

## 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 Krinsky 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 9<sup>th</sup> 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 26<sup>th</sup>, 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 30<sup>th</sup> 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.<sup>1</sup> 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.<sup>2</sup> 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 22<sup>nd</sup> 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 6<sup>th</sup> 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 17<sup>th</sup> 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.<sup>3</sup>

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) (Bradburne, 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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<sup>1</sup> 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.

<sup>2</sup> Skid-Row- a quarter inhabited by alcoholics and vagrants (Cassell's English Dictionary, 2000, p. 1174).

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<sup>3</sup> 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)