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 – ! <u>Conspiracy!</u>* (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

---

[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

---

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).