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 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."
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> (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

[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.