

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 American 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 foreseeable 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 Tuskegee Syphilis 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.