment of multiple data sources and methods to cross- check and validate findings continuously should permeate all studies and lead to the goal of confirmation." I found this approach useful as my questionnaire participants were already identified as haemophilia patients and their relatives and I also appreciated that the more variety of information I gathered the more cross-checks were in place to balance against researcher bias.

I was able to gain easy access to haemophiliacs and their families through long established personal contact and was able to utilise the "snowball effect" (Resnik, 1999) in this case the process where one haemophiliac would contact another who would then get in touch with another to enrol in my study and so the numbers built by word of mouth. I am aware that the majority of participants agreed to take part in my study because of their personal connection to me and their trust in me to maintain their confidentiality. It was therefore extremely important that I respected that fact and did not abuse my privileged position. I also needed to take into account that participants may have written answers to "please" me or may not have been entirely open in their responses. It was also necessary to consider the part my gender played in relation to both male and female participants. I considered the possibility that male participants may have found it particularly difficult to write to a female researcher about very sensitive issues which may have identified their own emasculation through contamination. However I found a number of personal notes attached to the returned questionnaires where male haemophiliacs and their partners spoke of their relief at being able to "have a voice." There was also an acknowledgement in some cases from participants that this was a difficult but useful process on the road to empowerment. I felt that these notes were too personal to include as they were not strictly part of the questionnaire replies.

Methods Of Research

I adopt several different methods of research to reflect two distinctive but interlinking areas of interest, the first area of interest is a study of documents where I utilise secondary sources of information and the second area of interest is the study of a community, in this case haemophiliacs. My research is qualitative. One research method I employ is textual analysis. I focus on two key areas, firstly the theme of the politics of blood and secondly the representation of haemophiliacs and their personal identity politics. Textual analysis is defined as "a data-gathering –process- for those researchers who want to understand the ways in which members of various cultures and subcultures make sense of who they are, and how they fit into the world in which they live" (Mckee, 2006, p.1). My aim was to examine text in the context of my thesis question and link this to an exploration of the haemophilia subculture examining how haemophiliacs have adapted to their contamination through blood borne viruses. Mckee also acknowledges that researchers that undertake textual analysis are using a range of methodologies "many of which are mutually contradictory and incompatible" (p. 2).

In order to analyse the content of the *SSR* I looked at a wide variety of texts, books, letters, official reports, documentary scripts and litigation evidence to compare against the Government's research. I also looked at the intended audience for the texts, any conflict of interest in relation to the author of any given text, the purpose of the text and the anticipated audience response. Mckee (2006) identifies that two different researchers describing the same text will do so in different ways and that subcultures within nations will also produce different definitions of a text. I acknowledge that my study is limited in that it is one person's study of texts, my own personal interpretation of documents.

I deemed it important when analysing a text to identify the author's background, personality and interest and the techniques he/she uses in writing as well as the type of language in use. This was extremely difficult in the case of the Government report as there was no identified author. This in itself is worthy of comment as no specific individuals could be challenged on the content of the report. I tried to identify key themes and provide other textual evidence to support or challenge the unnamed author(s) work. It is also important to recognise the effect of texts in sustaining or changing ideologies (Thompson, 1984) and that "ideologies are representations which can be shown to contribute to social relations of power and domination" Fairclough (2006, p. 9). He goes on to suggest that "textual analysis needs to be framed in this respect in social analysis which can consider bodies of text in terms of their effect on power relations." This is useful to consider when examining Government, medical and legal texts and the social control exerted over the patient population.

I decided to use Susan Resnik as my role model in terms of the ethnographic research approach to my dissertation. Resnik (1999) detailed the collective experience of the U.S. haemophilia community from her position as a lecturer teaching medical students and former Director of the National Hemophilia Foundation. Resnik writes "I approached this task both as an 'applied anthropologist,' using an ethnographic approach and an 'emic' orientation (that is attempting to 'see' through the eyes of the informants), and as an oral historian, using a tape recorder. In this way I captured the views and voices of the shapers and the witnesses in the US hemophilia community" (1999, p. 4). I found this research method particularly suitable for someone like myself who is already embedded in the haemophilia community and wanted to give UK haemophiliacs and their partners a voice. I chose to analyse the questionnaires by concentrating on the key themes which arose from participant replies.

I also studied the research methods of Clifford Geertz (1973) and his work on symbolism in society to investigate the symbolism of specific words within the haemophilia subculture. This research approach was combined with Michel Foucault's research on power as I also wished to investigate which institutions haemophiliacs believed to hold power in relation to the haemophilia community, what form did that power take and how did that affect haemophiliacs and their families. I used the work of Richard Titmuss (1970) to provide a theoretical framework for exploring the ethics and politics of the blood industry and how that subsequently affected health policies in the UK and beyond.

Use Of Questionnaires And Ethical Considerations

My initial task was to approach the ethics committee of Sunderland University for approval for my study. It was important to go through this process in accordance with the ethical principles as stated by Green (2002, p. 43) that "every research project should be preceded by careful assessment of predictable risks in comparison with forseeable benefits." Until recently the haemophilia community was a very closed community as a result of years of stigma and shame attached to living with HIV/HCV. This is now changing as haemophiliacs take control of their lives and stand up for their rights.

However it is important to acknowledge that the majority of people within the haemophilia community are still not open about their viral status and a great deal of sensitivity is required when working with this community. I have outlined the way in which I have tried to minimise risk and support participants throughout this section. I adopted an anti-discriminatory stance to respect participants in terms of their race, gender, class, age, sexuality and disability. I devised two questionnaires, one for haemophiliacs and one for partners. I used open-ended questions to allow each participant to give a detailed response if they so wished as I wanted to elicit as much information as possible. It was important in this situation to code the details of participants to respect their confidentiality and I have kept this information separately from the questionnaires so participants could not be identified. The questionnaires were designed to explore the personal feelings of the haemophilia community in relation to their contamination and also participants' attitudes towards a number of institutions linked to the haemophilia community. I chose to use questionnaires as I acknowledged it would be time consuming and expensive to travel around the country to visit haemophiliacs in their home setting (see Chapter 5 for a detailed description of the study group).

Each participant was sent a detailed letter (see Appendix B1) explaining the purpose of the study and asked to sign a letter giving informed consent (see Appendix B2) to use the information contained within the questionnaires. Any questionnaires returned without a signed consent form were excluded from the study. Participants were assured of confidentiality and given a phone number and e-mail address they could contact to discuss any concerns or raise questions about the study. They were also informed that they could withdraw from the study at any time if they wished to do so. Participants were also made aware that the dissertation would be available for public use once completed and a copy would be placed at Sunderland University and alongside the "Life Stories" haemophilia project undertaken by the Haemophilia Society and Brighton University and housed at the British Library (see Appendix B3 and Appendix B4 for all questionnaire responses). I was very aware of the researcher's ethical code to do no harm to participants in any way and in order to follow this I also read the work of James H. Jones (1981) as the unethical practises unleashed on the black community in the Tuskagee Syphillis Experiment have many similarities to the abusive practises used by the medical profession in earlier research on the haemophilia community, it was essential therefore that I reject any such unethical behaviour in my own research. I also wanted to avoid plagiarism, misrepresentation of data, and obfuscation as outlined by Greenfield (2002). I am aware however that my subject can be confusing to the layperson and I have tried wherever possible to simplify medical terms and produce notes at the end of each chapter. I have provided appendices of additional documents to assist the reader in their understanding of the research.

CHAPTER 4

THE GLOBALISATION OF BLOOD, FAILURE TO ACHIEVE SELF-SUFFICIENCY AND THE IMPACT ON THE UK HAEMOPHILIA COMMUNITY: A CRITIQUE OF A GOVERNMENT REPORT

> The most practical method of reducing the hazard of serum hepatitis from blood is to stop using blood from prison and Skid Row donors.
>
> (J. Garrott Allen, M.D. *Annals Of Surgery*, 1966)

Introduction- Background To The Self- Sufficiency Report 2006

In 2006 the Department Of Health (DOH) released a report entitled *Self- Sufficiency In Blood Products In England And Wales: A Chronology From 1973 to 1991* (*SSR*) (see Appendix A1 for full report). The definition of self-sufficiency in this case is the ability to produce and supply enough blood and blood products to cover the needs of UK patients as referred to in the *SSR*. The DOH report was published in direct response to a haemophilia "Bad Blood" campaign run jointly by the Newcastle *Journal* and Haemophilia Action UK.[1] The report was much anticipated by the UK haemophilia community in the hope that it would provide some answers to the many questions on how haemophiliacs came to be infected with HIV and hepatitis C (HCV) previously referred to as non-A, non-B hepatitis (NANB) through their NHS treatment.[2] In 2001 former Health Minister Lord David Owen gave an interview in the Newcastle *Journal* recalling his parliamentary commitment to self-sufficiency in blood products back in 1975 on the grounds of "medical safety" and expressed his anger by questioning past Government policy in the following statement:

> I was absolutely staggered to discover years later that what I had promised had never been done. It was argued they (the government) had run out of cash but why? My commitment was to become self-sufficient and to find the funds whatever the cost. This was a parliamentary commitment I had made, not just an internal administrative matter. Once a decision has been taken it is perfectly legitimate for a new minister to change it, but only if they tell parliament and that never happened. (Houldcroft, August 2nd, 2001)

It was Owen's interview with the *Journal* that finally sparked a reaction from Government that same year and the newspaper reported, "the Department Of Health has now agreed to re-examine all valuable documentation after copies of the Journal's Bad Blood Campaign was sent directly to Tony Blair by the President of the Haemophilia Society, Lord Morris," (IC Newcastle Website, Dec 5th 2001). The haemophilia community had fought for years for a full and open public inquiry while Government repeatedly rejected haemophiliacs' demands insisting that there was no evidence of wrongdoing and offered instead an "internal, informal review." The *SSR* took several years to compile, was subject to repeated delays during which time more haemophiliacs died from their treatment, and the report was undertaken without consultation with any of the interested parties.

The basic conclusions of the report were that although the UK Government had failed to achieve self-sufficiency in blood products no individual or Government department was found to be at fault for this failure, or for exposing haemophiliacs to a greatly increased risk of viral infection from imported plasma products sourced from "high-risk" donors.[3] One of the aims of this study is to provide a critique of the *SSR*, to contest Government findings, examine the manipulation of facts and the withholding of key safety information from NHS patients. The Haemophilia Society, the national organisation set up to represent the haemophilia community released a press statement voicing their own dissatisfaction with the report, Chief Executive, Margaret Unwin, stated that,

> The Society has pointed out that there are glaring holes in the document- there is no mention of what information was given to patients about the safety of products so that they could give informed consent to treatment at the time. The report also mentions testing new products on previously untreated patients to determine whether they were still transmitting blood borne viruses and again does not make clear whether they were told of the risks or any given alternatives. (Unwin, Haemophilia Society Website, 28th Feb, 2006)

It is not argued here that the infection of haemophiliacs with HIV/HCV was entirely preventable but there is compelling evidence to suggest strongly that infection rates could have been significantly reduced had appropriate safety measures been adopted. It is important to point out here why I have chosen to critique only one report and why this particular report is so significant. The *SSR* is the only major report to look at the issue of self-sufficiency from the 1970s onwards. For the first time the Government has produced a review that brings together a collection of internal blood policy documents not previously seen by the general public after application was made under the Freedom Of Information Act (FOI). Self- sufficiency wasn't an issue that the Government wanted to be scrutinised in the public arena as this would have highlighted inefficiency and maladministration as detailed by former Health Minister David Owen in his complaint to the Parliamentary Ombudsman (see Appendix A2). It has always been difficult in the past for academics to critique Government blood policies thoroughly without the necessary documents from the UK and abroad being made available to the public, even so many are still missing. My critique looks at past Government policies by studying documents within the *SSR* alongside my own collection of papers gathered over many years.

This chapter attempts to illustrate how organisations handled the contamination crisis once the haemophilia population became infected and raises ethical questions with regard to haemophilia treatment. My study examines the medical establishment from a Foucauldian perspective as identified in Peterson and Bunton (1997, p. 99) who state that "power as it operates in the medical encounter is a power that provides guidelines about how patients should understand, regulate and experience their bodies." By examining medical documents in my analysis of the report I aim to look at the extent to which this power is exercised by the medical profession and the State in gaining control over a patient's body in relation to their haemophilia treatment. This study also draws on the theory of Richard Titmuss (1970) who analysed the impact of the blood donor as a commodity in relation to economic versus social good.

My critique of this report is not only a review of the written content of the *SSR* but is also a textual analysis of some of the material that is excluded. I examine the politics of deceit by deconstructing the Government version of the "truth", namely the presentation of erroneous information as accurate fact and by challenging the view that this narrative must be accepted simply because the report emanates from an official body. Although I interpret evidence up to 1991 I have chosen to focus mainly on documents before 1985. This was the period prior to the introduction of heat-treatment (which eliminated HIV and hepatitis viruses from factor concentrates) a time when haemophiliacs were most at risk of becoming infected.[4] It is important to note that hepatitis C was still being transmitted to the general population through whole blood transfusions until the introduction of an HCV test in 1991 (see section - *Testing Of Blood For HIV And Hepatitis C*). However any haemophiliac receiving whole blood at this time would very likely have already been infected with HCV through treatment with factor concentrates.

It is argued that the *SSR* which is described by the author as "at times contradictory and incomplete" (p. 28) is written in a way that makes it difficult for some haemophiliacs and non- health care professionals to understand. This is an example of the power of language used by professionals to control lay persons as identified in the work of Foucault (1980) who described the "politico-medical hold on a population" where the physician places himself as the "expert" in an almost unquestionable position of authority. The *SSR* which was supposed to address questions from the haemophilia community makes extensive use of politico-medical terminology to disempower and confuse the reader. It is not difficult however for educated and informed campaigners to dissect the content and see through the Government's diversion tactics of focusing on pages of facts and figures of treatment output (*SSR*, p. 13-27) which could have easily been summed up in one word a *failure* in terms of self-sufficiency whilst Government downplayed the key issue of safety. The sourcing of evidence is poor in that whoever compiled the material for the report (the Government has never identified the author) failed to work with other key organisations during the collection of evidence stage despite the fact that campaigners offered to share their own documents to ensure that the *SSR* was as accurate as possible. It is argued that this was a deliberate ploy to censor sensitive material. If the Government had taken key evidence from campaigners they would have been forced to acknowledge incriminating material. The author of the *SSR* chooses a careful selection of extracts from the documents that are presented in the report to avoid showing successive governments in a negative light and the wider health issues are often hidden. The *Chronology Of Events* (*SSR*, p. 42-44) is also incomplete due to the exclusion of key documents which were "inadvertently" destroyed (Connon, 2006).

Haemophiliacs have expressed a feeling of anger and betrayal at the way in which the Government and other institutions such as the medical profession have dealt with the contamination of their community. The Haemophilia Society and haemophilia led campaign organisations question the accuracy of the report and are challenging the findings that are based on incomplete records.[5] In order to do so they have requested full access to the evidence used in the *SSR* under FOI and to all documents originally held by solicitors acting for infected haemophiliacs. (Government documents were sent to legal firms in the late 1980s as part of an information exchange during the UK haemophilia HIV litigation against the DOH).

In 1991 Justice Ognal the presiding judge in the HIV litigation had advised that the Government must submit all their blood policy documents to be viewed in court. On hearing this opinion and after years of legal wrangle the Government decided to settle claims out of court providing haemophiliacs with an "ex-gratia" payment and avoided any embarrassment of having potentially damaging documents revealed to the general public. Much of this evidence which was excluded from the *SSR* and went unseen by haemophiliacs for many years was recalled by the Government in recent months and they have now decided which papers to release to the public and which documents they wish to withhold on commercial grounds under the FOI Act. This goes against the Government statement that all the evidence pertaining to the infection of haemophiliacs is already in the public domain. As Margaret Unwin of the Haemophilia Society is keen to point out,

> The Government has already admitted that it has shredded many of the documents that refer to the time period in question, but that still doesn't explain the strange assortment of references they have made in the report- ranging from clinical journals to the Sun Newspaper. (She goes on to say) This document is greatly flawed and has, I believe been produced to deflect the call for a wide-ranging public inquiry into the whole issue. The report has been produced internally, informally and very poorly by the Department of Health. It is not public, not an inquiry and merely reflects the views of the Department itself. (Haemophilia Society Website, 26th Feb, 2006)

The Globalization Of Blood: Haemophilia And The Introduction Of Factor Concentrate Treatment

Britain's initial introduction to the globalization of blood was a very positive experience. Starr (1999) documents the success of the *Plasma For Britain* programme set up in 1940 in cooperation with the Blood Betterment Association and the American Red Cross. Charles Drew (the first African America to be awarded a Doctor of Science degree) supplied Britain with shipments of plasma from the US and prided himself on the highest standards of safety virtually eliminating viral contamination in blood supplies (Red Gold Website, date not stated).[6] Over the next three decades Britain strived to develop its own blood collection service with a view to becoming self-sufficient in blood products and utilized a volunteer unpaid donor system. Haemophiliacs however experienced discrimination with regard to their treatment and were subjected to a much lower standard of safety than other NHS patients that required blood. In 1973 the UK government began licensing factor concentrate products from large American corporations. The importation of plasma/plasma products continues to this day as it is no longer possible to use white cell plasma from UK citizens because of the risk of new variant Creutzfeldt- Jacob Disease (v CJD).

Prior to the introduction of testing for HIV and hepatitis viruses the medical profession and Government bodies acknowledged that the single most effective measure to minimise the risk of blood borne diseases was the careful screening of plasma donors and the need to use volunteer donors as opposed to commercial donors on the grounds of safety (Titmuss, 1970).[7] The emphasis however during the 1970s and early 1980s was profit over safety and blood became an extremely lucrative commodity. Titmus, an expert on the welfare state placed the selling of blood in the wider context of the global economy and went so far as to predict future ethical dilemmas (which are now present reality) when he stated:

> Short of examining humankind itself and the institution of slavery- of men and women as market commodities- blood as a living tissue may now constitute in Western societies one of the ultimate tests of where the "social" begins and the "economic" ends. If blood is considered in theory, in law, and is treated in practice as a trading commodity, then ultimately human hearts, kidneys, eyes and other organs of the body may also come to be treated as commodities to be bought and sold in the marketplace. (Titmuss, 1970, in revised edition, Oakley and Ashton 1997 p.219)

From the early 1970s haemophiliacs in many UK hospitals were repeatedly treated with US blood products manufactured from the plasma of "high-risk" commercial donors which included prison and "skid-row" donors. Craske (1975) reported a rise from 3 to 50% in cases of hepatitis in his UK patients after the introduction of American plasma products in haemophilia treatment. U.S. companies also had a history of importing raw plasma from Central and South America and shipping it to Europe where it was made into factor concentrates to be used by UK haemophiliacs (Gould, 1975).[8] This exploitation also highlights the north-south divide where those in the poorer countries of the southern hemisphere were viewed in terms of the market value of their blood and used to supply the markets of the north with little regard for the health of the donor.

Prior to the invention of factor concentrates UK haemophiliacs were treated with cryoprecipitate. This was manufactured from single donor units (*SSR*, p. 5) and was therefore considered safer than factor concentrates pooled from thousands of donors which increased the hepatitis risk.[9] The Government have on many occasions tried to use the argument that had haemophiliacs not been treated with factor concentrates they might have died from bleeding (*SSR*, p. 12). This might well have been the case with the earlier treatment using whole blood and fresh frozen plasma ***prior*** to 1960 and ***before*** the use of cryoprecipitate (see SSR, p. 5) however it is important to note that many haemophiliacs did not receive their first factor concentrates until adulthood and had survived for many years using cryoprecipitate. It could be argued that as Government (DOH) had both failed to estimate the correct level of treatment needed and failed to achieve adequate production levels of cryoprecipitate and factor concentrates within the UK then the Government could have been putting haemophiliacs at risk of death. I contend that the Government realised the implications of its failure to achieve self-sufficiency and sanctioned the use of "high- risk" products from the U.S. to supplement UK produced plasma products.

Factor concentrates which were produced from large pools of donor plasma i.e. 10,000 donors" in the UK (*SSR*, p. 5) and up to 60,000 in the US were however acknowledged to be a more convenient treatment for haemophiliacs (Treatment Of Hemophilia Website, date not stated). Patients could be taught to inject themselves with "home treatment" using small amounts of these freeze dried products mixed with sterile water to prevent bleeds wherever possible whereas taking cryoprecipitate meant a visit to hospital often after bleeding had started and undergoing extended treatment. Many haemophiliacs have stated that had they known the risks from imported factor concentrates they would have chosen to remain on cryoprecipitate until such time as a process could be introduced to eliminate hepatitis and later HIV in plasma concentrates which was eventually the case in the mid 1980s. Haemophiliacs also had a right to abstain from using treatment if they felt the risks were too great.[10] The vast majority of haemophiliacs however were never given the information they needed in order to make an "informed" choice which is integral to a partnership of trust and respect between doctor and patient as is pointed out by Faulder (1985, p. 27). Faulder supports Foucault's work on power inequality in the clinical setting by arguing that "if the doctor does not confide in the patient as the patient confides in the doctor, then the relationship is unequal and unjust."

The Politics Of The Paid Donor And The Infection Of Haemophiliacs With Hepatitis Viruses

Since the 1970s there had been a long running debate amongst health professionals about the need for the UK to become self-sufficient in the collection of blood and manufacture of plasma products for haemophiliacs on the grounds of safety. Titmuss (1970) had documented his concerns exploring the fact that where donors were paid for their blood this attracted individuals who were less worried about their own health and suitability to donate and more focused on the financial reward offered to them. He noted that:

> In the United States in 1970, blood group identification cards are loaned at a price to other sellers; blood is illegally mislabelled and updated; and other devices are adopted which make it very difficult to screen and exclude as donors drug addicts, alcoholics, and carriers of hepatitis, malaria and other diseases. (Titmuss, 1970, p.129)

The UK on the other hand had a system of volunteer unpaid blood donors that donated blood not for remuneration but for altruistic reasons. Further concerns about paid donors were raised by Martel Dailey MD (1972) in a letter to an American medical journal. He began by quoting personal communication from respected surgeon Dr J Garrott Allen,

> To the editor- The probability of a recipient developing serum hepatitis (SH) is 10 to 50 times greater when the blood donor is a commercial donor. (*JAMA*, 24th July, 1972, Vol 221. No 4)

Owen supported the evidence provided by Titmuss and Garrott Allen when he spoke at length about his commitment for the UK to become self- sufficient in blood products by mid-1977 acknowledging in his own words "the terrible risks associated with importing blood" (Houldcroft, *Journal,* Aug 2nd 2001). He recalls having to fight hard on this issue in parliament but stated that, "no-one argued against me on the grounds of medical safety- it was purely a case of money." It is argued here that the Government's reliance on imported plasma products was in fact false economy, the *SSR* actually states that the primary goal of self-sufficiency was to "reduce reliance on expensive imported treatment" (*SSR*, 2006, p.1) this statement also emphasises the fact that the Government placed economy over safety. Klein (1994) provides a wider picture of patient treatment issues during the 1970s documenting the "politics of disillusionment" within the NHS at a time of economic crisis, financial cutbacks and growing militancy towards Government from the medical profession. This supports the concerns repeatedly raised by campaigners that the Government failed to commit adequate financial resources for UK plasma production. Haematologist, Dr Peter Jones, interviewed for a documentary programme "The Blood Business" *World In Action* (1980) voiced his own anxiety with regard to underinvestment in haemophilia care and also claimed that the level of product demand for factor concentrates was known by Government years earlier however the UK output remained insufficient to supply the needs of patients.

I contend that the title of the *SSR* is itself misleading and incorporates a level of government "spin" in that the author of the report uses the positive phrase "self-sufficiency in blood products" so readers might at first sight assume that this had actually happened. It is argued that the report should have used the phase "failure to achieve" or "lack of" self-sufficiency to accurately reflect the negative content of the report in the title. The Haemophilia Society state that,

> Reading the report- which does not have a named author- it appears to be a fairly blatant attempt to gloss over the details of the events of the time and even to lay blame at the door of the patients themselves. (Unwin, Haemophilia Society Website, 28th Feb, 2006)

It is argued here that this is a common tactic used by government and the medical profession to absolve itself of responsibility for flawed decision making and avoid potential litigious action by shifting responsibility onto individuals.[11] Government officials in an attempt to divert from their own failure to estimate and produce the correct level of treatment needed for the haemophilia community have portrayed haemophiliacs as "demanding" attempting to place the blame for shortages onto patients themselves. (I will explore further the issues around inadequate treatment production at a later stage in this chapter). It is important to note however that the risk of viral infection from blood products before 1985 was so high that during HIV legal proceedings both lawyers for haemophiliacs and lawyers defending the DOH accepted that on the balance of probability haemophiliacs would most likely have become infected through their NHS haemophilia treatment.

This study contests the argument sometimes put forward by Government that there were not enough volunteer blood donors in the UK to achieve self-sufficiency. I support my viewpoint by drawing on the work of Titmuss (1970) who studied a variety of reports on supply and demand from 1948 and noted "what is particularly striking is the orderly, progressive and sustained rate of growth in the number of blood donors, blood donations and supplies to hospitals." He also suggests that had there been shortages of blood, "one obvious answer would have been to have bled donors more frequently than twice a year," (p. 94-95). He noted that the UK had a very strict standard of bleeding donors only twice a year whereas the U.S. bled donors up to 5 times a year and there could have been some flexibility in this area.

In the 1970s Owen was very clear in his view that "medical safety" had to be prioritised over economy. It is important therefore to examine documents written before 1973 the year importation of blood products began in order to establish the dangers known by Government at that time. The *SSR* chronology provides only vague entries from 1970 up to the end of 1973 (*SSR*, p. 42) and fails to mention known high risks related to the newly introduced factor concentrates particularly those imported from the US. Owen's name is barely mentioned within the *SSR* despite the fact that he has written a number of letters of complaint to the Parliamentary Ombudsman accusing the Government of "gross maladministration" (telephone conversation with Owen 2001). He has repeatedly tried to establish the facts around the breaking of his parliamentary commitment and was a key figure with regard to self-sufficiency policy. When Owen tried to access his Government papers from the period he was in office as Health Minister he was informed that they had in fact been pulped. (see Appendix A3 and A4).

The Government with access to both researchers and resources has failed to emulate campaigners and document evidence of risk prior to 1973 easily obtained from medical journals of that era which remain available through any medical library in the UK. Cohen and Dougherty (1968) detailed a study on narcotic addicts and suspected addicts that sold blood at a local proprietary blood bank in America and exposed the donors as the significant source of serum hepatitis. The study concluded that "the risk of it (hepatitis) developing in recipients of blood known to have been donated by convicted or suspected narcotics addicts was 70 times that in the controls" (*JAMA*, Feb 5th, 1968: Vol 203, No 6). This is only one of dozens of medical and health journal studies that linked outbreaks of hepatitis to commercial blood donors prior to 1973. Titmuss (1970) documented a clash between a local hospital and a US plasma company fighting for the right to bleed prisoners as far back as 1966. This once again highlights commercial venture taking priority over patient safety. In 1971 Kliman et al wrote an article on hepatitis and HAA (Australian Antigen testing) for hepatitis B and echoed the findings of Titmuss stating that,

> The HAA- positive donor does differ from the general population of blood donors, and in this finding is the hope that as we identify high-risk populations, the overall risk of hepatitis from the blood collected will be diminished. The elimination of prison donors is a case in point although it must be admitted that there was abundant evidence that this was a high-risk group before HAA testing. (*New England Journal Of Medicine*, Sept 30, 1971)

A meeting of the Expert Group On The Treatment Of Haemophilia 1973 (see Appendix A5) was held at the UK Government's own offices and identified the increased risk of hepatitis once the number of donors in the plasma pool was increased, and also the importance of screening for hepatitis B in blood and blood products.[12] Factor concentrates were noted to be "expensive" and deemed to be "in limited supply" and that "the limiting factors are the capacity for production (and the cost) of this preparation." The minutes of the meeting emphasised the importance of "reducing and as soon as possible ending purchase from foreign sources." Haemophilia campaigners ask the following questions:

1. How could US factor concentrates from "high-risk" sources be licensed for treatment as safe by licensing authorities in the UK?
2. How could treatment from such "high-risk" sources manufactured from plasma pools of up to 60,000 in the U.S. be licensed by UK authorities *before* processes were developed to eliminate hepatitis viruses?
3. Why were patients and their families not told of the very high viral risks linked to factor concentrates?

It is argued throughout this study that the DOH failed in its duty of care to provide sufficient funding to invest in adequate production facilities to provide the safer UK plasma products for haemophiliacs. As Owen has stated once he left his position as Health Minister no-one in Government carried out his parliamentary commitment. Many haemophiliacs recall that the DOH and its doctors actively encouraged the use of the new innovative treatment (factor concentrates) which was meant to improve the quality of life for haemophiliacs. The promotion of these new products by medical staff alongside the failure of the Elstree blood processing plant to reach the required levels of treatment output in the UK had thus created a market that Government owned facilities could not supply. "At present, UK production is considerably less than the required amount of the freeze dried preparation" (DHSS Meeting, 1973, see Appendix A5). The Government does not address this area of investigation sufficiently and refuses to accept any responsibility for its failings. It could be argued here that UK doctors did attempt to challenge DOH policy on importing blood products as stated by Dr Mark Winter who recalls that representation was made to Government on this matter both in 1975 and 1978 (Meridian documentary, 2000). However despite safety concerns the medical profession continued to prescribe "high-risk" imported treatments without consulting patients on the risks associated with their treatment.

In 1975 a well respected television documentary programme "Blood Money" *World In Action* (parts 1 and 2) investigated the self-sufficiency issue taking a look back at Elstree which had been established in the mid-1960s and should have covered the treatment needs of the English and Welsh haemophilia community.[13] A copy of the "Blood Money" documentary was presented to Lord Hunt by campaigners at a meeting at the DOH but was not included in the *SSR* although the later *World In Action* documentary "The Blood Business" (1980) was included, (*SSR*, p.7). A reporter from the 1975 documentary made this comment about Elstree:

> the completion was delayed by administrative changes, building hold-ups and disagreements among doctors about whether (factor) concentrates were the best way to treat haemophiliacs. The plant was finally ready in the early 1970s but by then because of the popularity of home treatment, the amount it needed to produce had shot up to 10 times the original estimate. To fill the gap England imported factor concentrates. ("Blood Money" *World In Action*, 1975)

In "Blood Money" an investigative journalist interviewed several haemophiliacs and their families from the north-east of England about their treatment. The television crew travelled to the US after a hepatitis outbreak in UK haemophiliacs and traced the factor concentrates used by these patients back to the plasma collection centres. The *Times* published an article 12 months prior to this program which noted that in the United States

90% of transfusion associated hepatitis was caused by hepatitis NANB (*Times*, Nov 12th 1974). The "Blood Money" team were accompanied in their travels by Dr Arie Zuckermann a leading hepatitis expert who described a Hyland blood collection facility in Los Angeles as "an offense to human dignity" noting that donors were "derelicts" and "alcoholics" that any British physician would have "rejected straightaway " (Starr, 1999, p. 235).[14] Zuckerman (1968) had already expressed his concerns about the greatly increased hepatitis risk from paid donors years earlier (*British Medical Journal*, 20th April 1968 p.174-175). The UK government however chose to support the commercial practices of US domestic blood policy rather than support self-sufficiency in the UK and it could be argued that these policies reflected many of the wider commercial ventures between the two countries which continue to this day.

William Maycock the person in charge of producing Factor VIII concentrates in England and senior advisor to the Department of Health on blood transfusion policy was interviewed in 1975 on the same "Blood Money" documentary programme in which the following exchange of opinions took place:

> **Reporter. (Question)** Was it in your view ever possible that we (the UK) could have produced Factor VIII concentrate much earlier in Britain given the work that was done on some of the processes associated with it?
>
> **William Maycock (Reply)** Well, it's always easy to look and see what might have been done: I think had certain decisions and certain things been made and certain things not happened we obviously could have done this.

("Blood Money" *World In Action*, 1975)

The exclusion of the "Blood Money" documentary from the *SSR* after it was accepted by the Lindsay Tribunal in Eire to assist Irish haemophiliacs in their version of a public inquiry has increased the mistrust of haemophiliacs in the UK Government to provide an objective and accurate history of the events leading up to haemophiliacs' contamination with HIV/HCV. This adds to the anger felt by many within the haemophilia community that they were used as "guinea pigs" for studying infectious diseases and officials had little care for their wellbeing. It is argued that the Government blatantly ignored the safety guidelines laid down by the World Health Organisation (1975) not to use paid donors from countries such as the US with a higher incidence of hepatitis in the general population than the "home" country, in this case the countries within the UK. The following letter from a staff member at the Viral Diseases Division, Bureau of Epidemiology to the Director, Centre for Disease Control, (CDC) Atlanta, US shows that the American Government responsible for disease prevention and monitoring at the highest level were aware of the type of donor used within the US prison system (see Appendix A6). The letter was marked "For administrative use, limited distribution, not for publication." The following statement appeared,

> **Summary**
>
> Over a 2 –week period in February- March 1974, 11 clinical and 8 subclinical hepatitis cases were detected among prison inmates at the Kansas State Penitentiary. The majority were HbsAg – (hepatitis B) positive. Investigations revealed that 18 of these 19 cases were in prison plasma donors at the prison plasmapheresis center; however risk of hepatitis could not be definitely associated with the plasmapheresis operation, since intravenous drug abuse- including the sharing of equipment –was commonly practised by plasma donors. (Centre For Disease Control, Document, 24th July 1975)

The UK government appears to have absolved itself of any responsibility in its part in sanctioning treatment manufactured from prison plasma despite repeated warnings from hepatitis experts. In 1975 Dr J Garrott Allen supported Zuckerman's findings (1968) in a letter to Dr William Maycock (see Appendix A7) describing one US product as "extremely hazardous with a 50 to 90 per cent rate of icteric hepatitis developing from it." He writes of his concerns related to an emerging strain of hepatitis which is not hepatitis A or B, which appeared in "high-risk" donors. Garrott Allen stated that,

> Whatever this agent may be, it still seems to be more frequently encountered in the lower socio-economic groups of paid and prison donors.... (and) until we understand this problem better, I would hope Great Britain would give some thought to what the purchase of Factor VIII and IX from the United States tends to do to our attempts to secure a volunteer program. (Garrott Allen letter, 1975)

An adjournment debate in the Commons, (*Blood Transfusion Service,* 1980) illustrates that the UK Government continued to be fully aware of the type of "high-risk" donors used and the increased hepatitis risk from imported products yet there was still no move to withdraw US plasma as Government had also continued to fail to invest enough money to produce adequate treatment supplies in the UK.

Hepatitis C: Risk-Taking, Research, And Reinfection

Craske et al (1975) and (1978) documented outbreaks of hepatitis in the UK haemophilia community following on from the importation of American plasma products.[15] Many haemophiliacs claim that haematologists failed to tell them about the seriousness of being infected with NANB hepatitis and this is a source of a great deal of anger as detailed in the replies to my questionnaires which examine testing for hepatitis C without a patient's knowledge and consent. Even well into the 1990s some doctors were still claiming hepatitis C was "nothing to worry about" during face to face contact with patients yet for years unbeknown to most haemophiliacs the medical profession had been studying the haemophilia population in relation to this infection.

Walford (1980, see Appendix A8) expressed her concerns a decade earlier and wrote to the UK Blood Products Laboratory that NANB hepatitis "can be rapidly fatal or can lead to progressive liver damage." Although this letter is referred to in the *SSR* (p.15, [98]) in relation to "demand" for factor VIII there is no inclusion of this particular statement as the Government have tried to claim that they were not aware of the dangers associated with NANB until around 1983. A report from the Haemophilia Centre Directors Hepatitis Working Party 1980-1981 (see Appendix A9) recorded once again the higher risks of hepatitis from imported treatment with "a 4-20 times higher incidence of overt non-A, non-B hepatitis (NANB) associated with US commercial concentrate compared with NHS" (p.1). The study noted 283 episodes of hepatitis in haemophiliacs recorded by Haemophilia Centre Directors and stated that several patients had experienced repeated attacks of hepatitis and were being ***re-infected*** with one or more strains. The report also found that "70-80% of cases of NANB hepatitis were associated with the first dose of concentrate a patient received" (p. 2) yet the parents of small children and adult haemophiliacs recall that they were repeatedly told not to worry about the safety of their treatment and if they were told anything at all, hepatitis was compared in seriousness to being similar to "a dose of the flu." The 1980-81 report was also a study of factor concentrate treatment brand by brand examining American treatment and UK treatment as well as the hepatitis infection rates over a 6 year period. There appears to have been a total disregard for the fact that had patients been made aware of the 90% NANB hepatitis risk associated with transfusion of US products (Wright, *Times*, Nov 12th 1974) they may have wished to reject imported treatment and return to cryoprecipitate made from small numbers of UK volunteer donors. (The risk with UK factor concentrates however was now also starting to rise with an increase in the size of the donor pool). Haemophilia campaigners ask a further question on safety,

4. How could the DOH have sanctioned the use of UK factor concentrates manufactured from large donor pools *before* processes were developed to eliminate hepatitis viruses?

An international symposium held in Glasgow in 1980 covered the subject of haemophilia treatment and hepatitis risk whose findings were published in 1982. Craske speaking on behalf of the Public Health Laboratory stated that "hepatitis B was strongly correlated with the use of factor concentrates made from *large* plasma pools and spoke of the increased risk of infection with NANB hepatitis from *commercial* plasma products" (HIV Haemophilia Litigation Claim, 1990, p. 30). Craske noted that "of the 138 cases where the transfusion history was known 103 cases of NANB hepatitis had been associated with concentrate but only 7 with cryoprecipitate" (HIV Haemophilia Litigation

Claim, 1990, p.52). Craske concluded here that there was "a ***high-risk*** from the use of factor VIII or IX that the patient will contract non-A, non-B hepatitis."

Gerety (1981) supports concerns over the increased risk of patients acquiring hepatitis through commercial products. He examined non-A, non- B hepatitis in his book of the same name which includes chapters on haemophiliacs and donor sourcing yet there is no reference to this text in the *SSR*. A journal article by Gerety (1982) is included (*SSR*, p.6) yet there is careful selection of material taken from this article to mention only the minimal risk of viral infection from albumin and immunoglobulin while carefully excluding any mention of the known danger of NANB hepatitis from factor concentrates at this time. Gerety (1981) notes that the transmission rate of hepatitis in haemophiliacs was around 1.8% in the UK ***before*** the use of imported treatment prepared from ***large*** pools which utilized ***paid*** donors, after importation the risk jumped to 17.7%. Shortly after this book was published Haemophilia Centre Directors recorded at a meeting in 1982 that surveillance into hepatitis in haemophiliacs was being carried out in the UK. Craske was documented in the minutes as stating the importance of continuing to collect data on "suspect" treatment batch numbers received by patients that developed hepatitis. He also stated that he would be "most interested to receive samples of liver from patients who came to autopsy where there was evidence of chronic liver disease" and his hope that Haemophilia Directors would "continue to report cases of chronic hepatitis to the Working Party on the appropriate form" (UKHCDO Minutes, p, 20, see Appendix A 10).[16] Requests from haemophilia campaigners for the full data collected on hepatitis C surveillance under the FOI Act have been met with anger and avoidance tactics from both the Government and the medical profession.

In 2002 as part of a legal challenge to Government I requested a chronology of the history of NANB hepatitis from a medical expert in order that my husband Peter Longstaff could challenge a "hepatitis waiver" that appeared in the 1991 HIV litigation (see section *Testing For HIV And Hepatitis C: Delays, Devious Deals And Dangerous Practice*). Professor Eric Preston a specialist in liver disease who is well respected for his research into hepatitis in haemophilia patients provided a report for Queens Council (QC). When the *SSR* was published in 2006 I was able to compare Preston's findings to those in the *SSR* and discovered several discrepancies. The Government report fails to recognize the seriousness of NANB hepatitis until 1982/83 yet Preston reported for Queens Council that back in 1978,

> Even at that time, our patients exhibited a wide spectrum of chronic liver disease, including hepatic cirrhosis. We expressed the view that the chronic liver disease was attributable to non-A, non-B hepatitis. We concluded that histological liver disease is common in haemophiliac patients and is probably related to clotting factor concentrate replacement therapy.

These findings were published in the *Lancet* by Preston et al (1978). It was a well established fact at that time that hepatic cirrhosis and liver disease could lead to death so this is rather more serious than the suggested likeness to "a bout of flu" the term used by some doctors to explain hepatitis to haemophiliacs. Haematologists go so far as to record the fact that "there are no further deaths directly or indirectly attributed to liver disease in the past year" (Haemophilia Centre Directors' Hepatitis Working Party Report, 1980-81, p.1). A study by Galbraith et al (1979) supported the findings by Preston and his colleagues on the serious nature of NANB hepatitis. The Government report however fails to document the significance of these findings in the *SSR* and in the *Chronology* there is no entry whatsoever for the year 1978, the year the Preston study was published. In the *SSR Conclusions* section the report states,

> The prevailing medical opinion in the 1970s and early 1980s was that NANB (hepatitis) was mild and often asymptomatic. Therefore, as always, patients with haemophilia, their parents, and doctors, were required to balance the improvements in quality of life and the dangers of bleeding against the risks of treatment. (*SSR*, p. 28)

Patients have questioned why even up to the late 1990s some were still being told that hepatitis C was "not a problem." Patients that did raise concerns were often labelled totally inappropriately as the "worried well" by "panicking professionals" eager to playdown their infection by implying that patients' concerns were unfounded. Many of the "worried well" are now dead.[17]

What is very disturbing for haemophiliacs is the fact that they appear to have been used in trials to test out infectivity of treatment however as Harriet K Beecher points out "A study is ethical or not at its inception; it does not become ethical because it turned up valuable data" Henry K. Beecher (quoted in Faulder, 1985, p. 75). The following information on haemophiliac studies appears in a letter from haematologists Rizza and Bloom (1982),

> It is therefore very important to find out by studies in human beings to what extent the infectivity of the various concentrates has been reduced. The most clear cut way of doing this is by administering those concentrates to patients requiring treatment who have not been previously exposed to large plasma pools. Those patients are few in number but a study along those lines is being carried out at Oxford to determine the infectivity of factor VIII concentrates produced by the Plasma Fractionation Laboratory, Oxford and Blood Products Laboratory, Elstree. This study shows that it is possible to demonstrate infectivity using quite small numbers of previously untreated patients. (Rizza And Bloom Letter 1982, see Appendix A11)

As haemophilia is an hereditary condition and most haemophiliacs are diagnosed in the first years of life, previously untreated patients would generally be very small children or mild haemophiliacs as opposed to those considered to have moderate or severe haemophilia. In Foucauldian terms this experiment can be viewed as an abuse of clinical power where doctors have access to key information which is not passed on to patients resulting in an abuse of human rights.

In 1985 Preston and his colleagues followed up their earlier research carrying out liver biopsies in patients and produced a further report which concluded,

> We were able to demonstrate that progressive liver disease is a potentially serious problem in haemophilia, nine of our biopsied patients had hepatic cirrhosis. In our report, we predicted that deaths attributable to liver disease in haemophilia will become more common in haemophiliacs. (Preston Legal Opinion, 2002).

AIDS- A Conspiracy Of Silence: The Contamination Of A Community

It is argued that had the appropriate precautions been taken with regard to the UK achieving self-sufficiency and the appropriate screening of donors in the US in relation to hepatitis viruses alongside the exclusion of paid donors and large plasma pools many haemophiliacs worldwide would not have become infected with HIV. AIDS hit the population of America ***before*** it reached the UK and many other countries (African countries excluded). Therefore many of the arguments presented and documents discussed in the previous sections on hepatitis C can equally be applied to the infection of haemophiliacs with HIV. In 1981 a DHSS letter from Harris (see Appendix A12) to

Prescott in the Treasury office detailed the progress or it could be argued lack of progress in terms of self-sufficiency in the redevelopment of Blood Products Laboratory (BPL) owned by the Government. The following statement appears,

> Although BPL's production has increased steadily over the years and it is currently worth about £11m a year to the NHS, health authorities are obliged to supplement supplies from BPL with expensive, and because of the hepatitis risk, **less safe imported commercial blood products** at a cost of up to £10m annually. (Harris, 1981)

The letter noted that BPL fell "considerably short of the standards of good pharmaceutical manufacturing practice applied by the Medicines Inspectorate under the Medicines Act 1968." Harris states that the Laboratory was inspected by the Medicine's Inspectorate (1979) and he writes,

> The gist of the Inspectorate's report was that conditions of manufacture at BPL were **unsafe and potentially hazardous to patients**. The report concluded, 'If BPL were a commercial operation we would have no hesitation in recommending that manufacture should cease until the facility is upgraded to a minimum acceptable level.'(Harris, 1981)

The Inspectorate recommended complete rebuilding of the plant and the letter stated that self-sufficiency although desirable was a long-term goal.[18] This was a far cry from Owen's parliamentary commitment for the UK to be self-sufficient by 1977. The *SSR* makes no mention of this letter in the chronology although does refer and quote from an adverse Medicines Inspectorate Report in 1979. The *SSR* claims that "the report did not say that the products were unsafe" (*SSR*, p. 24) however the SSR fails to mention the unsafe conditions of manufacture documented in the Harris letter. This is an example of the author selecting material for the *SSR* which does not give a true and accurate picture of the issues around self-sufficiency and there is also no mention of the increased hepatitis risk and added expense of importing commercial blood products at that time as detailed by Harris. The continuing failure of the UK Government to achieve self-sufficiency was to have disastrous consequences for a generation of haemophiliacs in the 1980s as they learnt for the first time of the link between their "life-saving" treatment and AIDS.

An early report on the possible risk of haemophiliacs becoming infected with the AIDS virus via factor VIII appeared in *New Scientist* (Sattaur, 3rd Feb 1983). The year 1983 was very significant for the haemophilia community in terms of how the news of AIDS, (a new blood borne virus at that time) was handled by the Government, the medical profession and the press. I have documented here an incident that appeared in the *Mail On Sunday* which does not appear in the *SSR* yet is an important part of the history of AIDS in the UK and one that the Government and the medical profession are keen to forget. I question why this important article was omitted when the DOH utilized a later newspaper article on AIDS in the *SSR* from the *Sun* (18th May, 1983). On 1st May 1983 Susan Douglas, a journalist for the *Mail On Sunday* wrote a well-researched and controversial article reporting on the dangers of importing "**killer**" blood from the US due to the sourcing of plasma from "high-risk" donors and the risk of AIDS for UK haemophiliacs. Douglas had identified the first two British haemophiliacs with AIDs which led to a strong reaction from a leading haematologist and a dismissal of her concerns from the Government. A complaint to the Press Council was filed by Dr Peter

Jones Consultant Haematologist at a Newcastle hospital who claimed the report was "sensationalized."

The Government reacted to the article by stating that the evidence presented by Douglas was "too slight for immediate action." The Press Counsel went on to censor the Douglas report as "extravagant" and "alarmist" (Douglas, 1984). This had the effect of temporarily closing down some news stories on AIDS but haemophiliacs had begun to question the risks associated with their treatment and once again were met with the repeated response "not to worry." The national Haemophilia Society responded on 4th May 1983 (see Appendix A13) sending a letter telling members that "the importation of licensed blood products has always been strictly monitored and controlled" and that "it would be counter-productive to alter our treatment programmes radically." Under the FOI Act the name of the author of this letter has been blocked out. Galbraith (1983) based at the Public Health Laboratory Service (PHLS) Communicable Diseases Surveillance Centre was becoming increasingly concerned at his own findings. He wrote a letter on 9th May to the DHSS in London (see appendix A14) which documented the first known case of AIDS in a UK haemophiliac in Cardiff who had been treated with US factor concentrates. This letter is notably missing from the *SSR*, Galbraith expressed his concern over AIDS and informed the DHSS of 11 similar cases in the U.S. and 3 in Spain and warned,

> I have reviewed the literature and come to the conclusion that all blood products made from blood donated in the USA after 1978 should be withdrawn from use until the risk of AIDS transmission by these products has been clarified. (Galbraith, 9th May 1983)

Galbraith attached his reasons for the withdrawal of treatment and urged an early meeting with haematologists, virologists and others concerned. He also stated, "I am most surprised that the USA manufacturers of the implicated blood products have not informed their customers of this new hazard. I assume no official warning has been received in the UK" (Galbraith, 9th May 1983.) Here it can be argued that once again commercial interests were prioritized over safety. Galbraith failed to get a positive response to his concerns. A meeting of Haemophilia Reference Centre Directors dismissed his worries declaring that there were was insufficient evidence to withdraw US concentrates although they agreed to review the situation (Bloom and Rizza letter, June 24th 1983, see Appendix A15). Galbraith identified that the first known case of AIDS in a U.S. haemophiliac was in October 1980 although the first recorded case of AIDS in the general US population was in 1978. He attempted to warn the medical profession that although at that time the number of cases might be small that did not mean the risk of infection was small. The national Haemophilia Society funded in part by the American plasma companies responded to the issue of AIDS on the 18th May 1983, the *SSR Chronology* states that the "Haemophilia Society appeal not to ban imported blood products and urge patients not to stop treatment in response to concerns over potential risks" (*SSR*, 2006, p. 44).

In the US the plasma companies were slow to react although a meeting between the Food And Drug Administration (FDA), the Centre For Disease Control (CDC), plasma companies and other interested bodies met on a number of occasions to discuss the problem of AIDS. A plasma company letter from Hink (1st June 1983) advised that gay donors (considered a high-risk population for hepatitis viruses) should voluntarily exclude themselves from donating plasma (see Appendix A16, Gay Donor Adverts). The letter also stated "there are no data to support the emotional arguments that prison plasma collected from adequately screened prisoners is 'bad'" (Hink letter, 1983, see Appendix A17). Although the FDA went on to tighten up controls on plasma donors both the U.S. and the UK continued to use up old stock on haemophilia patients manufactured from donors known to be high-risk for HIV and hepatitis C and failed to withdraw this treatment (Glenarthur letter, undated, see Appendix A18).

On November 25th 1984 Douglas hit back at the UK Government and medical profession by writing a second article for the *Mail On Sunday* entitled "AIDs: This Scandalous Cover-Up." She noted that there were now 90 cases of AIDS identified in Britain and 38 people had died from AIDS including one of Dr Jones's own patients, Newcastle haemophiliac, GRO-A In the same month the American Correctional Association (1984) produced an information bulletin entitled "Plasmapheresis Centers In Correctional Institutions" which noted the strong link between intravenous drug-users in prisons and infection with hepatitis viruses and the AIDS virus. The following statement appears in the document,

> Using "prison" blood is controversial within the plasma industry itself. It is also controversial at the consumer level, especially among the hemophilia population. Medical, ethical, and moral concerns have been voiced publicly; they must be considered in any decision-making process. (American Correctional Association, 1984)

Testing Of Blood For HIV and Hepatitis C: Delays, Devious Deals, And Dangerous Practice

In 1985 the first heat-treated factor concentrates were introduced in the UK which should have eliminated both HIV and hepatitis viruses. A test for the presence of the HIV virus in blood was also available for the first time in 1985 which meant that blood products could be tested as well as the testing of haemophiliacs suspected of being infected with HIV. It was left up to individual doctors whether to tell their patients that they had been infected with HIV (Smithies letter, 1984, see Appendix A19).

A first generation test for hepatitis C in blood was not available until 1989. The UK Government chose not to introduce the first generation HCV test as there was concern over too many false negative and false positive test results, (Preston, Legal Report, 2002). A second generation test became available and was introduced in 1991. During this two year period from 1989 to 1991 it is argued here that the UK Government failed to err on the side of caution and did not introduce the testing of blood donations for hepatitis C earlier as they did not want to waste blood that tested as false positive but might not be infected. During this time however other European countries did test blood and patients for the hepatitis C virus and saved many patients from becoming infected (Murray, Notes for *Panorama* Documentary, 1999, see Appendix A20). In 1991 wide-spread testing of the haemophilia community for hepatitis C did commence with very high infection rates recorded. It became apparent years later that many patients were tested during this period without their knowledge and "informed consent" and were not informed of their positive test results which put wives and partners at risk of infection. It is argued here that this was a dangerous abuse of power by the medical profession.[19] To make matters worse haemophiliacs also co-infected with HIV recall being made to sign an official Hepatitis Waiver (1991, see Appendix A21) by solicitors acting for them in the HIV litigation which required haemophiliacs not to take further legal action with regard to hepatitis "in the unlikely event" they were infected.[20] Haemophiliacs also recall being advised by their solicitors that hepatitis C "was nothing to worry about" and "less of a problem than hepatitis A and B" this advice was very far from the truth.

The practice of collecting plasma from American prisoners existed for many years with one centre in Arkansas having its licence reinstated even after it was closed down on the grounds of safety in 1984 (Ruddy and Limbacher Jr, 2001). The Arkansas prison plasma program was in fact reopened and ran until 1994 allegedly sanctioned with the authorization of Governor Clinton. It became the subject of a recent documentary "Factor VIII: The Arkansas Prison Scandal" made by American film-maker Kelly Duda (Factor 8 Movie Website, date not stated). Many UK haemophiliacs only realized the true extent of the safety violations regarding plasmapheresis in prisons and the treatment they had received after a screening of the documentary in London in 2006. Haemophilia Action UK campaigners had previously presented two letters to officials in meetings at Westminster offering evidence of past safety violations in the collection of plasma. One letter came from Kelly Duda (2003, see Appendix A22) and the other came from American GRO-A (2001) whose brother was a regular prison plasma donor at Arkansas State Penitentiary and had died from hepatitis C (see Appendix A23). GRO-A s letter addressed to Tony Blair was presented at 10 Downing Street by a group of campaigners and MPs. The UK Government failed to respond to both letters. In the 1970s and 80s at a time of gross safety violations in the collection of plasma 1,252 UK haemophiliacs became infected with HIV and 99% of HIV positive haemophiliacs were also co-infected with HCV. In addition to this many other haemophiliacs became mono-infected with HCV with a total infection rate of hepatitis C in haemophiliacs around 3,000 (Macfarlane Trust, conversation with Martin Harvey, Chief Executive, 2006). Haemophiliacs had been repeatedly exposed to the hepatitis virus from the early 1970s.

Conclusions- Government Failure To Achieve Self-Sufficiency: An Iatrogenic Disaster

The critique of the SSR is an attempt to challenge some of the findings within the report and present an alternative viewpoint by studying documents from Government, the medical profession and other organizations not included in the report alongside the official report. My aim was to identify when information on treatment risks were known, and also to establish the importance of UK self-sufficiency in relation to minimizing viral risk to haemophilia patients. My conclusion is that the exclusion of documents from the *SSR* significantly changes the content and timeline of the report. This study provides documented evidence that treatment risks were known at an earlier time than admitted by Government and that there was also withholding of key safety information from patients by doctors. This amounted to unethical behaviour with regard to failure to obtain informed consent to treatment in relation to "high-risk" products, and failure to achieve informed consent in relation to participation in research studies on factor concentrates when introduced in the 1970s. This behaviour contravened the code of conduct laid out for medical professionals within the Hippocratic Oath (Nova Online Website, date not stated) and also established by the Nuremburg Code, (National Institutes Of Health Website, date not stated). Faulder (1985) stresses the importance of the patient being adequately aware of what they are consenting to and argues that true informed consent "ensures that they (patients) freely volunteer their bodies, being neither manipulated nor coerced into a trial which they do not understand" (Faulder, 1985, p. 43). Documents from the 1970s onwards show that haematologists were closely involved in developing treatment policies on the use of factor concentrates in cooperation with the DOH and repeatedly breached the moral principle of ensuring that the doctor does not cause the patient harm. It feel it is also important to consider the ethics surrounding the globalization of blood and to highlight the exploitation of donors, in the words of Richard Titmuss:

> The commercialization of blood and donor relationships represses the expression of altruism, erodes the sense of community, lowers scientific standards limits both personal and professional freedom….. (and) places immense social costs on those least able to bear them – the poor and the sick…. The redistribution of blood…. from the poor to the rich appears to be one of the dominant effects of the American blood system. (Titmuss quoted in Seaton, 2005, p.25)

I would conclude that failure to achieve self- sufficiency in UK blood products combined with a reliance on imported plasma products from "high-risk" donors in the US and the use of large plasma pools put haemophiliacs at greater risk of becoming infected with HIV and hepatitis viruses. I also conclude that the use of pooled plasma products (factor concentrates) before the introduction of a viral inactivation process to eliminate hepatitis and subsequently HIV was a high risk policy in terms of spreading blood borne viruses within the haemophilia community. I believe that the evidence within this study justifies a full and open public inquiry as it contradicts the evidence put forward by Government in the *SSR*. A public inquiry with appropriate terms of reference agreed by all sides would ensure that all relevant documents could be placed in the public domain.

I contend that not only should individuals be able to question official organizations within a liberal democracy but that they should be positively encouraged to do so as it is a healthy response to examine institutions that are empowered to provide services to the people and this action also empowers the people to take some responsibility for their own lives and the lives of others within society. The following chapter in this study looks at the identity and self-image of haemophiliacs and their partners, and examines their thoughts and attitudes towards the organizations that were set up to provide health care and support to the haemophilia community.

Notes

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[1] Haemophilia Action UK (formerly Haemophilia North) is an independent campaigner led organization based in Newcastle which was set up to represent haemophiliacs infected with blood borne viruses.

[2] Tests for hepatitis A and B in blood samples were developed in the 1970s. Some haemophiiliacs had already been exposed to hepatitis B and when a vaccine became available developed by Blumberg and Millman it was given to protect haemophiliacs against infection (Inventors Hall Of Fame Website, date not stated)

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[3] Plasma-a) the fluid part of milk, lymph or blood, the sterilized plasma used for transfusions (Cassell's English Dictionary (2006, p. 940)

[4] Factor concentrate- Factor VIII concentrates are a commercially prepared lyophilized powder prurified from human plasma to treat patients with haemophilia A or Von Willebrands Disease.
Factor XI concentrates are a commercially prepared lyophilized powder purified from human plasma to treat patients with haemophilia B (Blood Products Website, date not stated).

[5] The Haemophilia Society is the national organization representing UK haemophiliacs. In recent years some haemophiliacs have questioned whether this organization can truly represent them as the Society receives funding in part from international plasma companies involved in litigation in relation to the contamination of haemophiliacs with blood borne viruses and this is often pereceived as a "conflict of interest."

[6] Charles Drew was well respected for tackling not only blood safety but institutional racism in American teaching and medical establishments. Drew had to continually face the "Negro versus white blood" issue in blood collection where use of "negro" blood in the US was either restricted for use in black patients only or banned altogether. Despite the exemplary service provided by Drew, Britain came only partway to addressing the race issue accepting blood from "negro" donors but "labelled the plasma so the users would know the race of its origin" (Starr, 1999, p.98).

[7] Starr (1999) also wrote at length on safety issues surrounding the use of paid donors. He investigated the commodification of blood describing America as the *OPEC* of plasma with the world market value of whole blood in 1998 at $20,000 per barrel in its crude state compared with the market value of crude oil at $13 per barrel. America was identified as the world's biggest exporter of plasma products.

[8] One centre in Belize run by Cuban American doctor Pedro Ramos bled impoverished donors up to 50 times a year against World Health Organisation guidelines which were set up to protect the health of

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donors. Harriman (1980) notes that some donors fed their drink and drug habits by selling their blood. A description of a similar plasma collection centre can be found in Starr (1999, p. 234- 6 and 243-5.) The centre had such a poor reputation for safety it was nick-named, (Casa de Vampiros) and was eventually burnt to the ground by a rioting mob.

[9] Cryoprecipitate- (Cryo) is a low purity concentrate of three hemostatic proteins prepared from donated whole blood (Blood Products Website, date not stated.)

[10] During the early 1980s when AIDs was discovered to be infecting factor concentrates some doctors reverted back to prescribing cryoprecipitate for children as "cryo" was considered to be a safer treatment.

[11] When patients accessed their medical records for litigation purposes some haemophiliacs discovered that there were covert and unsubstantiated references to alcohol abuse in their notes. Patients challenged doctors to produce evidence of this and asked the reason why any identified problem had not been discussed openly with them. Even in accurately identified cases of alcohol abuse it is important to establish whether any identified problem came as a consequence of the of the stress of living with HIV/HCV which doctors often ignored.

[12] As freeze-dried concentrates are made from thousands of donations of plasma which are then pooled together, if one donation is infected it can affect the whole pool which is why donor sourcing was such an important issue before a viral inactivation method was developed in 1985 (Blood Products Website, date not stated).

[13] Scotland had a separate collection and production facility and provided much of the treatment for Scottish haemophiliacs although at times Scotland also used imported US plasma. The situation in Scotland requires a study in itself therefore my focus is on England and Wales although I acknowledge that at the time contamination of haemophiliacs occurred Scotland was governed by Westminster.

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[14] One Newcastle haemophiliac returned his factor concentrates to his local haemophilia centre after the screening of the 1975 "Blood Money" *World In Action* documentary. He recalled being angry at what he had seen but was falsely reassured that the treatment wasn't coming from "dangerous sources" anymore. After years of silence a spokesperson for the hospital finally admitted in 2005 that the hospital had used treatment from prisons for many years, no formal apology was given.

[15] One haemophiliac agreed to speak to me by phone about his own personal recollection of hepatitis during this time when he was a young teenager. This gentleman had been a resident pupil at Lord Mayor Treloar School where children with disabilities were often sent to be educated. He recalls waking one morning to find his haemophiliac friend "glowing yellow." He stated that pupils were told by the headmaster that there were two types of hepatitis and that those infected had the less serious kind, (he believed this to refer to hepatitis B.) The children identified as being infected with a strain of hepatitis were then given plates with red spots attached to signify infection. This was a precursor for the tragedy that followed often referred to by Lords Winston and Morris in Government Hansard reports as "the worst medical treatment disaster in the history of the NHS."

[16] The UKHCDO Minutes (1982) also noted the appointment of a nursing sister whose post would be funded for two years by four pharmaceutical companies and that this person would work closely with the Haemophilia Society and Haemophilia Centres. This demonstrates the close financial ties to the plasma industry also noted in Starr (1999.)

[17] The term the "worried well" appears in a journal article by Miller, Acton, and Hedge (1988) and refers to patients who test negative for AIDS but have the conviction that they are infected with this virus and display irrational and obsessive behaviour. In the case of haemophiliacs the fear was not irrational as many haemophiliacs actually did test positive for HIV and HCV and were worried because they were sick and dying.

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[18] Blood Products Laboratory (BPL) is largely protected against litigation under Crown Immunity.

[19] Haemophiliacs often had their blood tested for clotting levels with consent but testing for HIV/HCV requires pre and post test counseling of patients with appropriate support mechanisms for patients introduced from 1985 the year HIV testing was introduced in the UK. (I was involved in developing good guidelines for practice in HIV testing in Newcastle in 1985 as a practicing nurse). However as my questionnaires reveal good ethical practice was not carried out in many cases. The guidelines are available in General Medical Council (GMC) Serious Communicable Diseases Booklet, (Oct 1997).

[20] Haemophiliacs were informed that if one person did not sign the hepatitis waiver the "ex-gratia" payment for HIV would not be granted to anyone by Government. The solicitors had full access to haemophiliacs' medical records and on reviewing the legal files it was apparent that Government, the medical profession and solicitors on both sides were fully aware of the dangers of hepatitis C and the very high likelihood of haemophiliacs being infected and having progressive liver disease. 99% of haemophiliacs infected with HIV were also co-infected with HCV (GUT Online Website, 2002)

CHAPTER 5

QUESTIONNAIRES: AN ANALYSIS OF THE THOUGHTS, ATTITUDES, AND AND OPINIONS OF AN INFECTED COMMUNITY

> Those like hemophiliacs and blood transfusion recipients, who cannot by any stretch of the blaming faculty be considered responsible for their illness, may be ruthlessly ostracised by frightened people, and potentially represent a greater threat because, unlike the already stigmatized, they are not as easy to identify.
>
> (Sontag, 1989, p. 26-27)

Aims Of The Questionnaire

The main aim of my questionnaire was to explore how the global politics of blood had impacted on the UK haemophilia community by enabling haemophiliacs and their partners to express their thoughts and opinions on this issue. I wanted to identify the key themes highlighted by the haemophilia community itself and I was particularly interested in investigating the interpretation of shared symbols which bind together a group of people (in this case infected haemophiliacs) as identified by Clifford Geertz (1973). I set out to explore the identity politics of the haemophilia community through the symbolism of particular words such as "blood", "haemophiliac", and "HIV positive". I also wanted to establish how this infected community viewed the institutions that were supposed to provide safe treatment, care and support to some of the most vulnerable members of society. I had always been impressed by the positive attitude of many within the haemophilia community in the face of adversity and wanted to discover what disempowered and empowered those infected with blood borne viruses. Did empowerment largely emanate from a person's internal psychological resources or externally through the support of institutions, or was there a combination of both.

I was also able to critique the work of Foucault by drawing on participant responses and examining further the power relations in the field of medicine. A Foucauldian perspective (in Peterson and Bunton, 1997, p. 99) argues that "it is impossible to remove power from members of the medical profession and hand it over to patients". My criticism here is that this statement implies that all patients are passive and others always act on their behalf. Foucault ignores the possibility of a patient taking the initiative to seize back some control within the clinical setting. It can be argued however through analysis of the questionnaires that once a patient gains knowledge about his/her medical condition and asserts the right to view personal clinical records he/she can then make informed choices. The patient can then take appropriate action where necessary and bring about a shift in the balance of power. He/she can empower themselves by challenging treatment strategies, educating others and setting up self-help, campaign and support groups.

I chose to utilize the questionnaires not as a systematic scientific method of data analysis but simply as a tool to elicit key themes within the haemophilia culture that dominate the lives of those infected. I have been able to categorise the main subjects presented by haemophiliacs under three broad headings, symbolism and identity, betrayal of trust and inadequate response, and disempowerment/empowerment. When Geertz attempted to define an interpretive theory of culture, he wrote that "cultural analysis is (or should be) guessing at meanings, assessing the guesses, and drawing explanatory conclusions from the better guesses, not discussing the Continent of Meaning and mapping out its bodiless landscape," (1973, p. 20)

The Study Group

I sent out 40 questionnaires to haemophiliacs and their partners and 24 replies were received, 4 questionnaires were rejected as they were returned without signed informed consent forms or were returned too late to be included. There were 12 haemophiliacs in the group aged from 41 to 65 years and 8 partners aged from 32 to 68 years. The partner group consisted of 4 wives, three widows and one partner. The questionnaires showed that 1 haemophiliac was female and one participant in the partner group was male. There were 8 haemophiliacs who identified themselves as co-infected (infected with more than one virus in this case HIV and HCV) and 4 were mono-infected (infected with one virus, HCV). The partner replies showed that 4 of their haemophiliac partners were co-infected with HIV/HCV and 4 were mono-infected with HCV. In the haemophilia group 6 stated that they had been exposed to vCJD and 6 didn't know their vCJD status. In the partner group 4 partners stated their haemophiliac partners had been exposed to vCJD, 3 did not know and 1 partner stated her haemophiliac partner had not been exposed to vCJD.

The haemophilia community is a very small group within society at large and within this group only a tiny number come from an ethnic minority background. Those that returned the questionnaires all came from the White British ethnic category with representation from England, Scotland and Wales with the exception of one partner who described herself as Irish. There was unfortunately no representation from other ethnic groups I am aware that individuals that did contribute to research projects in the past were from an ethnic minority background and have since died. In order to respect confidentiality each haemophiliac was given the letter H followed by a number as a mark of identification for example- H14. Similarly each partner was identified by the letter P followed by a number for example- P6. The responses to questionnaires are printed in italics.

Symbolism And Identity

Jean Seaton (2005, p. 26) states that:

> Blood may be less prominent in how individuals think of themselves than it used to be, in part because it has been medicalized and rendered less mysterious. The rise of genetics has also meant that blood and heredity are now separated. In the past there were "bloodlines" and "blood feuds" and blood itself was seen more directly as the carrier of social and individual identity. Yet blood is still unpredictable but vital.

In my questionnaires I was interested to discover what the word "blood" meant to the haemophilia community in terms of a shared identity. I discovered that the word has been collectively re-defined by many haemophiliacs from its literal meaning of "the red fluid circulating by means of veins and arteries" (Cassell's English Dictionary, 2000, p. 134) to a single word in some cases signifying *"death"* H1, *"poison"* H13, "*disease*" H12, and *"trouble"* H15, or a negative phrase such as *"a sesspit* (sic) *of infection"* H17. Although some participants gave a text book answer and used positive terms such as *"life blood"* H12 and *"essential for the body's survival"* H8, most haemophiliacs produced extended meanings which were incorporated into their personal identity and also bound individuals together. H8 emphasises the shared experience of haemophiliacs when he defines blood as "*a word and substance that has decided the direction of my life in terms of what I can* *and cannot do.*" Blood has also become a symbol of ethics to haemophiliacs with H14 defining the word as "*one substance produced by the human body that no other human being has the right to sully, tamper with or destroy.*" The definition of the word blood was frequently ambiguous to participants: a substance that was supposed to enhance the quality of life had ultimately become a symbol of death. There was underlying anger that blood described by P1 as *"something that should keep you alive"* was according to P13 *"unknown, unproven, unpleasant"* and regarded by P11 as an *"infection, needless contamination, pain, suffering, death."* P14 summed up her feelings in the following statement: *"If I hear the word blood, I think HIV + and all the other problems we have to deal with."*

In the same way that "blood" has developed symbolic and extended meaning so too has the word "haemophiliac" which to H21 has become synonymous with *"somebody who is probably HIV + Hep C (now)."* Although a few participants interpreted "haemophiliac" purely as a person with a blood clotting disorder, H8 echoed the majority when he wrote that haemophiliac *"means a lifetime of bleeding into joints and muscles causing severe physical pain and disablement together with resulting psychological stress and social isolation.*" H2 interprets "haemophiliac" as meaning *"a hard, lonely and painful life"* whereas to H15 the word symbolises *"someone who is faced with an uncertain future in life. Not being able to make plans for the future, a walking time bomb. Someone with the word caution tattooed across their heads. Handle with care."* Participants' answers incorporated the common fear of how haemophiliacs are viewed by others in society and their own fear of infecting loved ones.

The only female haemophiliac in the study H14 identifies being a haemophiliac with *"bleeding, pain and suffering."* She also highlights the gender discrimination she experiences as a female with a bleeding disorder, being in a minority group, receiving treatment within a paternalistic system and having a genetic condition usually identified with men. She describes *"being treated with contempt by haematologists* (sic) *because I was not atypical of the condition as a woman with Haemophilia "A" and having to prove my being a symptomatic haemophiliac by bleeding first and then treated after the event – reactive not proactive. My entire life has been a medical learning curve for GPs and anyone I have contact with in the course of haemophilia care. I have been the educator!"* The response from H14 again calls in to question Foucault's general notion of the patient as a passive recipient of treatment, here this particular patient uses her lived experience and acquired knowledge of her condition to take back some control from the professionals. The questionnaires show that haemophiliacs are aware that they are often seen as victims but they also demonstrate that this word does not necessarily equal passivity. It is important that those who engage with the haemophilia community understand that the level of a person's action in empowering themselves is often hindered by their very poor physical condition and chronic fatigue. Haemophiliacs may wish to take a more active stance in fighting for their rights but they can also become resigned to remaining passive through extreme ill health.

P11 highlights a shared interpretation of the word within haemophilia culture as *"someone who has been neglected, ignored and treated like a second class citizen by the very Government that allowed haemophiliacs to become infected."* P13 writes that *"maybe for the older haemophiliac it is too late to make any decisions in life maybe they* *have already been made for them!"* This last statement signifies the feeling of loss of control, helplessness, resignation and inevitability of outcome now felt by many within the UK haemophilia community. In countries such as Eire where haemophiliacs received better support from their Haemophilia Society which helped empower infected patients the meaning of the word "haemophiliac" has changed to become a symbol of strength, resistance, and determination as identified by Daly and Cunningham (2003). This demonstrates that words do not always have a static symbolism within society.

Participants were also asked to identify what they thought the word haemophiliac means to the general public. One popular misconception was identified by H12 who stated that the public interpreted the word haemophiliac as *"a bleeder- if you cut yourself you will bleed to death"* whilst P7 identified society as having *"a perception that the bleeding is external."* H16 believed that the public saw a haemophiliac as *"somebody who is HIV positive has AIDS or who is a leapor* (sic)*."* P13 summed up a common feeling within the haemophilia community, *"I would be surprised if the general pubic* (sic) *know what the word means, never mind how it afects* (sic) *someone."*

How then did participants interpret the words "HIV positive?" In conversations with other infected communities such as the gay community I discovered that there is now a more positive outlook on life for those infected. The use of antiretroviral medication means that HIV is no longer necessarily equated with terminal illness but is seen as more of a manageable chronic disability with some infected individuals even returning to full-time employment. A minority of the haemophilia community reflect this attitude but to the majority the outlook is bleak as many haemophiliacs are also co-infected with hepatitis B and C in addition to the difficulty of living with the painful condition of haemophilia, and the resulting problems of arthritis and permanent joint damage. H21 saw being HIV positive as *"an illness waiting to happen and part of my life not to be discussed"* which reflected the stigma and isolation felt by many others. H12 stated that *"being HIV positive means that life can never be the same. A life of concern, ill health and constant battles, medication, hospital intervention and restricted prospects."* P17 felt that *"it means the 'death penalty' no possibility of a family or a normal relationship, more hospital visits 'stigma attached to it' a sexual transmitted disease, predominatly* (sic) *within the gay community, rarely within the hetrosexual* (sic) *community, drug addicts, who would have thought that a haemophiliac with all the problems associated with it would end up in such dire straights, normal life ceased to exist for the next 15- 20 years."*

Some participants associated the disease mainly with the gay and drug using community which was the case at the time that most haemophiliacs were infected with HIV in the early to mid- 1980s and the disease for haemophiliacs is forever linked with treatment from "high-risk" donors. Today however the virus is very much established as an issue for heterosexuals also. The response given by P7 is typical of many as she sees being HIV positive as *"pain, fear, humiliation, intrusion, loss of control. A relentless cruel and terminal game of 'space-invaders' where no matter how many attacks you fight off, they just keep coming, faster and harder. No matter how sharp your game, how bravely you play, eventually you are fighting on so many fronts you're overwhelmed. There is no rest, no respite, and no off switch."*

My questionnaires illustrate that there is little difference in the way infected haemophiliacs and their partners interpret the words "HCV positive" compared with the term "HIV positive." H17 wrote that *"'HCV Positive'" means that I have as equally a serious problem as somebody infected with 'HIV'."* H12 viewed being HCV positive as *"living with a virus that is able to cause my liver to scar and eventually become inflamed and cancerous. HCV+ means stigma, fear, worry, ill health, tiredness, nausaeus (sic) and more contagious than HIV. Being HCV+ could be fatal to me. It definitely impacts on my daily wellbeing."* P7 a widow, refers to being HCV positive as *"the one we were told was harmless! Huge distended abdomens and wasted arms. Exhaustion (or was that the HIV?) The complaint that flares up when you're treated for HIV related lymphoma. The 2 for 1 disease according to the government! The one on my husband's death certificate, given as secondary to haemophilia as though there was a causal link that somehow excluded infected blood."* The answers provided by participants also emphasise the state of denial demonstrated by many within the medical profession and a failure to openly acknowledge the serious nature of the patient's condition. This could perhaps be interpreted as a coping mechanism for doctors who feel the need to distance themselves emotionally from the contamination of their patients. There is a clear void in relation to how patients view their condition and the views often expressed by the medical profession. It could also be argued that doctors subconsciously adopt a paternalistic attitude where they feel the need to protect dying patients from the truth in relation to the seriousness of their medical condition.

Participants were asked to explain what the phrase "exposed to v CJD" meant to them. H13 who was exposed to vCJD explained that it signified *"a very uncertain future, unfortunately the medical profession don't know what is in store in the future."* H14 felt that vCJD was *"preventable"* and writes *"I have had 6 exposures to CJD through plasma* *and live in fear of developing this disease. The letters CJD should mean 'Criminal Justice Denied.'"* P7 the widow of a haemophiliac fears *"the dreaded 'next wave.' The uncertainty of living not knowing if my husband had it. Having samples stolen from his body (PM report) to find out but not being told the result. The awareness that successive govs* (sic) *had learnt nothing from the two previous disasters except slicker ways to cover –up."* Throughout the questionnaires the phrase "exposed to v CJD" symbolised fear and uncertainty and a feeling that the Government had once again withheld information from families.[1] The answer provided by P7 again demonstrates how doctors maintain power by controlling the flow of clinical information and exclude relatives from the decision making process: the widow finds out that her husband is being examined post mortem for the presence of vCJD only by chance after the investigations have taken place.

Participants were also asked to explain what the word "disabled" meant to them. H4 who puts himself in the category of "disabled" writes that being disabled means *"a person who has a limited capacity to perform and live a life without taking into consideration the consciequances* (sic)*."* H8 adds to this stating *"my body is badly deformed causing pain and discomfort in everyday life and restricting my ability to do the things I want to do with my life."* H14 explains that it means *"I was born an able person but that has changed by the NHS treatment that was supposed to 'make me better."* The reply from H14 demonstrates that she did not see herself as disabled before she became infected with HCV but she now blames the Government for making her *"disabled"* and cites their failure to implement a self-sufficiency policy and a reliance on imported treatment.

H8 reflects on his reliance on others stating, "*I have to pay others to do things I could do better*" while to H13 the word signifies being "*unable to reach one's potential in life, discrimination, pain suffering, which is only going to get worse due to other peoples ignorance.*" P17 a widow writes that being disabled "*has degrees of disadvantage that is measured by the benefits system, many occasions this process produces unfair results, medical practitioners and experts should be more involved in the process.*" P12 the husband of a haemophiliac equates his own sense of "disability" with a failing to understand the disability of others, he writes, "*Would I see myself disabled? Physically no, but mentally yes, because again even as an informed person I still struggle to see or recognise a disabled person.*" Participants in the study go beyond defining the word "disabled" in terms of the individual and incorporate a wider interpretation, the family unit itself is perceived as "disabled."

In the haemophilia community the words "disabled" and "carer" often go hand in hand. The following two descriptions provide firstly the view of a haemophiliac that has relied on a carer to assist with day to day living and secondly the view of someone who has been a carer. H14 gives a detailed description of what the word carer means to her "*I underwent the harrowing and painful treatment interferon/ riboviron* (sic) *and had to totally rely on my husband to look after me and my child, whilst trying to work and look after our home.* She writes "*the experience was frankly hellish and truly tested my husband's promise to look after me 'in sickness and in health.' How many relationships do not survive because of the enormous task of becoming a carer? The 'carer is greatly undervalued and sadly the Government take full advantage of that.*" P17 who was herself a carer states "*a carer has many meanings, those that care for others, that the local* *authority determine are unable to care for themselves and need the protection of the state/public, the community care act enabled this, following the acceptance of the human rights act in 1996. For myself it meant 24-7 "care" of my partner/husband with very little reward or respite*." The responses of the participants reflect the lack of support carers receive from the Government and the fact that many haemophiliacs would not be able to function in the community without this 24 hour care. This is seen as both positive by haemophiliacs in terms of quality of care and understanding of the illness/ disability by the carer (who is often also the partner) but negative in terms of pressure on the relationship. The answers received also reflect how much carers have given up themselves which although recognised by the haemophilia community is often ignored by the State.

Betrayal Of Trust And Inadequate Response

Throughout the questionnaires there was an overwhelming feeling from participants of feeling let down by the institutions designated to care for them. H15 reflected the majority view that the medical profession had responded to their contamination *"very, very poorly."* H1 gives an account of his own personal experience, *"When I was told by my consultant at the Newcastle RVI I was HIV positive at the same time he told me I would have to use up all unheated products in the fridges before going onto the new supposedly virus free heat-treated products. On asking if I would be re-infected by using up unheated treatment my consultant said he did not know. I feel we have just been used even up to the present time as a long-term study."* P14 felt that doctors *"don't want to know"* while P11 saw doctors responding *"with indifference and contempt."* H12 writes

" with contempt- with malice. The doctors in the 80s never told us the truth about risks, never told patients the truth about tests being carried out on them or where treatment was sourced.

P17 felt that there was *"no support"* while P7 saw the doctors response as *"very variable"* but acknowledged that *"one wonderful doctor, Dr Sweetenham, was very helpful but he struggled to drag his staff along with him."* P7 once again identifies denial as a response and recalls the following conversation with a doctor, *"I see your husband has picked up HIV along the way, (on pointing out he didn't pick it up) he was given it, 'well it's the same thing.'"* P7 then writes of a similar attitude after her husband became infected with hepatitis B, *"letter between doctors, 'he seems to have picked up Hep B along the way, he doesn't know yet, we'll cross that bridge when we come to it.' After my husband died I discovered his notes were marked DNA (do not resuscitate) neither my husband nor I were asked about this."*

H14 describes the medical profession responding by *"removal of medical records and refusal to give access to medical files." The most heinious* (sic) *crime of all was to deny haemophiliacs informed choice of treatment when there were safer options by quoting 'the benefits outweigh the risks.' I also believe that they closed ranks by refusing to support a public inquiry into the 1,400 dead haemophiliacs."* H17 states *"I believe all 'haemophiliacs' have been medically raped!"*

The questionnaires identified that 19 out of 20 participants believed that they or their partners had not been asked their permission with regard to "informed consent" to testing for HIV/HCV or with regard to their treatment. The following replies are typical of the responses received. H2 stated *"they never asked to test, never told us the results until they* *had to. Never informed us at any time of the risks. They did not ask because they did not want us to know what they already knew."* P12 explains that *"it has been frightening to discover over the years that doctors knowingly infected patients with contaminated blood products. I have even witnessed a doctor claiming 'it was worth the risk' to use contaminated clotting factor but didn't feel it necassary* (sic) *to inform the patients* (sic) *family of the risk so they could make an informed decision."* P17 writes *"always it was a battle the curtains were closed once the contamination was realised, they knew that compensation would be an issue therefore from day one they closed ranks the fight was on."*

The haemophilia community felt a similar inadequate response was shown by Government. H5 and H16 thought that the Government had *"brushed things under the carpet."* The words *"cover-up"* was repeatedly used and H14 believed that the Government had *"wilfully destroyed public records in their determination to keep the truth of the disaster hidden from the general public"* and there was a *"refusal to be accountable."* In addition to this P7 thought that the Government *"had failed to learn from their mistakes"* and H1 felt that the Government had *"not had the decency to apologise for this tragedy, the worst in the history of the N.H.S."*.

Participants were asked for their opinions on the Macfarlane Trust which was set up by Government to provide financially help to haemophiliacs infected with HIV. (See Appendix B). H8 thought that the *"level of service was variable depending on experience and/or training received."* P14 expressed that to approach the Trust for items *"feels like begging with all the forms to fill out for a new dryer"* while P1 supported this view adding that it *"seems to be run on DSS guidelines."* H16 thought that the service provided was *"generally good, but they change all of their policies from month-month."* H12 believed that the Macfarlane Trust had been *"set up to keep us quiet in 1990. The service has been extremely poor"* he also felt that *"staff have been corrupt."* [2] He writes that the MFT are *"selective with registrants, out of touch with our needs at times and unresponsive to our actual real concerns. Payments pay the bills and keep me ticking over –that's all- I survive under national average income with more than average life costs."* (H1) felt that *"one off grants are more difficult to get, only half the cost of an item is sometimes given."* (P17) felt that *"the Trust has responded with adequate support, however the social services dept's* (sic) *are almost unaware of its existence and we have to constantly suffer the opening of old wounds by having to explain to the social services where my money is sourced and why the interest is exempt from social services calculation of benefits (sic)."*

The Skipton Fund set up to administer payments to those infected with hepatitis C and administered by the Macfarlane Trust was generally seen as failing to meet the financial needs of registrants. H13 thought that the payments are *"totally* (sic) *inadiquate* (sic) *and an insult to all haemophiliacs and their families"* while H16 felt that *"we will only get it when it's too late."* (H2) felt that the payment *"does not reflect what we have gone through, what we are continuing to suffer or the further limits it has put on our lives".* There was also an overwhelming feeling of anger expressed within the questionnaires with regard to the fact that many widows were excluded from the Skipton payments. P14 felt *"disgusted, they have as much right to that money (as pathetic as the amount was) as their partners"* while P11 felt that *"all carers, partners, widows all of whom have been ignored by the Government deserve inclusion in the Skipton Fund."* The differences between the two schemes were also highlighted with H8 pointing out that *"the scheme should have operated under the same guidelines as the two HIV payments i.e. payments should be made to the estate of those deceased."*

Participants also expressed anger at the unethical practice and the power held by the plasma companies, P7 provided a typical response *"these people are no better than arms dealers or drug traffickers"* she thought that the contamination of haemophiliacs was *"in some ways predictable given the unrestrained power of large companies"* she added that what the companies wanted was *"profit at all costs."* There was a common feeling that the British and UK governments were complicit in allowing the companies to carry out unethical practice and not being held to account for their actions. H1 provides a typical response writing of his *"extreme anger"* (underlined) stating *"how these companies have not been held accountable for their actions against the haemophilia community is beyond belief. These companies must have realised the places they were sourcing blood from were very high risk areas. i.e.:-* (sic) *prisons, drug users.* H12 goes on to say that he feels *"hatred- the worst thing is I still have to use their products"* he continues by stating *"it screws me up. Their shareholders are still pocketing on the back of my illness."*

The Haemophilia Society, the national organisation representing the interests of the haemophilia community was viewed by H5 as responding to the contamination tragedy of haemophiliacs *"very slowly and with more concern for their relationship with pharmaceutical* (sic) *industry than their own members."* H4 saw this as being related to the fact that they are *"concerned with their own actions and the loss of funding which they need to exist"* a point echoed by H13 who wrote *"it seems that they are in the Governments pocket with regard to their funding."* One partner P7 vocalised the opinion of the majority when she stated that the Society had responded *"with cowardice. Not wishing to upset the apple-cart we were marginalised. Things have improved a tiny bit but they failed to show leadership or act as a rallying point. In occupying a position of authority and failing to take action, they undermined the efforts of those trying to get an inquiry."* The view of the organisation is now changing a little however as new staff take over the reins, H12 writes *"the society have at least turned the corner and are now pursuing campaign aims and truth for its patients. In the early days they were part of the contamination system, backing up doctors rather than patients."* P11 states *"I think they are limited in what they can do by the Government cover-up."*

Participants' views on the legal profession were mixed. H13 thought that the lawyers that represented infected haemophiliacs were *"frightened by the Government"* while H15 felt that *"they started off with good intensions then faded very quickly when (Big Wigs) got to them."* P17 replied that the legal profession had *"sold the group short, we were told if we didn't accept the offer we were on our own. Blackmail is the term that should be used."* H16 stated *"I like to think they are trying their best."* Participants viewed their American legal representatives generally in a more positive light than the lawyers that represented haemophiliacs against the UK Government. H17 an HCV positive haemophiliac identified that he had been unable to get to court *"in spite of trying no fewer than (5) groups of solicitors, I am still waiting 18 years on, there is only one answer to all this, its called – ! Conspiracy!* (underlined)" H8 wrote that *"the legal profession has consistently failed the haemophilia community. They supported a government waiver preventing HIV infected haemophiliacs from pursuing compensation for hepatitis viruses and did so knowing many more were infected with hepatitis C."*

Participants were also asked to comment on how the media had responded to the infection of haemophiliacs with blood-borne viruses, again views were mixed. H2 believed the press showed *"disinterest"* while P1 thought that the media was *"very positive at times."* There was a general feeling expressed that the media were to some extent controlled by Government and P12 thought that *"the media is more interested in Posh's hair extensions than trying to bring the Government to task."* H8 felt that the media response was *"to sensationalise and misrepresent the risk of infection"* referring to haemophiliacs as *"ticking timebombs."* P7 believed the media had *"their own agenda"* and that the interest generated by press articles was *"shortlived."* H5 deemed that a haemophilia story *"does not sell enough"* however some participants chose to acknowledge specific newspapers that had been supportive to their plight.

Disempowerment/Empowerment

Participants were asked to describe what had disempowered or empowered them in their fight for justice and recognition of their infection. There was a general consensus that fear and prejudice from others disempowered the haemophilia community as those infected chose to remain anonymous in order to protect themselves and their families. This led to what H16 described as *"living two lives"* a common issue in the haemophilia community where many prefer to keep their viral status hidden sometimes even from close family members. In some cases there was also an element of denial or trying to ignore the issues around infection. The pressure from living with HIV/HCV had in some cases led to marriage breakdown and isolation from the wider community. The majority of participants however gained great strength from family and friends that helped to empower them.

The depression that arose from constantly seeing fellow haemophiliacs die was disempowering for some as they fought to stay motivated. P12 writes *"sadly the light that once shone bright is now only a flicker struggling to stay alive."* Haemophiliacs and partners felt that they had been disempowered by the medical profession withholding their medical records and failing to allow them informed choice in their treatment. Illness from viral contamination, and arthritis and joint damage from haemophilia were also seen as disempowering. The feeling of the unknown led some participants to live life day by day as it was difficult to plan for the future. Self-belief and a need for justice were also strong motivating factors for haemophiliacs and partners to empower themselves. They did this by employing practical solutions such as utilizing the media to highlight their stories, accessing their medical records to educate themselves and others and initiate litigation, and also by fighting for the best possible treatment available. H1 empowered himself by *"putting posters up in my local hospital (RVI) to inform people just what had happened to us through contaminated treatment and how the Trust and Government were actually playing it down."* This again challenges the Foucauldian view of the passive patient. Some participants also criticised the Haemophilia Society for not offering enough support and the Government and the DSS for not providing enough practical and financial help to those infected. Many within the haemophilia community chose to seek support from others in the same position and empowered themselves by setting up their own campaign organisations and self-help groups. However there was also a recognition that a lack of cohesion among the groups and different agendas had at times disempowered the haemophilia community.

Participants were asked what had helped them to maintain a positive outlook on life. H14 reflected the positive attitude displayed by many within the haemophilia community when she identified that what helped her was *"a good healthy sense of humour and a bloody minded determination never to give up on what life I have despite the NHS, doctors, the UK Government and the plasma companies efforts to destroy and take it away from me."* The answers received showed the importance of support from family and friends in empowering individuals to take control of their lives wherever possible. The politics of the global blood trade had brought about a catastrophe within the haemophilia community which led to the majority of haemophiliacs and their families bonding together in their adversity. The questionnaires demonstrate that haemophilia culture has experienced a period of evolution and adapted to incorporate a shared symbolism of collective values and grievances as a means of interpreting the world of disability and disease. It is also evident that haemophiliacs have re-evaluated the institutions involved in their care as part of a cultural shift from passivity to activity and remain positive through a strong desire to fight back at the systems responsible for endangering their community and obtain justice for the living, the dead, and the bereaved.

Notes

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[1] This is borne out by evidence in letters where a plasma company knew that haemophiliac patients were exposed to v CJD and decided to withdraw the treatment but not tell haemophiliacs the reason for this see (Appendix A). The Government finally in initiated a look-back study after campaigners confronted the

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Government on the issue of the "right to know" of exposure to v CJD when they became aware of the letter in 2000.

[2] This last statement refers to the alleged embezzlement of the Trust and stealing of around £450, 000 by a staff member who is currently awaiting trial. (Conversation with Martin Harvey, Chief Executive of the Macfarlane Trust in 2006).

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 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
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
PTH	Post-transfusion hepatitis
PFL	Plasma Fractionation Laboratory
RHA	Regional health authorities
RIBA	Recombinant immunoblot assay
RTC	Regional transfusion centres
RTD	Regional transfusion directors

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