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Don't let the sun go down on me: The relationship between gay men living with HIV and their physicians (Immune deficiency)

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Don't Let The Sun Go Down On Me:
The Relationship Between Gay Men Living With HIV and Their Physicians

by

Adele Parkinson-Heyes

Bachelor of Arts, Wilfrid Laurier University, 1990

THESIS
Submitted to the Department of Psychology
in partial fulfilment of the requirements for the
Masters of Arts degree

Wilfrid Laurier University
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Dedication

To my friend Bill, whose life I will ever celebrate, whose friendship I will always cherish, whose death I still grieve. After a lengthy fight with AIDS, Bill died on February 10, 1995 but not before he touched the lives of a great many people... especially mine. Thank you Bill, I love you.

Acknowledgements

To the men who courageously shared their personal stories with me, I say a sincere thank you. If not for each of you this thesis would not have come full circle, you truly are the wind beneath my wings. My promise is that the sun will never go down on you...not while I am around.

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To my Mum and Dad, for always being close in my heart though many miles away.

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To my dear friend Judy whose friendship is a true gift from the spiritual realm; you were right, turtles do finish.

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To Karen, Steve and Maddison for celebrating my triumphs, however small, and for cushioning my sometimes unplanned landings with soft hugs.

To my 'constant friend' Jim for being a supportive friend and a pleasant distraction.

And finally to 'my kittens' a.k.a. Hastings for his unconditional love and constant companionship in the 'wee' hours.

ABSTRACT

In this thesis I examine the doctor-client relationship from the perspective of gay men living with HIV. I asked six gay men living with HIV the following open-ended question "Could you tell me about the relationship you have with your physician?" during in-depth interviews. I used narrative analysis to interpret the verbatim transcriptions of each interview. In the findings section I present each man's story in his own words supplemented with my interpretative comments. The findings revealed that gay men living with HIV had both positive and negative experiences in their relationships with physicians. I identified two contrasting themes: connection versus disconnection and empowerment versus disempowerment which capture the overall experiences of the men. I presented the findings from four interviews to medical residents at the University of Western Ontario for the purpose of educating future physicians about the doctor-client relationship for gay men living with HIV. I conclude with thoughts for future research into this understudied topic and with personal reflections of the meaning of this thesis for me.

Preface

This thesis was an incredible journey. The work has been extremely rewarding, very touching and at times quite sad. I began on my journey without making a conscious effort to do so. In 1992, AIDS touched my life intimately. I learned that a very dear friend was HIV positive. Over the past years, I have listened to my friend describe his relationship with his physician using words such as empowering and respectful. The more Bill and I talked, and the more I listened to his stories, I began to wonder about the relationship other people living with HIV infection had with their physicians. I pondered answers to the questions; "Is it important to a person's physical health to have a doctor-client relationship which is empowering?", " Are people living with HIV disease, an exception in the amount of control they want over their health care?" , "Are physicians trained to engage in shared decision-making?".

I began by immersing myself in information about HIV disease and AIDS. I met with members from the caregiving community, a physician, a peer counsellor, an HIV educator and nurse, and a positive-approaches coordinator to familiarize myself with the issues surrounding HIV disease. I spent hours and hours in conversation with my friend Bill discussing the dynamics of his relationship with his physician. I also read a great deal of literature pertaining to the psychosocial aspects of living with HIV disease and the doctor-client relationship. In addition to this academic body of literature I also read personal stories of people living with HIV disease such as Arthur Ashe's biography, Days of Grace (1993), and newspaper and magazine articles. Every single person I told about my thesis had a story about an experience of someone they knew or something they had read or heard in the media. I learned that AIDS has touched the lives of a great many people. It is my belief that AIDS has touched all of our lives as it has had a huge impact on our society.

The title for my thesis comes from a song written by singer/composer Elton John. The song was written in 1974, long before the AIDS epidemic began, but the words seem to reflect both the tragedy of a life ending too early and the fear AIDS has created in our society.

Don't Let The Sun Go Down On Me

I can't light no more of your darkness
All my pictures seem to fade to black and white
I'm growing tired and time stands still before me
Frozen here on the ladder of my life

Too late to save myself from falling
I took a chance and changed your way of life
But you missed my meaning when I met you
Closed the door and left me blinded by the light

Don't let the sun go down on me
Although I search myself, its always someone else I see
I'd just allow a fragment of your life to wander free
But losing everything is like the sun going down on me

I can't find oh, the right romantic line
But see me once and see the way I feel
Don't discard me just because you think I mean you harm
But these cuts I have oh, they need love to help them heal

Elton John
Source: Elton John Live in Australia album (1987).

Throughout my thesis you will notice that I describe the participants as people <u>living</u> with HIV disease and physicians who have <u>chosen</u> to care <u>about</u> people living with HIV disease and

AIDS. I have chosen these words with a specific intent. First, I believe that the emphasis must be placed on living with this illness as opposed to dying of it. Statistics are showing that people with HIV disease are living an average of ten years (Maclean's Magazine, 1999). They are people first, who just happen to be ill, second. In my opinion it is imperative that people living with HIV disease are empowered to take control of their lives and their illness.

Secondly, I believe that the majority of physicians who work with people living with HIV disease have chosen to do so. From readings and conversations I have had with a few physicians about my thesis, it is apparent that it takes a special kind of person to face the challenges associated with caring about people living with HIV disease.

Thirdly, I use the term caring about rather than for, since I believe the word "for" denotes that someone is unable to do the activity him/herself and he/she requires assistance. Again, it is imperative that people living with HIV disease are empowered by their physicians to actively participate in the treatment of his/her illness.

This thesis is the culmination of unstructured interviews with six gay men living with HIV disease. I met with each of the men on two occasions and with two of the men more than four times. In total I spent a minimum of three hours with each man, up to a maximum of six hours. Although I had created an interview guide based upon my discussions with members of the caregiving community, I did not use it. Most of the men were quite comfortable in their role of storyteller, while others wanted me to pose questions to begin the interview process. However, as the interview progressed, all of the men talked openly and with very few questions or guidance from me. During most of the interviews I simply used basic listening and attending skills: nodding, saying "uh hum" and paraphrasing. Throughout other interviews I found myself playing more of an active role often engaging in discussions about societal views and treatment of persons living with HIV disease. I also had the opportunity to speak with the mother of one of the participants and two partners of men who are HIV positive. These engrossing conversations gave me even more depth into understanding the experiences of living with HIV disease.

The ultimate purpose of the study was to understand more fully the dynamics of the doctor-client relationship of gay men living with HIV disease. In light of the fact that I began each interview with "Could you tell me about the relationship you have with your physician?", each person shared with me a great deal more. I learned about issues of sexuality; the stigmas attached to being gay, being HIV positive and being both HIV positive and gay; the importance of a supportive environment and diverse coping techniques. These insights helped me to understand more fully what it is like to be a gay man living with HIV and are touched upon in the thesis.

Throughout this study I paid particular attention to the issue of confidentiality. I highlight this fact because it has shaped the extent to which I can describe the participants. Some of the men shared with me their age while others did not. I know the occupations of only four of the men. Information was revealed to me as it related to their specific story. One man shared with me his age as he described his anger at being 26 years old and having to see a doctor every month. Another man explained that it was difficult for him to find work as a cook since a great many people were aware of his health status. I was given permission by some of the men to share any information about them, including their names, while for others most personal information was deleted from the transcriptions.

Support for me was also something on which I needed to concentrate. As I reflect back, I realize that I received most of my support from the men whom I interviewed. They became my friends and I found myself sharing with them my grief over my friend Bill's death. In this case they were the experts, each of them had experienced the death of a close friend, and I found true comfort and compassion in their kind words and warm hugs. Bill was my first friend to die from this horrendous disease.

When I first began my thesis a number of people asked me what would happen if Bill were to die before my thesis was finished. I simply told them that if Bill lived I would do my thesis with him, and if he died I would do it for him. As my dedication says, this is for Bill.

The layout of this thesis is as follows. In Chapter 1 I review the literature pertaining to community psychology and AIDS, the incidence and prevalence of HIV/AIDS, the issues experienced by gay men living with HIV, and the doctor-client relationship for gay men living with HIV. Methodological issues are addressed in Chapter 2 including a literature review of narrative analysis and a description of my personal approach to this qualitative method. I present the findings of this study in Chapter 3 which includes each man's story and my interpretive comments, and a summary of the mens' stories presented in the form of a community narrative. In Chapter 3 I also present a summary of the talk I gave to medical residents at the University of Western Ontario. In Chapter 4 I discuss the findings of my study in relation to the literature and conclude with thoughts for future research and my personal reflections of the meaning of this thesis for me.

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CHAPTER 1

REVIEW OF THE LITERATURE

Community Psychology and AIDS: A call to action

Community psychology recognizes the interdependence of elements in a social system and believes that disabling environments can and do contribute to persons' social and health problems (Heller, Price, Reinharz, Riger & Wandersman, 1984). It is my opinion that community psychology as a discipline has a great deal to offer to the fight against AIDS. I am not alone in my view, as researchers and community psychologists J.R. Newbrough, Raymond Lorion, Stan Schneider, Linda Garnets, and Anthony D'Augelli also believe that it is imperative that community psychology accept the challenges associated with this epidemic.

Community psychologists possess the skills to design community-level prevention programs which could contribute to inhibiting the spread of this disease. We are willing to promote and support self-help groups and grass roots interventions enabling those most affected by this disease to build and strengthen their own social support networks, and finally we are committed to enhancing the possibility that people living with HIV can more actively control their own lives, in keeping with the construct of empowerment (Rappaport, 1981). Community psychology also has at its core a commitment to working with the underserved, disenfranchised, and oppressed people in our society.

It is my belief that people living with HIV are an oppressed group of people. In contrast, I believe that physicians are a powerful group of people. Therefore, it is the main purpose of this thesis to explore the interaction between gay men living with HIV and their physicians. My advocacy position for gay men living with HIV is clearly demonstrated throughout this thesis as I present only the stories and experiences of the gay men living with HIV whom I interviewed. In keeping with the values of community psychology, it was essential to me that I design and conduct a study which gave a voice to this underserved group of men. In this next section I will highlight what it is like to live with HIV with an emphasis on the experiences of gay men.

HIV and AIDS

It is rare during the present times to watch a television program, read a newspaper, or flip through a magazine without encountering some form of information about the disease known commonly by the acronym AIDS. AIDS stands for Acquired Immune Deficiency Syndrome. AIDS is the result of acquiring or becoming infected with a virus (HIV) that attacks and destroys the helper T cells of the immune system, rendering the immune system deficient and unable to fight off infections and diseases (Soloman & Temoshok, 1987). Usually AIDS is diagnosed through the presence of an unusual opportunistic infection that results from the impairment of the immune system.

HIV stands for Human Immunodeficiency Virus. It is this viral agent that is transmitted by the exchange of body fluids, especially semen and blood, and leads to the diagnosis of HIV positive. The virus may lay dormant within helper T cells for many years with no visible effects, or it may begin growing very rapidly within the first few weeks of infection and spread throughout the body. The early symptoms associated with the HIV virus have been experienced by all of us as our bodies attempt to fight off infections other than HIV: such as swollen glands, fatigue, fever, diarrhea, weight loss and night sweats. However, with an HIV infection the symptoms gradually become more severe and include a variety of viral, bacterial, and fungal infections until a diagnosis of AIDS is reached.

The World Health Organization (WHO) estimates that over 30 million people worldwide are living with HIV infection as of the end of 1997 (UNAIDS/WHO Working Group on Global HIV/AIDS and STD Surveillance, 1998). In Canada, as of November 1998, there have been a total of 20,000 reported cases of AIDS since the beginning of the epidemic (Health Canada, 1998). To date 73% of the reported AIDS cases are reported to have died. The incidence of AIDS for gay men has declined from 77.7% of all AIDS cases before 1990 to 61.7% in 1996 (Bureau of HIV/AIDS Laboratory Centre for disease control, 1997).

Health Canada (1998) estimates that at the end of 1997 a cumulative total of between 50,000 and 54,000 Canadians had been infected with HIV since the onset of the epidemic. The incidence of new HIV infections is on the rise with the number of new infections rising from 2500 - 3000 for the period of 1989 to 1994 up to 3,000 to 5000 in 1996. The majority of this increase in HIV infections appears to be occurring among injection drug users and young gay men. As of November 1998 it is estimated that 26,540 men who have sex with men are HIV positive.

Recently new hope has been offered to people living with HIV and AIDS with new drugs known as protease inhibitors (Maclean's Magazine, 1999). These drugs inhibit the HIV virus from reproducing thereby improving immune functioning. The present trend is to advise clients to begin taking a combination of these drugs as soon as they are diagnosed rather than waiting until T cell counts fall below 500 as was the case a few years ago.

Living with HIV

One of the major issues that face gay men living with HIV infection and all people living with AIDS is the negative attitudes of the public. Gay men have grown up in a world where they are a minority and have often experienced discrimination, hatred, and even violence at the hands of the majority. The AIDS crisis has exacerbated this climate. In his essay regarding the stigma suffered by gay men with AIDS, Steve Cadwell (1991) explains that gay people who have already been stigmatized as deviant are now stigmatized as contagious. In a review of articles pertaining to stigma and disease, Crawford (1996) discovered a greater degree of stigma expressed toward individuals with AIDS than towards individuals with other comparable illnesses. No other disease of the nineties has as much fear associated with it as AIDS. In Susan Sontag's (1990) view, AIDS has replaced cancer as the disease of fear in our culture. People living with HIV/AIDS experience multiple and severe physical and psychosocial stressors. Specific psychosocial stressors include stigmatization, discrimination, loss, and isolation. These stressors interact to create considerably more psychosocial problems and needs among people living with HIV/AIDS than any other potentially fatal disease (McCain & Gramling, 1992). It appears that even the medical profession is not exempt from discriminating against people living with HIV, as Garnets and D'Augelli (1994) reported that lesbian and gay men often receive inadequate and insensitive health care and mental health services.

The Medical Profession and AIDS

In 1992 Jon Gates a prominent AIDS activist addressed physicians attending a workshop held during the Canadian Medical Associations 4th annual Leadership conference and stated that

AIDS is changing the nature of the doctor-client relationship (Sullivan, 1992). Gates contended that physicians and patients have to form an equal partnership if the quality of care is to be improved, but he believed that this could be difficult for some doctors to accept and to put into practice. As early as 1988 the College of Family Physicians of Canada began offering AIDS education to family physicians across Canada (Barron, 1994). Unfortunately, there is no reported evaluation of this continuing education initiative in the Canadian Medical Association journal. More recently, Dr. Gary Gibson, an adjunct professor of family medicine at the University of Western Ontario, has drafted a gay and lesbian curriculum for postgraduate family medicine that includes a module entitled, "Sex, Drugs and HIV" which has been endorsed by the Canadian Medical Association (CMA) (Robb, 1996).

In spite of recent advancements in the education of medical students it seems that stigmatization and homophobia still exist. In their 1997 study Green and Platt found that persons living with HIV reported experiencing stigmatization in health care settings. More recently, Klamen, Grossman, and Kopacz (1999) found that 25% of their second-year medical student participants indicated that they believed homosexuality to be immoral and dangerous to the institution of family. In addition, 14% of the participants reported feeling more homophobic since the beginning of the AIDS epidemic. The authors conclude that physician homophobia may disallow a healthy doctor-client relationship to form. On a positive note, Siminoff, Erlen, and Sereika (1998) found that the nurses in their study did not avoid patients who were HIV positive. These researchers concluded that nurses' attitudes had no impact on whether or not a person living with HIV was shunned by nurses. It appears that HIV-related stigma might be declining as health professionals become more familiar with treating people living with HIV, however, I believe that there is still much work to be done to end discrimination within the medical profession.

The Doctor-Client Relationship

Since the main purpose of this thesis is to explore the interaction between gay men living with HIV and their physicians, I will now explore the literature related to the doctor-client relationship. Historically the doctor-client relationship has been described as a paternalistic interaction which is generally ineffective in meeting the needs of clients (Seigler, 1981). The unilateral decision making used by the majority of physicians breeds dependency and undermines client autonomy (Wegmann, 1988). Within the doctor-client relationship, the physician is seen as the expert requiring the client to trust the physician's decisions absolutely (Engel, 1977), while the client is passive and compliant and follows the doctor's orders without question (Brody, 1980; Katz, 1984).

Critics charge that most physicians believe that clients are too ignorant to make decisions on their own behalf, typically underestimating their ability to understand information about the origins, diagnosis, prognosis, and treatment of their illness (Katz, 1984; Waitzkin, 1985). Furthermore, physicians have been trained to make decisions for patients (Numann, 1988). Despite the fact that communication skills between doctor and client to a large extent can determine effectiveness of health care (Ballard-Reisch, 1990), little emphasis is placed on communication skills during medical school and residency programs. The financial reward structure for physicians reinforces this lack of communication, because procedures pay more than consultations (Numann, 1988). Wyatt (1991), for example, found that physicians, residents, interns, and medical students spend very little time with clients, and when given the opportunity physicians choose not to talk with their clients. Admitting to an error of diagnosis or treatment has been described in medical schools as an act which would lead to self doubt and the potential inability to act in time of crisis (Numann, 1988).

During the last decade, partially due to the heightened emphasis on informed consent, the doctor-client relationship has begun to shift from one in which the physician prescribed and the client complied to one in which there is shared decision-making between the physician and client (Ballard-Reisch, 1990). Shared decision-making involves open communication between the client and the physician about issues of information gathering, information interpretation, exploration of treatment alternatives, and treatment decisions, implementation, and evaluation.

To summarise, the doctor-client relationship has started to change from the historically disempowering, paternalistic approach to a relationship that recognises the worth of the individual, values his/her participation in the decision making process, and responds to his/her capabilities and needs. These changes stem from social movements such as consumerism, the holistic health movement, and the women's health movement, all of which have as their premise the notion that human beings have the capacity to chart their own course of action in accordance with a plan they themselves have chosen (Katz, 1984).

The Doctor-Client Relationship and People Living with HIV

Very few studies have explored the doctor-client relationship from the perspective of the client. The number of articles that explore the doctor-client relationship from the perspective of people living with HIV is even fewer. Some of the studies I discovered were qualitative in nature, but the majority consisted of quantitative information obtained through questionnaires and surveys and revealed minimal information about the experiences of people living with HIV.

None of the studies I review below explored the doctor-client relationship in its entirety. That is, all of the studies chose to focus on certain aspects of the relationship- such as, control, communication, decision-making, information-seeking, hope, loneliness, and empowerment versus the sick role. Next I will review this literature and will highlight the authors' findings as they relate to the doctor-client relationship and people living with HIV.

In one of the earliest studies investigating the experiences of people living with AIDS and their physicians, Valdiserri, Tama, and Ho (1988) collected 27 questionnaires from persons with AIDS to determine the training needs of health care professionals. The authors believe that their data indicate a need to improve communication skills among health care providers who will be caring for people living with HIV. Although 63% of the participants felt that their doctor had accurate medical information, only 44% of the participants agreed that they had been given an accurate description and explanation of what to expect throughout their illness.

Catalan, Brener, Andrews, Day, Cullum, Hooker, and Gazzard (1994) studied the views of people with HIV and their professional carers about patients' views on involvement in decision-making and information seeking. Sixty gay and bisexual men and 82 staff of an AIDS unit, including 38 doctors, 32 nurses, and 12 social workers, completed a self-report instrument assessing autonomy preference. Both patients and staff showed generally a high preference for patients' involvement in decision-making and information seeking. However, within the professionals and patients at various stages of illness there appeared some interesting differences. Social workers, followed by nurses, had the highest autonomy preference for their patients with doctors having the lowest. Patients actually reported a lower level of autonomy to that of nurses and social workers but higher than the autonomy preference of doctors. The presence of disease symptoms was associated with a reduction in patients' wish for decision-making, indicating that patients' views are variable and are influenced by outside factors such as their physical condition at the time. In contrast, the patients' preference for information seeking was much greater than the professional carers assumed it to be. The authors conclude that it is imperative that there be good communication and sharing of views both between patients and staff and within professional teams in order to minimize any discrepancies regarding expectations of autonomy.

In a recent study, Crossley (1998) interviewed 38 people living with HIV to explore where on the continuum between the "sick role" and empowerment their lived experiences fell. Through the in-depth interviews, the participants revealed ways in which they rejected the "sick role" and moved towards empowerment by questioning medical authority and asserting their own experiential authority. Of particular relevance to my study are the quotes from participants that revealed a general scepticism of the medical profession stemming from physician uncertainty and lack of knowledge of disease prognosis and treatment. Participants also criticized the medical profession for its lack of dissemination of relevant information and its dismissal of experiential knowledge.

In 1997 Wong-Wylie and Jevne reported a qualitative study that investigated interactions between physicians and eight people living with HIV to understand their personal meaning of the construct of hope. During in-depth interviews each of the participants was asked to describe experiences with her/his physician that she/he perceived to enhance or diminish hope. The authors use the words of the participants to highlight the categories associated with hope-enhancing and hope-diminishing interactions. The categories that emerged from the data denoting a hope-enhancing interaction were: being known as human, connecting, descriptive, welcoming, and informing. The hope-diminishing interactions were being known as a patient, disconnecting, prescriptive, dismissing, and poorly informing. In conclusion, the authors stated that the quality of the doctor-client relationship for people living with HIV is central to the hope potential within each interaction.

In 1993 Reed, Taylor, and Kemeny explored the relationship between control and psychological adjustment to illness in a longitudinal psychosocial study of gay men living with AIDS. The 24 participants completed questionnaires and interviews relating to their self-reported health status, psychological adjustment, and personal and vicarious control. The men also reported on their belief that others have some response that can reduce, modify, or terminate an aversive situation that affects the self. During the interviews each man was asked to rate on a five-point scale how much control he felt he (or others) had over (a) fatigue, pain, or other symptoms experienced on a daily basis; (b) maintaining or improving health; and (c) medical care and treatment. Of particular interest to my study is the question regarding how much control the participant felt he, or others, had over the medical care and treatment of his illness. The predominant means of control reported by participants during the interviews consisted of being well informed about their treatment and options, and viewing their treatment as a cooperative venture between themselves and their physician with the ultimate authority for decision-making resting with each participant.

The overall findings of the study revealed that psychological adjustment to AIDS diagnosis was significantly and negatively correlated with beliefs in control by others over medical care and treatment. That is, the men who reported greater control by others over these areas exhibited poorer psychological adjustment. The authors concluded that these men living with AIDS saw themselves as having a high degree of personal control over their experiences related to having AIDS. The men living with AIDS viewed their doctors as also having some control but generally less than they perceived themselves to have.

Cherry and Smith (1993) interviewed nine men living with HIV to study the construct of loneliness. The authors analysed the transcribed interviews using a narrative analysis approach and explored three states of loneliness: emotional isolation, social isolation, and existential loneliness. Of particular interest to my study is what the authors term social isolation engendered by the institution of medicine. The participants described physicians as contributing to their feelings of social isolation. The men described feeling objectified by doctors who discussed their HIV status without paying any attention to the emotions associated with learning one is HIV positive. The men also stated that they felt judged by the medical profession and were often treated as "lowlifes of society." Finally, the men described the dehumanizing experience of being labelled as an AIDS patient. The authors gave some suggestions for the medical profession: The emotional aspects of an illness must be focused on just as much as the physical aspects. Also, health care professionals could speak out against stereotyping of people with HIV. Finally, effective care-givers should treat people with AIDS as total human beings who happen to be ill.

The Language of HIV and AIDS

People living with HIV and AIDS often find themselves immersed in a world which includes routine blood tests, monthly doctors appointments, and lab results that reveal their T cell counts. As with many other diseases there is also a language associated with HIV disease that the person who is HIV positive soon learns. Because the men in this thesis discussed many aspects of their relationship with their physicians and the medical profession, using the above terms, I thought it would be helpful to include a glossary of HIV and AIDS.

The Language of HIV and AIDS: a Glossary

AIDS: The abbreviation for acquired immune deficiency syndrome.

Antibody: A special protein that is created in our body and used to fight specific agents that cause infection. In the case of HIV infection the virus is not destroyed by the antibodies.

HIV: The abbreviation for human immuno-deficiency virus.

HIV Positive: This term describes a person who is infected with HIV.

Immune System: The immune system protects the body from infection. In this system, specialized cells in the blood and other bodily fluids work together to rid the body of disease-producing agents and other toxic foreign substances.

Immunosuppression: This term indicates that the immune system has been weakened.

Opportunistic Infections: Infections that take the opportunity of attacking persons whose immune system has been weakened, as in the case of AIDS. The most common opportunistic infections associated with AIDS are : Pneumocystis carinii pneumonia (PCP), cytomegalovirus (CMV), mycobacterium avium intracellular and toxoplasmosis.

Person With AIDS (PWA): PWA is a positive term for someone who has AIDS. This term is much less negative and judgemental than terms such as AIDS victim, innocent victim, or AIDS carrier.

Seroconversion: When a person's blood changes from having no HIV antibodies (seronegative) to having HIV antibodies (seropositive).

T Cell (also called CD4 Cell): A type of white blood cell that is vital to the proper functioning of the immune system. It is the Tcells or CD4 cells which are the target of the HIV virus. The virus encodes itself into the genetic information of the Tcell/CD4 cell to create new viral particles. The body's immune system is destroyed because T cells/CD4 cells are the alarm clock" cells which wake up the immune system to fight off infections. Because HIV tends to reduce the number of Tcells/CD4 cells, this count is often used as a marker of the severity of the HIV infection, (The New Our Bodies, Ourselves, 1992).

CHAPTER 2

METHODOLOGY

The Men

Due to the issue of confidentiality and anonymity blanketing the interview process I recruited the participants for this study through the use of key contact people. The key contact people were a physician from the Grandview Medical Centre in Cambridge; friends of people living with HIV disease; and a person who worked for the AIDS Committee of Cambridge, Kitchener, Waterloo and Area (ACCKWA). These resource people provided me with the names of individuals whom they had previously contacted about my research. That is to say, prior to my having any contact with a potential participant, the key contact person had provided the potential participant with specific information. This information included my name and the fact that I was a student at Wilfrid Laurier University conducting research into the doctor-client relationship from the perspective of gay men living with HIV disease and that the study would involve an interview which could last two hours. Thus, I was given the first names and telephone numbers of only those individuals who expressed an interest in participating.

I then contacted each person by telephone. Upon reaching the participant I introduced myself, briefly described my study, and asked him for their consent to participate in the study (see consent form in Appendix A). If the participant was not available, I left a message which included my name, that I was a student at Wilfrid Laurier University and my home telephone number, and that I would call back later. I was given the names and phone numbers of eight men, five of whom agreed to participate in this study, with the sixth person being my friend Bill.

Following, I introduce each of the men who courageously shared with me the dynamics of his relationship with his physician. At the beginning of each man's story I share in his own words his reaction to the diagnosis, the reaction of his support network, his feelings on being gay, and his feelings on living with HIV. I chose carefully the word "courageously" because, although the first case of a person diagnosed with AIDS in Canada was in 1982 (Greig, 1987), there still exists a great deal of stigma associated with this disease. Persons living with AIDS are often discriminated against and morally judged. Consequently, confidentiality and anonymity are treated as paramount issues throughout this study and influence the extent to which I disclose personal information about the men.

Each man is unique in his desire for anonymity within this thesis. Three of the men are completely comfortable in my sharing all personal information including their first name. Conversely, one man's participation was dependent upon an assurance of complete confidentiality. The other two men asked me not to disclose their names, but allowed me to include all other personal information. With respect to each of their requests, I have created pseudonyms for three of the men and have used the real names of the other three men.

The Research

This study is a qualitative study of the doctor-client relationship from the perspective of gay men living with HIV. I began this investigation with a research question which I believed would allow me to study this area in depth (Strauss & Corbin, 1990). I set out to find the answer to the question of what does the doctor-client relationship look like for gay men living with HIV. Initially I thought perhaps that my research question was too narrow and would therefore exclude discovering any new information to be added to the literature. However, after I had completed my first interview, I realised that the men were describing their relationship with their doctors and a great deal more. I conducted the initial interviews with the participants during the summer of 1994 and had completed all of the follow-up interviews by April of 1995. All of the interviews took place in the region of Waterloo.

Their Stories

I tape recorded and then transcribed each man's interview. I kept all tapes and interview transcriptions in a locked cabinet until the study was over, at which point I destroyed the interview transcriptions and deleted the tapes. I provided each participant with a copy of his interview transcription prior to a follow-up interview. As Reinharz (1992) suggests, this process provided the participant with an opportunity to correct, qualify, add, or delete any part of his interview. Reinharz (1992) also points out that the use of multiple interviews increases the potential for a bond to form between interviewee and researcher. At the follow-up interview I asked each man for his permission to reproduce his interview in my thesis.

In our day to day lives we tell stories, or narratives, to describe our experiences to others and to share our personal her/histories (Viney & Bousfield, 1991). Individuals also use narratives to claim identities, often narrativising particular experiences in their lives when there has been a breach between ideal and real, self and society (Riessman, 1993). Narrative analysis examines these narratives, looking closely at how storytellers impose order on the flow of experience to make sense of events and actions in their lives.

To each man's story I applied the narrative analysis technique used by Viney and

Bousfield (1991) to specific narratives from each man's interview. The purpose of this analysis was to identify the meaning attributed by each gay man living with HIV to his experience with his physician. I chose to follow the method of Viney and Bousfield (1991), because the authors share a similar perspective to my own on the merits of narrative analysis particularly with respect to people living with HIV. I believe, as do the authors, that since the voices of people living with HIV have historically been ignored or overpowered by the voices of the medical establishment (Shilts, 1987), a research method which listens intently to the voices of this oppressed group of people may help to alleviate some of the stigmatization they experience and may aid in their sense of empowerment.

Literature Review of Narrative Analysis

Narrative analysis is a qualitative research method which takes as its object of investigation the story itself (Riessman, 1993). It is based upon the assumption that people create meaning in events by telling stories about them; it is through narratives that humans make experiences meaningful (Polkinghorne, 1988). Narratives can be easily located in our day-to-day lives, and I think all of us can remember someone recounting an event and describing in detail what happened. Narratives can also be located within interviews. According to Mischler (1986), if respondents in interview settings are not interrupted with questions they will often speak for long stretches of time and will sometimes organize their replies into stories.

The first area of debate within narrative analysis theory centres around the issue of what constitutes a narrative. Loosely defined, a narrative is talk which is organized around consequential events (Riessman, 1993). A teller in a conversation will take a listener into a past time and explain what happened to make a point. Labov (1972) defines a narrative in a quite restrictive manner and makes the assumption that all narratives are stories about past events and that they contain six common elements: orientation, in which time, person, and place are identified; abstract, in which the story is summarised; complicating action in which the story is told; conclusion during which the storyteller emphasises the point of the story and brings listener and teller back to the present.

Critics of Labov's definition point out that not all narratives are told in a chronological order nor have a clear beginning, middle, or end. Riessman (1993) suggests that there is validity in viewing narratives as episodic representations of events, whereby the narrative describes episodes connected by a theme rather than by time. It is Riessman's (1993) belief that the influence of time in our Western culture may make it difficult for researchers to "hear" narratives which are not temporally sequenced and therefore lead us to reorder narratives along a chronological framework.

Narratives in interviews may take the form of a modern day novel, that is, they may contain flashbacks and events described out of chronological order. According to Polkinghorne (1988), it is the researcher's role to take these specific stories and parse them together to create more general life stories that provide self identity and give unity to the person's whole existence. However, authors such as Riessman (1993) and Mischler (1986) argue that this approach eliminates the sequential and structural features of the narrative, which they believe are as important as "what" was said.

Narrative analysis is viewed as an alternative to traditional approaches of qualitative analysis which have been critiqued for often fracturing narratives into categories for the purpose of making generalizations (Mischler, 1986). In contrast, narrative analysis preserves the narratives, respecting the teller's way of constructing meaning and analyses how meaning is accomplished (Riessman, 1993). Viney and Bousfield (1991) believe that because narrative analysis does not attempt to make generalizations it is both more respectful and more representative of study participants.

In her book, Narrative Analysis, Riessman (1993) describes and critiques three models of narrative analysis, one of which is a life story approach. I would like to highlight her description and critique of the life story model, since I have incorporated both elements of the model and Riessman's critique of the model into my personal approach to narrative analysis.

Riessman presents the work of Ginsburg (1989; as cited in Riessman, 1993), to demonstrate a life story approach to narrative analysis. Through qualitative interviews Ginsburg created a story for each of the 35 women she interviewed, centered around the topic of procreation experiences. Ginsburg created each life story by presenting direct quotes from the interview, longer summaries of the content of the interview, theoretical statements from the literature, and key themes that cut across all 35 interviews.

Riessman's (1993) critique of Ginsburg's work stems primarily from the fact that Ginsburg uses the whole interview to create the life stories, yet she only presents the reader with small excerpts from the interview which she chose specifically to support her evolving theory. Riessman states that the reader must take the author's word that the story is sequenced as she says because we do not see enough of the interview. The presentation of these small excerpts also, according to Riessman, severely restricts any opportunity for an alternative reading of the data. It is Riessman's opinion that Ginsburg used the interview material much like traditional qualitative analysts, that is, she fractured the text by taking responses edited out of context and placing them within her framework. Riessman concludes her discussion of the life history approach by suggesting that we need to find a way to work with text so that the teller does not lose control over her/his words.

Validity, Significance and Trustworthiness

The concept of validity has been narrowly defined in psychology to mean the relationship between the measuring instrument and the concept it is attempting to measure. Within the realm of narrative research validity retains its ordinary meaning of well grounded and supportable. A valid finding in narrative research is a conclusion which is well-grounded. A researcher presents evidence to support the conclusions and shows why alternative conclusions are not as likely. A test of verisimilitude rather than mathematical validity is more practical in narrative analysis. Significance in narrative research retains its more general meaning of importance. A finding is considered significant if it is important. Within the formal sciences significance has come to mean the correlation among variables is probably due to the chance of random sampling. Significance in narrative research points to the notion of meaningfulness or importance. Narrative studies do not have formal proofs of reliability, relying instead on the details of the procedures to evoke an acceptance of the trustworthiness of the data.

From a community psychology perspective, I believe that the narrative analysis approach outlined by Riessman (1993) incorporates the values of community psychology much more readily than the other approaches. Her approach incorporates a respect for diversity, in that each story is treated as unique and is valued for its subjectivity. Furthermore, her use of narratives acknowledges the abilities and capacities of individuals to construct their own meanings, and it is the voice of the participant which is heard the loudest .

My personal approach to narrative analysis

It is my intention through my personal approach to narrative analysis to address some of Riessman's concerns, particularly with respect to whose story is being told and who is telling it. To summarise what I have outlined previously, Riessman (1993) advocates for a method of narrative analysis that presents verbatim transcripts of narratives in addition to the researcher's interpretations. This method ensures that the teller does not lose control over her/his words since the narratives are not re-ordered or edited out of context.

Viney and Bousfield (1991) applied narrative analysis to the interviews of people affected with AIDS. The authors make use of the method of narrative analysis refined by Mischler (1986), which makes use of the story structures defined by Labov (1972). Therefore, each narrative begins with an orientation in which time, person, and place are identified, followed by an abstract in which the story is summarised. Next, comes the complicating action in which the story is told, followed by a conclusion during which the storyteller emphasises the point of the story and brings listener and teller back to the present. In addition to these four structures, the authors, Viney and Bousfield (1991) also created a core narrative from each story. Labov (1982) describes a process whereby a core story or core narrative is abstracted from particular content of the interview. This core narrative can then be compared to other stories with a similar structure but told in other contexts. The core narrative is written by the researchers and represents the meaning of the story reflecting the informational content, the interpersonal impact, and the language in which the story has been told. The authors use these core narratives to summarize how people living with HIV live their lives personally, interpersonally, and in their community.

Since there is a direct link between the study by Viney and Bousfield (1991) and my study, I have chosen to follow in their footsteps by using the story structures identified by Labov (1972) and by creating a core narrative from each man's interviews. Then I use these core narratives to compare and contrast the doctor-client relationship of gay men living with HIV across the six men and create a community narrative, what I describe as a harmonising of the voices of the six men. According to Polkinghorne (1988), a full blown description of a story should include both the elements that are unique to that particular story and those that can be found, at least in essence, in other stories. "The uniqueness of the particular story being described by the researcher is as important as the features it has in common with other stories." (p.169).

After transcribing each of the interviews, I began the process of identifying narratives within the interviews. I started by reading each transcript and placing brackets around text which appeared to take a narrative form. Additionally, I looked for entrance and exit talk to assist me in further identifying narratives. For example, the participant identified as Moss prepared me for the fact that he was going to begin a narrative by saying, "...but the doctor I had in [name of city] is a different story."

Next, I used Labov's framework (1972) to identify clauses within the narratives as to their purpose: orientation, abstract, complicating action, evaluation, and conclusion. I identified these structures within the narrative by assigning each clause the appropriate code. This process served as a first step toward interpreting the narrative. While I did focus on the narratives as defined by Labov (1972) when reading the interview, I was not exclusionary. That is, if I believed something a participant said was important I included it the analysis even if it did not take a narrative form.

The subsequent step in analysing the narratives involved examining how the narrator ordered his story. Specifically, I looked at what topics he discussed preceding and succeeding each of his narratives. I then broke each narrative down further by considering the language used by the narrator. The result of this entire process is the creation of a composition that includes verbatim narratives and my interpretations of the meaning attached by each man to his doctor-client relationships. I share these compositions in the next chapter.

CHAPTER 3

THE MEN'S STORIES

Moss

Moss' Background

The first man I interviewed learned that he was HIV positive in a truly horrific manner. I have included this story of his experience within the *personal background* section as it is from this story that I created the pseudonym of Moss for this man:

> When I first found out I was HIV positive, I went in the hospital for a different reason, but while I was in there they wanted to know if I would get tested or whatever, so I had to think about it and then I agreed to it. I didn't get the results back and I was released from the hospital. I was supposed to go back for the results but I didn't go. So something happened and I ended up having to go to the emergency again, and the doctor just walked in and said "You didn't keep your appointment to find out your results." and I said, "No, I couldn't come that day." and he goes, "Well, you are HIV positive.", dadada, then he started with this "Count backwards from 100 by 7's and what does 'people in glass houses shouldn't throw rocks' mean..." and its like whoa my mind was just like, ah, I was like fuck, oh yeah. Three hours later I was up in the hospital room and ya know I was trying to deal with this and it was all trying, to register and he is like, well, ya know, "What does 'a rolling stone gathers no moss', mean?" Yeah. But that is how I found out. I was mortified. I started crying.

Moss and I met on a sunny yet quite windy August afternoon at a local coffee shop. We decided that since it was such a lovely day we would go over to Waterloo Park and have our interview outside on one of the park benches. Because Moss was the first man I interviewed, I was quite nervous about our interview. As I reflect back on our interview, I realise that I did quite a lot of talking and often interrupted the flow of our conversation to ask questions.

At the time of our interview, Moss was 26 years old, unemployed and receiving family benefits. He recently moved from Hamilton to the Kitchener-Waterloo area so that he could live with his sister. Moss explained to me that when he first found out he was HIV positive he wanted to be with his family, as he thought he only had six months to live, so he phoned his sister and they moved in together.

Moss taught me that two months can be a long time in the shortened life of someone living with HIV. After our initial interview in August, Moss and I spoke on the phone a few times and tried to arrange a convenient time for our second interview. This proved to be a difficult task, as Moss had planned a two-month trip to Florida. We agreed to have our second interview once Moss returned. After the two months had passed, I tried calling Moss, and left him several messages on his answering machine asking him to call me; unfortunately I did not get any reply to my messages. Finally, on one evening I spoke to Moss's mother, who told me that she would let Moss know that I had called. There were a great number of pauses during our brief conversation and I sensed that something was wrong. She asked me if I was Moss' friend, to which after a moment's hesitation I said "yes, in a way" but clarified that I did not need to know any more information about Moss and asked that she simply let Moss know that I called. Unfortunately, because of Moss's declining health I did not get to see nor speak to Moss again.

Moss' interview

Moss began our interview with a brief orientation to his current situation. He explained to me that he has had no medical problems associated with being HIV positive. He stated that he believed that he was not getting the best care until he met his present doctor whom he described as "*very, very caring.*" The stage set, Moss then began a narrative describing his experience of learning his HIV status which he introduced by saying, "***I have no complaints really...but the*** *doctor I had in [name of city] is a different story*":

> When I first found out I was HIV positive, I went in the hospital for a different reason, but while I was in there they wanted to know if I would get tested or whatever, so I had to think about it and then I agreed to it. I didn't get the results back and I was released from the hospital. I was supposed to go back for the results but I didn't go. So something happened and I ended up having to go to the Emergency again, and the doctor just walked in and said "You didn't keep your appointment to find out your results." and I said, "No, I couldn't come that day." and he goes, "Well, you are HIV positive.", dadada, then he started with this "Count backwards from 100 by 7's and 'what does people in glass houses shouldn't throw rocks' mean..." and it's like, whoa... my mind was just like, ah..., I was like fuck, oh yeah. Three hours later I was up in the hospital room. Ya know I was trying to deal with this and it was all trying to register and he is like, well, ya know, "What does 'a rolling stone gathers no moss', mean?" Yeah. But that is how I found out. I was mortified. I started crying.

Through this narrative, Moss took the listener/reader back in time to 1991 when he first learned that he was HIV positive. He recounted a brief interaction which took place between himself and the doctor from Emergency, detailing the doctor's actions, the conversation he and the doctor had, concluding with the impact this encounter had on him.

What we do not know from this narrative is the intention of the doctor in giving Moss what appears to be a psychological test. Were there visible signs that Moss was going into shock and therefore the doctor began this psychological test in an attempt to calm Moss down? Or is it the case that the doctor himself was dealing with his own uneasiness or even panic associated with having to tell this young man his test results? Whatever the doctor's reason, we do know that Moss did not understand the reason for this test and in fact viewed it as something which prevented him from "*trying to deal with ...trying to register*" the information the doctor had just given him. Most importantly, we learned that the doctor's method of informing Moss of his test results had a profound impact on Moss' emotional well-being. Moss stated that he started crying. It is my opinion that Moss began to cry for two reasons. First, he had just learned that he was

HIV positive, and secondly, he was forced to deal with this information on his own, without any support or words of encouragement from the hospital staff.

Moss concluded his description of this doctor-client interaction with the phrase, "*Three hours later I was up in the hospital room*." This short, succinct sentence highlights the abrupt manner in which Moss learned his HIV status. The doctor "*just walked in,*" gave Moss his test results, and left him to deal with the information on his own.

Moss' narrative illustrates a lack of compassion and understanding from the doctor. It appears as though the doctor is punishing Moss for not keeping his previous appointment and therefore necessitating this doctor to tell him his test results. I also believe that Moss experienced discrimination in the form of "AIDSphobia" from the physician. If Moss' test results revealed that he had cancer, it is my opinion that likely the doctor would have broke the news of his illness in a kinder, gentler manner and would have been emotionally supportive.

Moss then explained to me that the reason he ended up in Emergency was because he had turned yellow and was very sick with hepatitis. Due to his severe illness, Moss remained in hospital for observation for more than five days. While in hospital, Moss developed a positive relationship with a resident physician. Moss described his feelings of rejection when the relationship ended prematurely:

> I had a doctor who was a resident and he was very nice. Apparently I was the first person he had met who had the AIDS virus, and so I think I really opened his eyes. Halfway through while I was in the hospital and we got really close, and then he walked in and said, "I am really sorry about this, I really...you opened my eyes about gay people and HIV, you know. You are the first person I have met that is gay.", that he knew of, so you know, I said, "So what are you going to do now?", and he said he was going to be an anaesthesiologist. So I don't know if it was too much for him to handle, you know the death part of it or whatever. Well, I was mortified. I was..., I thought we were just getting really close, he can't even say this is my last day. I started crying. Do you know, you tell these doctors stuff,

> like, you know that you just don't tell everyone, and all of a sudden, six months later, he's like "See ya." You're going to be assigned to someone else. Ya, I was just starting to gain trust in him, and ya know, I have to find someone else and that was it.

Moss' narrative describes the strong bond he and his resident developed during Moss' stay in hospital. Moss stated that he felt really close to the resident, and that he had just started to gain trust in him when the resident told Moss that he had decided to become an anaesthesiologist and therefore would not be working with him anymore. Moss' response of crying in reaction to the resident's news highlights the fact that Moss valued their relationship and reinforces the notion that strong bonds can develop between doctors and clients.

Moss' narrative also illustrates the importance of trust within the doctor-client relationship. He explained that trust needs to be a part of the relationship, because you tell your doctor things that you would not tell other people. Moss also revealed that it is not easy to be assigned to someone else as the process of gaining trust and becoming close is something that takes time.

I also get the sense from Moss' narrative that he took the news that the resident was changing career paths very personally, perhaps even blaming himself. Moss stated that he wondered whether "*the death part of it*" was too much for the resident to handle. In this statement 'it' could mean HIV disease, or 'it' could mean the relationship with Moss. I wonder if Moss believed that the resident was pulling away from him to protect himself from becoming too close to someone who was going to die. It seemed that Moss would have preferred the resident to lie and tell him that this was his last day, thereby saving Moss from his strong feelings of rejection.

Moss returned to describing the relationship he had with his present physician and provides the listener/reader with a concrete example of the fact that his doctor "*is very caring and takes his time.*"

> Like, the first time I went to see him he booked me for about half an hour or whatever, and it took 45 minutes, 50 minutes and however long I wanted to stay that was fine, ya know like, there was absolutely no pressure. He sat down and he talked a little bit about himself and I told him about myself and, it was very much like we are talking now, and ya know if there was anything bothering I would bring it up.

This short description of Moss' first appointment with his physician provides us with a great deal of information. Initially, I was surprised to learn that Moss experienced no pressure from his physician as the appointment went longer than the allotted time. Furthermore, not only did Moss not experience any pressure, he also believed that however long he wanted to stay was fine with his doctor.

The next characteristic of this meeting that I find interesting is the fact that time is set aside in the initial visit for both the doctor and Moss to talk about themselves. Moss' narrative highlights how intimacy is fostered within the doctor-client relationship through personal disclosure. Through his actions, the doctor conveyed to Moss that he cares about him as a person. As I reflect on this information now, I wish I had prompted Moss to tell me a little bit more about what the doctor shared with him. I find myself wondering if, for example, the doctor shared his personal philosophy about the doctor-client relationship and explained to Moss how he envisioned them working together.

> I felt the other ones were there to make the money and, ya know... Because they came, he said, "How are you doing?", flick, flick, flick, (Moss imitated the noise made by turning the pages of his chart) "I'm going to send my resident in," or whatever and he is gone, you know. Sometimes he would ask my permission, or he would just bring him in and say, "By the way, this is da, da, da, I hope you don't mind.". Sometimes he would ask, "Would it be okay if..." but sometimes they

> didn't. Like sometimes the guy would come in, you know, it would always be someone different. You know sometimes it would be a woman, sometimes it would be a guy, and it would be like, "This is Sherry, da, da, da, she's going to sit in on this examination, you don't mind do you?". And I would say, "Well, I guess not since she is sitting down now.". It would have been nice if he had come in and said, "Would you mind if...," because some days you're just not in the mood, do you know what I mean?. After driving to [*name of city*] you just want to, you know, after waiting an hour and a half, and he is coming in with this person, like, ya know, I am just not in the mood, I just want to get back home. But I never felt that I could really say, "Yes I do..."

Moss contrasted the above description of his initial appointment with his present physician with a narrative about his appointment experience with a different doctor:

> At my other doctor in [name of a city], now there I felt rushed. There I would have to wait, and I understand that there are people who are sicker than I am. There I would have a 2:00pm appointment, and they would put me in the room at 2:00pm, and I probably wouldn't see my doctor until about 3:00pm, 3:30 pm. The nurse would come in and see if I was still there or if I had gone to the washroom or whatever. The nurse was very friendly, but I just felt like a factory, get them in get them out. And like I said, I understand that people were sicker than I was, and I didn't mind waiting but... When he came in it was "How are you?", checked me, weighed me, ya know, he was a very basic doctor.

By alternating between narratives about his experiences with his present physician and describing the treatment he received in [name of city], Moss emphasised the supportive nature of his relationship with his present physician. Moss used two expressions to describe each of these relationships, which I believe capture the essence of these two very different affiliations. Moss described his present doctor as, "there to make a difference" whereas he used the expression, "there to make the money", to describe the doctors in [name of city]. From Moss' narratives I believe that his doctor did make a huge difference in his life.

Bill

Bill's Background

At the time of our interview Bill was 38 years old and lived alone in a house, which he considered his "*safe place*"; the only place he could truly be who he was. He was the assistant manager and head floral designer at a flower shop, where for several years we both worked. His income level was about $40,000 a year.

Bill struggled with his sexuality for a long time, finally disclosing to his friends and family that he was gay at the age of thirty-two. His reason for getting an AIDS test was uniquely linked to his feelings of guilt about his sexuality. Bill believed that if he learned that he was HIV positive he would never have sex again and therefore would not feel the guilt associated for him with being Christian and gay. Bill learned that he was HIV positive in 1986. He told virtually no one about his HIV infection for the first four years. During this time a few of his close friends knew his status, however, neither his family nor his employer was aware that he was HIV positive.

Bill and I had many conversations regarding his relationship with his physician before I actually interviewed him as part of my thesis. The majority of our conversations took place over lunch breaks at the flower shop where we both worked; however, our taped interview took place one summer evening at Bill's home over a glass of red wine. I must admit that at first it felt a bit uncomfortable for us to assume the role of interviewer and interviewee and to tape our conversation, but after awhile Bill began to talk about a recent appointment he had with his physician and I motioned to Bill that I was turning on the tape; he nodded and smiled and shared with me his story.

Bill's interview

Bill was very open and was willing to share many of his experiences as a gay man living with HIV, including the relationship he had with his physician. Bill's first narrative highlighted the high level of autonomy Bill had within his doctor-client relationship:

> After the relationship was established I had the benefit of having about 6 years of virtually no problems, so there was very little need to negotiate how the treatment went, because there just wasn't treatment. And as therapies and counts started to drop then there were nudges on his part that really maybe you should consider this particular drug, and the drug was the AZT, and that he probably started making little comments probably 4 years ago- saying that you could certainly be eligible for it and I think by that point we had already known each other for 4 years or 6 years, and I was comfortable enough in being able to say to him that I didn't wish to do any medication, that the medication had a negative attitude, and that I did not want them to be a part of my life. In those days the AZT required that you take them every 4 hours, night and day, so it meant getting up and it was quite upsetting stomach wise, quite a strong drug, the doses were really heavy in the early days, but as they got to know the drug better the doses changed, but I avoided all medication until I could no longer avoid them. He was very supportive and told me that it was my own decision and that he would not force anything on me that I didn't want to do.

Bill's first narrative provided the listener/reader with information regarding the way in which decisions were made within his doctor-client relationship. From Bill's description, we learn that it was Bill who made the final decisions regarding the inclusion or omission of medication as part of his health care treatment. Bill used the words *"nudges"* and *"little comments"* to describe the way in which his physician brought up the topic of beginning drug therapy. These word choices seem to imply that Bill did not experience his physician's statements as threatening or forceful, but rather as gentle suggestions which he could or could not choose to follow. In addition, we learn that Bill's physician was respectful of Bill's wishes to not begin taking medication when the doctor suggests it. According to Bill, his physician stated that he would not force anything on Bill that Bill did not want to do. He provided Bill with options about treatment, but expressed his views in a way that left the control in Bill's hands.

Bill then shared with me his experience of learning that he was HIV positive. He explained to me that he had a very positive experience, but that he had heard horror stories from some of the members of his support group regarding how they were told their results. He contrasted the discrimination experienced by some of his friends with the positive qualities of his doctor:

> It's homophobic, it is truly homophobic, because there are certainly diseases out there, such as hepatitis, that are just as infectious and you would never get those responses. Doctors are not necessarily good at caring about people, I think over the last 10 or 12 years the doctors who have AIDS patients have them for a reason, it's because they do care. I mean my doctor is just so "there", I never feel like he is fitting me in. When he closes the door all his attention is on me, you feel like there is no other person, just you that he is listening to. He is just so focused. He will even work through his lunch hour without even thinking about it. I think he has true compassion for people, I think he does. I think that is part of why people become physicians.

Bill's narrative illustrates his belief that not all doctors are good at caring about people. In fact, he stated that he believes some of the men in his support group who were told that they were HIV positive and going to die all in one sentence had been discriminated against by their doctors. Bill seemed to imply that it takes a special kind of doctor to care about people who are HIV positive and that his doctor was one of the special ones.

Bill described his doctor as "so there" and "so focused" and explained that his behaviours made him feel like there was no other person that his doctor was caring about. Through his actions, Bill's doctor was able to convey to Bill that he valued him as a person and considered him and his health of paramount importance. It is my opinion that Bill had the ideal relationship with his physician. Due to the intimate nature of the doctor-client relationship it is essential for the doctor to be focused and willing to spend as much time as necessary with each of his clients. Bill was truly fortunate to have such a caring and compassionate doctor.

To summarize, Bill's narratives highlight both the autonomy and care and compassion he experienced within his doctor-client relationship. Bill and his doctor were able to engage in open negotiation of treatment issues with Bill remaining in control of the final decision making process.

Dave

Dave's Background

Dave was an extremely open, energetic and positive person with a great deal of energy and determination to fight for the rights of people living with HIV. He addressed the issue of confidentiality at our first meeting by telling me that his life was an open book and anything he said during our interview could be included in my research. At the time of our interview he was 37 years old and lived with his common-law partner. He gave talks to students and members of community groups sharing his personal struggles with being gay and living with HIV disease. He was an advocate for many causes including a campaign to erect an AIDS Memorial in the K-W area called Project Angel; AIDS Awareness; Waterloo Region Pride day and championed for the recognition of same sex relationships. His energy appeared endless.

Throughout our interviews, Dave did not talk at all about his relationship with his family. He explained to me that he got the majority and the best support from other people living with HIV. As I spent more time with Dave I learned that his family was not comfortable with his sexual preference and he had not seen his twin brother for over 18 years as his brother was ashamed of him.

Dave and I began our interview with a hand shake and ended with a hug. Dave said that if he felt like he had truly connected with someone then he liked to give a hug. He asked if he could give me a hug and I agreed. I indeed was honoured to think that this man who had done so much to promote a positive view of AIDS actually connected with me. I do not think it was a coincidence that Dave was the Positive Approaches Coordinator at a local AIDS organization.

Dave died on October 22, 1995. Dave was a tireless advocate involved in numerous local and provincial organizations dealing with gay rights and AIDS issues. He will be greatly missed by friends, colleagues and his community.

Dave's interview

Dave began our interview by relating to me that he saw four different doctors: his family doctor, a holistic doctor, a gastrointestinal (GI) specialist, and a HIV specialist. He had been with his family physician for several years and in the following narrative explained to me why he considered their relationship strange:

> Yeah, I have a very strange relationship with my doctor and this is just my family doctor, who I have been seeing for years. In fact, its kinda strange, because I had gone through years without telling him that I was a gay male, because I wasn't sure how he would react until I found out from another friend that he had in fact told this same doctor and he was fine with it and I thought, oh okay. So then I told him, and then lo and behold a couple of years later I discovered that I was HIV and again I didn't bring it up to him, because I wasn't really experiencing anything at the time. And then about a year and a half ago a lab report came back that I had an eye infection and that they had suspected HIV and the next time I went in he said "When did you seroconvert?" and I said, "Oh, did I not tell you (laughing) whoops!" And I was sort of gauging him for his reaction and he was pretty good.

Dave identified two reasons for referring to his relationship with his family physician as strange. The first reason stemmed from the fact that Dave actually went years before he told his doctor that he was gay. Secondly, Dave let a few years pass after knowing he was HIV positive before he shared this information with his doctor. It seemed that Dave was unsure of his doctor's opinion about gay people and therefore waited until he learned from a friend that his doctor was fine with homosexuality before he disclosed his sexual preference. Dave also appeared uncertain as to how his doctor would react when he learned that Dave was HIV positive, as Dave stated he was "*sort of gauging him for his reaction.*"

Dave's definition of a "strange" relationship with a physician seemed to be one in which there was a lack of openness and honesty between doctor and client. I believe that Dave's reason for describing his doctor-client relationship as "strange" stemmed from his personal views about doctor-client relationships. As an AIDS activist, Dave advocated for open communication and acceptance within the doctor-client relationship, therefore, it does seem a little bit "strange" that Dave would settle for less than complete openness and acceptance from his own physician. As Dave explained later, however, he believed he had changed his doctor's attitude to a level with which he felt comfortable.

Dave's next narrative revealed how the relationship Dave had with his family physician had grown and developed since Dave's HIV status was revealed.

> So, I thought well okay here we are face to face with it and the next time I went to see him it was because of a suspected infection and I knew what I thought it was but I didn't...and the word came back and he said to me "I suspect CMV (cytomegalo-virus)." I thought, wow, he knows a little more than I thought so I gave him credit and we talked about things. So we have developed a relationship where he is learning. I don't feel like I have to go elsewhere so I thought, we will see how this goes. He is very open and honest with me and he says if I don't

> know something I will tell you and because I work in this I know a lot, and I have a lot of information and I can take it to him and I have done that many times. I have worked out that sort of relationship with him. He said to me one day, "Ya know I don't know a lot about this and I am going to have to learn as I go along," and I said, "Well, that's fine."

Dave's narrative describes a doctor-client relationship which may be considered atypical from the traditional relationship. Dave explained that it is his physician who is learning from him about HIV/AIDS. As the Positive Approaches Coordinator with the AIDS Committee, Dave had access to a great deal of information about HIV/AIDS and, therefore, in the beginning, was tentative about the relationship since he was not clear how much his physician knew about HIV/AIDS. When the doctor revealed that he did have some information about HIV infections, it seems that Dave gained some trust and faith in his doctor and they began to develop a more open and reciprocal relationship. The doctor's openness with Dave about his lack of knowledge provided Dave with the opportunity to share with the doctor his own personal knowledge about HIV and information available to him through the AIDS Committee. Although Dave's relationship with his family physician began as one in which openness and honesty were not part of the foundation, it appears that their relationship developed into one in which the doctor felt comfortable in his role as learner and Dave felt comfortable in his role as teacher.

As Dave's illness progressed his family physician referred him to a GI (gastrointestinal) specialist who worked with people living with HIV. In the following narrative Dave described the frustration he experienced as he tried to talk with the specialist.

> Then when things started getting a little weird, he referred me to a doctor in London, who again is someone who I heard about as being very good. So he referred me to a GI specialist who also was very good with HIV, and that is the primary person I have been seeing for the last few months. And again I get into the situation, this guy is very clinical, he doesn't want to sit there and talk, this is

> what he thinks and if I say, " Well I sort of feel...", well he said to me the last time he goes, "You want to treat the symptoms and not the cause.", and I said, "Well I just want to relieve... I do want to relieve the symptoms because they have been going on for a year and they are pretty...", so I got kinda frustrated with him.

The lack of discussion between doctor and client is very evident in this narrative. By flipping from his own words to the words of the specialist in midsentence, Dave provided the listener/reader with a clear example of how difficult and frustrating it was to discuss treatment issues with his specialist. It appears that the specialist was uninterested in hearing Dave's views, since as soon as Dave tried to express his opinion the specialist interrupted him and restated his own views.

In addition to his traditional allopathic doctors, Dave also saw a homeopathic doctor who is a practicing counsellor. Dave described this relationship as being very supportive and the one in which he got the most opportunity to talk. Dave said about his other doctor-client relationships:

> I find that even with my other doctors that they all seem to be so intent on the medical stuff and they don't have the time for you. You can tell by their mannerisms like they sort of want you in and out. They don't have a whole lot of time to sit there and chat with you. It's like, "What's the problem," and lets find out and lets get out of here.

Dave went on to explain that his family physician was not very supportive of his homeopathic regime of minerals, supplements, and herbs but respected Dave's ability to make his own choices. In the following narrative Dave clearly outlined what he expected from his physician in terms of the decision-making process and provides the reader/listener with an example of a time when he experienced a lack of choice in the decision-making process.

> But on the other hand he allows me to make those decisions and I think that is very important especially when I am talking to other PHAs (People with HIV/AIDS) that I want them to be able to go to someone who will allow them to make their own choices. And I don't want somebody shoving AZT down my

> throat or whatever it is, if that is not what I want. But I also want somebody that is going to go along with me and explain things and say..., I mean I have a wealth of information here, I am lucky because I come back and I as soon as I get a prescription I look up in the drug compendium and I find out everything I can about it, but I want them to be able to discuss that with me and say. Like this GI doctor that I am seeing, the last time I went and saw him about a month and a half ago he put me on steroids but didn't really take the time to explain to me if you don't take them this is what will happen and if you do take them this is what will happen. So it was sort of like, well, I didn't really have that choice, and I thought well I had better take them, but I don't like being put in that position. But again he wasn't someone that I could discuss that with because he just sort of said... phuh. (Dave gestured as if to indicate that the doctor just can't be bothered).

Dave clearly stated what he does and does not want within the doctor-client relationship. He did want someone who was willing to discuss treatment options with him and explain things to him, and someone who would allow him to make his own choices. He did not want a doctor who would push medication on him against his wishes. Consequently, Dave was not happy when his GI specialist did not take the time to provide Dave with information about the use of steriods and thereby denied Dave the opportunity of making an informed decision.

Dave's narrative about the care he received at a local hospital clearly shows his inner conflict between the kind of care he believed he deserved and the kind of care past experiences led him to expect:

> I was telling the same thing on Tuesday that I had gone to a local hospital, actually I had gone to a clinic, and I had severe, severe pain in my head, and it wasn't a normal migraine, I knew there was something wrong, and I had gone to a clinic and I was lucky enough to get a very, very good doctor, and I told him that I was HIV and he was very sympathetic, and he sent me to the local hospital and met me over there. Actually no, not the first day, the first day he said "I will call," and gave me the care and that, and requested the tests, and they hooked me up to the IV, and I remember that the IV came out and I was sort of bleeding and I was like, "oh do you want me to get that," and I was going to clean up the blood and they said "don't worry about it." I was expecting them to be panicked and they weren't. The next day he came back the next day, he came on his day off, and I remember this doctor was so wonderful, I remember, and I kept bragging and saying "oh

> wow," and I really wanted this doctor for my own but he doesn't practice private practice and I thought oh damn. He was attractive but he was so good, so compassionate, and so wonderful a person because you expect people to look down on you when you tell them that you are HIV. I have had that experience, I didn't know what to expect, good care, bad care, and so he saw me through all of this, and I kept saying to people "Oh I had this wonderful experience, it was so good," and then I started realizing that that shouldn't be. This is the kind of care I should expect, it shouldn't be the exception, and I shouldn't have to brag about it and say they didn't don the gloves, they didn't put a red-plus sign on my chart and hand it around, or when you have been in for tests and they are kibitzing with you, and then they look at your chart and go mean to you, and it shouldn't be like that.

On the one hand, the nurses who attended to Dave did not appear to be panicked by the idea of cleaning up his blood, however, on the other hand, these same nurses had attempted to move Dave to a private room without asking his permission. It is not surprising to me that Dave stated that he, "*didn't know what to expect, good care, bad care*". Even in this poignant example of a positive experience involving a compassionate physician there seemed to be a blemish in the form of the staff undermining Dave's personal power.

Don

Don's Background

Don was diagnosed as HIV positive in 1989, two weeks after his partner of 13 years died of AIDS related pneumonia. Upon first learning that he was HIV positive, Don went through a phase where he thought about it a great deal. He had a happy go lucky attitude to living with HIV, basically his approach was to just live day to day and not really think very much about it.

All of Don's friends and family knew that he was gay and HIV positive and he received a tremendous amount of support from them. To exemplify this fact Don told me that he would rather go to his family for support than to a support group. Don's partner, who was present at our interviews, was also genuinely supportive. When Don first told him that he was HIV positive, Don's partner told Don that he knew how to deal with someone living with HIV and that he would be around to look after him. As of this writing, Don is still employed at a gay club where everyone he works with is gay, so he also receives a great deal of support from his co-workers, as he did at the time of our interview.

The interview between Don and I was the most fun I had during an interview. He had a very laid back attitude and certainly was extremely comfortable with himself.

Don's Interview

Don had an extremely positive outlook for the future. He began our interview by proudly sharing with me the fact that his CD4 counts were so high that the doctors who were doing the counting had to create a special chart just for him. He appeared to take everything in stride and tried to make people feel at ease and able to laugh. His first narrative highlights his technique for getting his doctor to relax:

> He's good. He's a laugh. It's a little bit sick and I guess my doctor forgot that I was gay and anyhow he was giving me the full body examination which I was expecting. Then he said now turn over, this is going to be a little bit more uncomfortable. I knew he was tense and that he was going to do an anal exam, so I thought this is going to be uncomfortable so..I turned over and I said "Doctor, if you are going to do that, use two fingers and make it feel good." Well, I thought he was going to die. "Oh my God", he said, "I completely forgot about that, I am really sorry." He just about shit. He kept apologising, "I forgot, I forgot.". So that kinda made him relax a bit after that.

Don and his physician have a remarkable relationship. Don began his narrative by saying that his doctor was good and a laugh. I believe that these two statements highlight one of the elements of their relationship which Don appreciateed the most, the fact that his doctor would laugh with him.

Don's narrative reveals that it was Don who directed the way and at what level he and his physician would relate. Don appeared to demand that his doctor relate to him on a personal level rather than a clinical level by saying, *"use two fingers and make it feel good,"* while his doctor was performing an anal examination. It is not clear whether Don was also uncomfortable, as he claims his doctor was, about the anal examination, but Don's comment certainly redirected the focus away from what the doctor was doing and to the more personal issue of how Don gets pleasure.

Don's following narrative provides the listener/reader with more information about how Don and his doctor related:

> He doesn't use technical terms on me anymore. I said if you are going to use those technical words I will have to get a dictionary out. I said, "if you want to know if I give 'head' [fellatio] tell me, don't use technical terms," so he doesn't say that anymore he just goes with it. He says, "well okay I have to say it this way," and I say, "okay, well, okay, then say it that way." I said I don't know the god damn biological words for that or whatever this shit is. Yeah, I said, "Well don't give me that thing, ya know, this is silly, if you want to know if I do this or that then just ask, just say it." He is alright with it. He's quite funny, ya got to get him going, I mean after he just relaxes. He's fun. I get a kick out of him.

Don's narrative highlights the fact that he and his doctor have negotiated how they will converse during their appointments. Don felt a high degree of personal comfort with his doctor and was not embarrassed to admit that he did not know the technical terms for some of his actions. Rather than Don pretending he understood what the doctor was saying or trying to learn the biological terminology, Don told his doctor directly that he was speaking in a language that Don did not understand and that he would prefer that the doctor use terms with which he was more familiar.

Don was explicit with his doctor and said: " *if you want to know if I do this or that then just ask,*" clearly telling the doctor that he was an open and honest person who was willing to discuss anything provided he understood the question.

Don and his doctor developed a relationship which met Don's needs. Don was a very personable individual and expected that his doctor would relate to him at a personal level rather than at a clinical level. It is obvious from both of Don's narratives that his doctor was willing to negotiate with his clients how they would work together.

Gloves

Gloves' Background

Gloves agreed to participate in my study on the condition that, in the final copy of my thesis, I did not include any information which may allow others to identify him. For this reason I decided to create a pseudonym for this participant. I chose the pseudonym "Gloves" because Gloves became very passionate during our interview when he described his experience with a medical student who touched him without wearing any latex gloves. There are very few people in Gloves' life who knew that he was gay and HIV positive. Within his family, while all of his family members knew that he was gay, only his mother knew that he was HIV positive. In addition, he had not "come out" at his place of employment and believed that if he revealed that he was gay and HIV positive he would likely have been discriminated against.

My interview with Gloves began with a handshake and ended with a hug. Gloves and I arranged to meet at our mutual friend Bill's house. I felt kind of strange sitting on Bill's porch waiting for Gloves to arrive, since I actually knew from Bill who Gloves was prior to meeting him, yet Gloves did not know who I was. After we introduced ourselves and shook hands in greeting, Gloves and I drove over to my house. We spent the first few minutes discussing the age and architecture of my home as my home is almost 100 years old and Gloves appreciates old homes. We then took seats in my living room and began the interview.

Gloves' interview

Gloves told the story about his relationship with his physician in his own unique way. He provided the listener/reader with a narrative about an event and then offered a description of what he needed or wanted from his physician. Gloves told two narratives about the relationship he had with his physician. Both of these narratives focused on the shortcomings of his doctor and their relationship. However, Gloves did not merely criticise his doctor and move on to a new topic, he offered an explanation as to his views and suggestions for ways in which the relationship could change. Gloves' first narrative highlights the "stalemate" which existed between Gloves and his physician:

> I guess we will start at the beginning. I have just passed the three-year mark in July. My diagnosis is fairly recent, and I don't particularly suffer from any, no sign of the AIDS, it still hasn't come out. My counts have not been the greatest, they have always been below what they classed as a normal level, so I always get the push to consider drugs. Each time I go to the doctor, again a part of that is denial, because taking drugs is admitting to the fact that something is happening and I just don't want to hear about it, but each time I go he says, "Your counts are still below 500 you should really consider AZT." That is what I get from him every time. He doesn't offer me anymore information, and he knows that my instincts inside me say to me I just don't want it. I'd rather die. Just forget it. Let's enjoy life for as long as the quality and quantity is there. Let's skip the AZT and all the side effects.

It is clear from Gloves' narrative that he had not dealt with or accepted the fact that he was HIV positive, in fact, Gloves himself admited that he was in denial. Gloves expressed that he had very strong views about taking medication and that for him taking medication was admitting that he was ill, that he had an illness. Gloves was simply not ready to admit that he was ill. I believe that before the doctor can begin to discuss treatment options the doctor needs to back up a step and actively listen to Gloves as he shares his emotions of fear and pain surrounding the fact that he is HIV positive. It is my opinion that if the doctor addressed Gloves' emotional needs and assisted him in accepting his HIV positive diagnosis, then Gloves would have been more open to discussing drugs as a treatment option.

Gloves' feelings of frustration with his doctor are evident in his narrative. Gloves stated that every time he and his doctor met he got "*the push to consider drugs,*" and his doctor telling him that he "*should really consider AZT*" without his doctor acknowledging that Gloves had strong feelings against taking medication nor offering Gloves any more information about AZT. Gloves' use of the words "push" and "should" in his description of what happens during his doctor's appointments indicated to me that Gloves was experiencing pressure from his doctor to do something with which he was not comfortable, that is, take medication.

It seemed as though Gloves' doctor was rigid in his approach to prescribing medication. He appeared unwilling to engage in shared decision-making with Gloves, as evidenced by the fact that he did not provide Gloves with additional information about AZT, therefore denying Gloves the opportunity to make an informed decision. I believe that Gloves and his doctor reached a "stalemate" in their relationship, with neither one of them openly communicating their frustration or making suggestions of different ways in which they could work together.

Gloves' next narrative illustrates the lack of emotional support he received from his doctor:

> My family doctor is not the person to go and talk to, he is the person to go and get your drugs and the blood count forms filled out so you can go and do it. Even taking it out of the context of HIV, a good quality in anybody or a physician is the people skills, you really, really need to have them. And I think a lot of doctors lack that, they just get so wound up in the job, and everybody is in for a cold, its like..."What is wrong?". I mean I am in and out in 15 minutes. In the beginning he would want a half hour, fine, I went in and I bawled, because I was just a mess, and he was there he handed me a Kleenex, and there weren't really any strong words of wisdom, and it was, "Here are some sleeping pills or here are some antidepressants." I spent 6 months on antidepressants and finally I took 10 of them, and it didn't do anything but that was all I had left. I am in and out, in and out, and there is not the bond, this emotional support. That means I think more than filling out a prescription, is to have, well, an issue there is acceptance, from the doctor, from anybody and emotional support, like the sense that this person cares about what is happening to you.

It is clear from Gloves' narrative that he had a very clinical relationship with his physician. When Gloves was crying, the doctor responded to his emotional distress by handing him a tissue and writing out a prescription for sleeping pills or antidepressants rather than providing Gloves with some form of emotional support. It seems as though the doctor was uncomfortable with Gloves' expression of his emotional pain and in light of his anxiety fell back on what he knew best, what he is trained to do, such as write out a prescription.

In his narrative, Gloves shared his belief that the doctor-client relationship involves more than writing out a prescription. He stated that getting both acceptance and emotional support from a doctor means much more than his/her ability to prescribe medication. Gloves' use of the phrase, "*I am in and out, in and out*" to describe the type of interaction in which he and his physician engageg clearly illustrates that neither emotional support nor acceptance were provided by his physician.

Both of Gloves' narratives provides the listener/reader with a sense that Gloves' needs were not being met by his physician. Gloves clearly would prefer a physician who was open to discussing issues such as medication and who was willing to relate to Gloves at an emotional level. It also seems to me that Gloves' doctor was uncomfortable and perhaps ill prepared to deal with the emotional aspects of living with HIV. Later on in the interview, Gloves explained to me that he was his doctor's first and only HIV patient and stated that he did not know "*if he* [his doctor] *is comfortable with the gay issue or the HIV issue.*" I agree with Gloves, I also am unsure whether his doctor was comfortable treating him.

In his next narrative, Gloves revealed more of his sensitive nature. He described a powerfully emotional experience he had at an AIDS clinic.

> When I went down to [name of city], they were very thorough. I mean I spent hours there and actually it was with a student doctor, female, and she was very nice, and she was the first person that touched me without wearing rubber gloves. It's just because all these stigmas in society about touching a person with AIDS, and she was the first person that ever touched me without a rubber glove from the time I got there.

At this point in his story, I asked Gloves if he meant that people wore latex gloves when they first greeted him. He replied:

> Yes, people won't... and I am always so conscious of that both, but like in daily living and when you go to the doctor, but that woman was the first person to touch me without the rubber glove. I felt like just this awful thing that should be swept under the carpet and never touched again. She was really nice very caring, very sensitive, she had the right people qualities to deal with the issues around HIV. She started to put the needle in and I pulled my arm back and said "Do you realize what is wrong with me?" and she said "Yea, I'll be careful, don't worry about it", and it's like I wanted to get up and hug this woman, because I can't believe you are actually going to draw blood from me without at least 6 layers of latex between you and me. She actually touched me. It was like, "Are you ok woman? Are you serious? Do you realize...?" It was like, wow, she finally made me feel human.

Gloves' narrative provided the reader/listener with a glimpse into what it is like to live with HIV. Gloves created a powerful image of what it feels like to live in a world where people are afraid to touch you through his phrase, *"I felt like just this awful thing that should be swept under the carpet and never touched again."* Gloves stated that because of the stigmas which exist in our society about touching people who have AIDS he has become very aware of people touching him.

Letters

Letters' Background

Letters experienced discrimination at the the hands of a dentist who refused to treat him after Letters disclosed on the intake form that he was HIV positive. Letters was so outraged by this experience that he began a letter writing campaign against this dentist. It is from Letters' description of this experience that I created the pseudonym "Letters" for him.

At the time of our interview Letters was 34 years old and had just begun a new relationship. Letters learned that he was HIV positive in 1989 and had just started taking medication for his illness the month prior to our interview. Although Letters realised he had feeling for boys when he was twelve or thirteen, he did not acknowledge that he was gay until he had been married for two years. Letters' entire family knew that he was gay and HIV positive and all his family were very supportive with the exception of one brother who had difficulty accepting the fact that his brother is gay.

Letters was the last man I interviewed for this thesis. Letters cancelled our initial meeting date due to illness, so we finally met on a rainy afternoon in October. Letters agreed to come to my home and we had the interview in my living room. Letters seemed very comfortable to discuss his relationship with his physician and he began the interview without any prompting from me.

Letters' interview

Letters learned that he was HIV positive 51/2 years ago. He had known his doctor for 10 years but the first two to three years he knew him as a friend, because his doctor used to come into the bar where Letters used to work.

Letters switched to the doctor he has now, because he was having what he describes as "a little problem" with his former doctor. His previous doctor was asking him questions about his sexuality that Letters did not want to answer. At the time of his previous doctor's questions, Letters was still denying his gay feelings and thoughts. Letters was not ready to accept that he was gay and as he explained, even if he was ready to admit to himself that he was gay, he was not going to come out to his doctor that he had been with since a child. Letters said that he felt very uncomfortable and intimidated by his first doctor, and therefore he did not share any personal information with him. Letters' description highlights the fact that one can not force someone to admit that he is gay if he is not ready. Physicians, in particular, even if they suspect their client may be gay, could consider waiting for the client to make the first signs toward disclosing and then provide a safe place for him to do so.

Letters' described his present doctor as very personable and explained that he was comfortable with him and could talk to him about anything. Letters' doctor was gay, and Letters believed that this fact helped their relationship because his doctor knew the lifestyle and therefore did not ask "stupid" questions. Letters highlighted how he felt about the fact that his doctor was gay in the following quote:

> I think my doctor being gay is just a bonus, like personal issues, but not even the medical aspect, we can sit and talk about things that are going on. To me that is important. It's just a comfort aspect for me, I feel comfortable. He doesn't necessarily have to be gay, but it just happens that my doctor is and it has worked out well for us over the past eight years. Like I say, it is just little personal things that we can talk about. When you get right down to it, it doesn't matter whether he is gay or straight, just a little more comfort for me.

At the time of our interview, Letters had just been prescribed AZT by his physician. Letters described his doctor as someone who did not push medication on anyone and described the process of his doctor prescribing medication as a long one. Letters seemed to mean that sometimes he thought he should have been on medication months before his doctor actually prescribed them for him, however, he also said that he trusted his doctor's judgement. It appeared that prescribing drugs for Letters' doctor was something that he only did as a last resort.

Letters revealed that when he first found out he was HIV positive he had qualms about ever taking medication. He explained to me that he had seen his aunts and uncles have a rough time as they went through chemotherapy, so from a young age he had said that he would never take medication. However, we know that something or someone made Letters change his mind. His philosophy towards taking medication became: "what the hell, like, it may help, it may stabilize my blood count anyway and that is important."

Perhaps the someone who changed Letters' mind was his physician. Letters stated that right from the very start his doctor provided him with a step by step outline of how his illness might progress and when he would recommend that Letters began taking medication. His doctor took the time to explain what the medication may do, how it may help, and what the side effects could be. Letters explained to me that his doctor encouraged him to ask questions during each appointment in case the doctor had forgotten to say something. If Letters had a question he just asked his doctor outright and his doctor would usually have the answer, since Letters described his doctor as "up on everything". Letters explained the decision-making process in which he and his doctor engaged in the following quote:

> The important thing is that things are talked out. Decisions aren't just made. He doesn't make them, I don't make them, we talk about them. And if I am comfortable with them, then we will go ahead.

At this point in the interview Letters switched from describing mostly the medical aspects of their relationship to describing the emotional, supportive nature of their relationship. Letters revealed his doctor's willingness to deal with non-medical issues. He explained to me that his doctor had always said that if anything comes up, something other than medical, then Letters was to call his office and he would fit him in for an appointment. Letters went on to explain that it was not just what his doctor said but also his actions that conveyed that he cared. Letters said:

> Like I have never been to a doctor where if you are having a rough time health wise, when you get up to leave his office, he will give you a hug and say I will see you next time. I have never had it and he does it. It's incredible. You just don't see it.

Interestingly, Letters followed this description of his doctor's compassionate actions with a narrative about an experience he had with a dentist who would not extract his tooth. Although it is not a narrative about the physician-client relationship, it is about the doctor-client relationship, and I believe it highlights the devastation a person experiences when he/she is discriminated against:

> I went to a dentist last year where pretty much the door was slammed in my face. I was upfront and I filled out their forms and where it said any diseases whatever, have you been tested for HIV? Yes. Are you HIV positive. Yes. Then he hemmed and hawed and gave me a prescription and sent me on my way. Would not extract the tooth. It was awful, it was the most devastating feeling I felt, like low, as low as you can get. Like I was second class. That was an awful time though. I am in total pain because I have a cracked tooth and this on top of it. I just couldn't deal with it. It was awful.

Letters' narrative provided the listener/reader with a description of an experience he had with a dentist who would not extract Letters tooth because Letters was HIV positive. Through Letters' narrative we learned that the dentist did not directly tell Letters that he would not extract his tooth because Letters had AIDS. Instead, the dentist told Letters that he would have to disinfect his whole office before and after he treated Letters, and therefore it would be an inconvenience to him and his other patients. The dentist merely gave Letters a prescription for some pain killers and sent him on his way, or as Letters explained, "*the door was slammed in my face.*"

Letters described his emotional pain through the phrases, "*it was the most devastating feeling*", "*I felt like low, as low as you can get, like I was second class.*" These expressions help us to understand the rejection Letters experienced. Whereas the actions of Letters' doctor showed compassion and acceptance, the actions of the dentist seemed to show rejection, discrimination, and the personal fear of the dentist. His statement that he would have to disinfect his office before and after he treated Letters reveals that his fear stemmed from ignorance, because he was implying that everything Letters touched, including the office chair could potentially be a source of spreading AIDS.

I must admit that as I heard this story I found it difficult to believe that a health professional would believe that he had to disinfect his whole office after treating Letters. I began to think that perhaps the dentist's story was just his elaborate excuse as to why he could not treat Letters, hoping that Letters would not realise that it did not make sense. I can appreciate that the dentist might have been fearful of treating someone with AIDS. He may be thinking about the fact that he will be in contact with Letters' blood when he extracts his tooth. He may be worried that his latex glove could tear during the procedure and therefore his skin would come in contact with Letters' blood directly and increase his risk of getting AIDS. All of these, I believe, are legitimate concerns, but the dentist was not honest with Letters, if Letters' side of the story corresponds to what actually happened. In contrast, Letters was honest with the dentist when he filled out his forms, which asked if he had ever been tested for HIV and if he had HIV. Letters' honesty resulted in him being discriminated against by this dentist and his tooth not being extracted. He was left in physical pain, and added to his physical pain was the emotional pain associated with the dentist's rejection and insensitivity.

Letters went on to say that he "*just couldn't deal with it,*" yet he dealt with his experience in a remarkable way. In spite of his pain, Letters wrote down everything he could remember about his experience with the dentist and sent letters to the Canadian Dental Association (CDA). Letters tried to prevent what had happened to him from happening to anyone else.

Letters labelled his experience as AIDSphobia and homophobia. He recapped what the dentist said to him in the following phrase, "*he would have to disinfect his whole office before and after he could have anything to do with me.*" This phrase, I believe, captures the implied meaning of the dentist's actions. It was not the case that the dentist would need to disinfect his office before or after extracting Letters' tooth but rather before or after having "*anything to do*" with Letters. This statement implies that Letters himself was the disease. Everything he touched must be cleaned, everything he touched could have AIDS on it; he was AIDS. It is not Letters' blood which the dentist views as carrying the disease but Letters himself.

Letters explained to me that he does not put any professional down for wearing latex gloves, but when that dentist turned him away, he explains that the gloves "*were something to me like, 'stay away' type of thing.*" He contrasted the way he felt after his dentist appointment with the relationship he had with the woman in the lab where he gives blood. He has been going to the same woman for over five years and she does not wear gloves. He described it as "*very comforting when I do give blood.*" He said that she was educated and knew what she was doing.

Returning to the story about the dentist who would not extract Letters' tooth, Letters explained to me that his previous partner phoned around for him, telling each person that he talked to that Letters was HIV positive, to try and find a dentist who was willing to extract Letters' tooth. Eventually a dentist was found whose response to the fact that Letters was HIV positive was "*Oh, of course, send him right over.*" Letters described his experience with this dentist in the following narrative:

> He was the nicest, just a young guy. So nice and he was outraged after I told him about the other dentist. He was super. He didn't do anything more than gloves and a mask. I told him how this other dentist said he would have to sanitize his whole room before he could send anymore patients in and basically he said it was total bullshit. His idea was mine...universal precautions. But he was very nice. I sent him a thank you card, I was so... You don't often see a doctor like that.

The dentist in this narrative provided Letters with a great deal more than just his professional service. He provided Letters with support for his anger about how he was treated by the other dentist and Letters' belief that universal precautions is all that is necessary. The dentist in this narrative also restored some of Letters' faith in health professionals, since Letters was able to find someone who extracted his tooth without anything more than mask and gloves.

I believe that it is really unfair that people living with HIV have to suffer discrimination at the hands of health professionals. It is also unfortunate that Letters' partner had to call around to find a dentist who was willing to treat Letters because he is HIV positive. It is also unfair that Letters felt the need to send a "thank you" card to this dentist who was willing to care about him. I do not send my doctor a thank you card for simply providing me with care. But Letters did, because for someone living with HIV, finding someone who will treat you is difficult enough, let alone finding someone who will treat you with acceptance and sensitivity.

Each Man's Message

I would like to conclude this section of the men's stories by sharing what I believe are the unique messages each man is conveying through his story. From Moss the message is "Consider my feelings before you act." Moss impressed me during our interview as someone who was extremely sensitive to the impact of others actions towards him or comments about him. From Bill the message is "Let me be free to be me". During our many conversations Bill spoke at length about his desire to be accepted for who and what he was, namely a gay man living with HIV. From Gloves the message is, "Touch me." Gloves appeared to me to have a deep desire for physical human contact and was very conscious of the fear and awkwardness that prevented people from touching him. From Dave the message is "Listen to me and take me seriously." Dave identified during our interviews that he disliked being discounted by physicians who did not respect his experiential knowledge. From Don the message is "Lighten up." During our interviews Don drew to my attention the fact that the focus of most AIDS literature is death. He shared with me that he enjoyed life and wanted to live his life to the fullest. Finally from Letters the message is "Have the courage to admit your fears." Letters expressed that he valued and respected physicians who could shared that they experienced some discomfort working with a gay man living with HIV and could admit that they did not have all the answers. While these messages come from stories about the doctor-client relationship, I believe they go beyond the confines of that relationship and speak to each of us, whether health-care professionals or not, about how we can relate to gay men living with HIV.

COMMUNITY NARRATIVE

Each man in this thesis is unique. He has dealt with being a gay man living with HIV in his own individual way. In the previous chapter I highlighted each man's uniqueness by sharing with the reader each man's personal story of the doctor-client relationship. In this next section I will present a community narrative, that is, a story about the collective experiences of the men with respect to the doctor-client relationship. As I reflected on the men's stories I realized that two main themes emerged that captured the men's experiences with their physicians. These themes are connection versus disconnection and empowerment versus disempowerment.

Connection versus Disconnection

Connection

This category characterizes a physician's commitment to knowing the client as a human being with both emotional and physical needs. Within this category the men identified several components of the doctor-client relationship which fostered a sense of connectedness. The most important component within this category is the establishment of a rapport between the client and the doctor. All of the men praised doctors who allowed enough time during appointments to listen to and talk with their clients, Don said:

> Oh you can talk to him, he's good that way. With my doctor you can talk to him, ya know. If you have a problem or things going on in your life you can talk to him. He doesn't use that high term psychological book shit. He asks how you are doing and if there is any problems with this or anything else, ya know, that is going on in your life. He's good, he takes the time to sit down and talk about...he'll go through the file and everything, however long it takes.

A physician who truly listened to his client's nonmedical needs is evidenced in the following quote from Moss:

> I'll tell you how caring my doctor is, about six months after I was going to see him, he was asking me how I was doing and all that, and my sister was pregnant at the time of the whole situation, and like she knew the whole situation and whatever, but in my mind I had six months to live...blah, blah, blah. I don't know, it must have come across to him that we needed help or whatever, and he didn't even mention it to me, but I got a phone call from a nurse at the Regional Health Centre that wanted to come over...like he cares enough that...because he didn't know if I needed meals or that kind of thing, and you know it just flipped me right out. It was like, wow, he didn't have to do that. There's not enough like him I tell ya.

Furthermore, a physician's willingness to share aspects of his own life enables a strong bond to form between doctor and client, moving the relationship into the realm of friendship. Moss said:

> I don't know what it is about him, I really can't pinpoint one thing. It's just because he tells me about himself and ya know what I mean, it's not like I'm seeing a doctor, it's like every two months I go to see, well, like a friend or whatever, and I can say anything I want to him and I know that is where it is going to stay. I don't know if it is because he sits and talks to me or whatever. But, afterwards when I leave his office, I feel good, ya know what I mean.
>
> He makes me feel very comfortable. Like, the first time I went to see him he booked me for about half an hour or whatever, and it took 45 minutes, 50 minutes

> and however long I wanted to stay that was fine, ya know, like, I just got the impression that he is not there to make the money he is there to make a differenece. That's the impression I get.

Bill said:

> I mean my doctor is just so there, I never feel like he is fitting me in. When he closes the door all his attention is on me, you feel like there is no other person, just you that he is listening to. He will even work through his lunch hour without even thinking of it.

Perhaps the ultimate connection for these men came from physical contact with their physician. As the men explained to me, having HIV makes you sensitive to people's action, including who and when a person wears rubber gloves, Letters described it this way:

> Like I have never been to a doctor where if you are having a rough time health wise, when you get up to leave his office, he will give you a hug and say I will see you next time. I have never had it and he does it. It's incredible. You just don't see it.

Gloves said:

> Yes, people won't... and I am always so conscious of that both, but like in daily living and when you go to the doctor, but that woman (student doctor) was the first person to touch me without the rubber glove. I felt like just this awful thing that should be swept under the carpet and never touched again. She was really nice very caring, very sensitive, she had the right people qualities to deal with the issues around HIV. She started to put the needle in and I pulled my arm back and said "Do you realize what is wrong with me?" and she said "Yea, I'll be careful, don't worry about it", and it's like I wanted to get up and hug this woman because I can't believe you are actually going to draw blood from me without at least 6 layers of latex between you and me. She actually touched me. It was like are you ok woman? Are you serious? Do you realize...? It was like wow, she finally made me feel human.

Getting to know someone takes time, active listening skills, and a genuine interest in that person's life. Doctors who take the time to inquire how their clients are doing physically, mentally, and emotionally as a human being first and as a person living with HIV second truly connect with their clients.

Disconnection

In contrast, this category characterizes a physician who ignored the emotional needs of the client and focused solely on the medical aspects of the disease, in fact treating the person as the disease, Gloves stated:

> When I go to visit my doctor, he looks at my chart tlls me what my numbers are, asks me if everything is alright, signs the blood form and off I go and get my blood tests. There is no real interaction between us.

Moss explained it in the following quote:

> I felt the other ones were there to make the money and, ya know... Because they came, he said, "How are you doing?", flick, flick, flick, (Moss imitated the noise made by turning the pages of his chart) "I'm going to send my resident in.", or whatever and he is gone, you know. Sometimes he would ask my permission, or he would just bring him in and say, "By the way, this is da, da, da, I hope you don't mind.". Sometimes he would ask would it be okay if... but sometimes they didn't. Like sometimes the guy would come in, you know, it would always be someone different. You know sometimes it would be a woman, sometimes it would be a guy, and it would be like, "This is Sherry, da, da, da, she's going to sit in on this examination, you don't mind do you?". And I would say, "Well, I guess not since she is sitting down now.". It would have been nice if he had come in and said, "Would you mind if...", because some days you're just not in the mood, do you know what I mean?. After driving to Hamilton you just want to, you know, after waiting an hour and a half, and he is coming in with this person, like, ya know, I am just not in the mood, I just want to get back home. But I never felt that I could really say, "Yes I do."

The lack of appreciation for the emotional aspects of living with HIV are clearly ignored by the student doctor in the following quote from Gloves:

> My doctor had a student one day. This student doctor came in and looked at my file and if he would have read any of the entries he would have known that my diagnosis was very new and that I was an emotional basket case. He came in, he sat down and he read for a few minutes, he introduced himself and then he said, "So what's it like living with AIDS?", I just looked at him and I started to cry and I shut right up. Then he left and I said to my doctor, "Don't ever do that to me

> again.". I said, "I don't mind helping people and this might be the best part of my life is to be able to eventually someday be able to talk about what is happening, to educate people so it doesn't happen to someone else, or to give some people some sense of caring and compassion and acceptance and understanding, but I said, "This is not the time in my life to do that. Don't give me a student.".

Dave explained:

> I find that even with my other doctors that they all seem to be so intent on the medical stuff and they don't have the time for you. You can tell by their mannerisms like, they sort of want you in and out. Its like, "What is the problem and lets find out and lets get out of here."

The ultimate experience of disconnection came from dentists and doctors who clearly discriminated against these men because of their disease, Letters said:

> I went to a dentist last year where pretty much the door was slammed in my face. I was upfront and I filled out their forms and where it said any diseases whatever, have you been tested for HIV? Yes. Are you HIV positive. Yes. Then he hemmed and hawed and gave me a prescription and sent me on my way. Would not extract the tooth. It was awful it was the most devastating feeling I felt like low, as low as you can get. Like I was second class. But I sent letters to the Ontario Dental College. It finally just disappeared because his receptionist phoned me after the incident and apologized for her bosses behaviour but then when it came down to it in her letter she denied even phoning us or.. Which we just let it go. But friends of mine were ready with pickets, they were going to picket in front of the office. That was an awful time though. I am in total pain because I have a cracked tooth and this on top of it. I just couldn't deal with it. It was awful. I remember the day. I remember the night I came home had a few drinks and then I called every support group I could think of. I called the local AIDS committee and I phoned Toronto and everything. I called everywhere I could. To change it, see what I could do and then I finally just called the CDA and wrote them letters and tried to recall everything I said wrote it all down and sent them letters.

Physicians who treated only the medical issues associated with being HIV and forget that their clients were human beings with both physical and emotional needs leave clients with a sense of disconnection.

Empowerment versus Disempowerment

Empowerment

This category characterizes a physician who consciously involves the client in the decision-making process and respects the client's ability to make his own choices. By sharing treatment issues, such as the pros and cons of medications, doctors invited clients to become equal partners in the decision-making process, Moss explained:

> Well he tells me the pros and cons of everything. He, like, he says, it is entirely my decision. And I have the choice of taking the medication and dealing with the side effects and maybe prolonging my life for six months and being miserable, or not taking it and feeling fine, and it may not give me those six months. but that is the chance you have to take.

The physician in the following quote from Bill clearly respected his client's ability to make his own decisions, supporting his client's initial choice of not taking any medication:

> After the relationship was established I had the benefit of having about 6 years of virtually no problems so there was very little need to negotiate how the treatment went because there just wasn't treatment and as therapies and counts started to drop then there were nudges on his part that really maybe you should consider this particular drug and the drug was the AZT and that he probably started making little comments probably 4 years ago- saying that you could certainly be eligible for it and I think by that point we had already known each other for 4 years or 6 years and I was comfortable enough in being able to say to him that I didn't wish to do any medication that the medication had a negative attitude and that I did not want them to be a part of my life. In those days the AZT required that you take them every 4 hours, night and day, so it meant getting up and it was quite upsetting stomach wise, quite a strong drug, the doses were really heavy in the early days but as they got to know the drug better the doses changed but I avoided all medication until I could no longer avoid them. He was very supportive and told me that it was my own decision and that he would not force anything on me that I didn't want to do.

Letters explained:

> The important thing is that things are talked out. Decisions aren't just made. He doesn't make them, I don't make them, we talk about them. And if I am

> comfortable with them, then we will go ahead.

Physicians who recognized and respected their client's ability to comprehend medical treatment issues and who shared with their clients the pros and the cons of drug treatments allowed for informed decision-making and empowered their clients to assume an active role in their health care.

Disempowerment

In contrast, this category characterizes a physician who gives directions rather than choice and denies the client the opportunity to be involved in his health care decisions. When doctors do not provide their clients with treatment information, such as the pros and cons of chemotherapy, the client is left feeling disempowered, Dave stated:

> Like this GI doctor that I am seeing, the last time I went and saw him about a month and a half ago he put me on steroids but didn't really take the time to explain to me if you don't take them this is what will happen and if you do take them this is what will happen. So it was sort of like well I didn't really have that choice and I thought well I had better take them but I don't like being put in that position. But again he wasn't someone that I could discuss that with because he just sort of said... phuh. (Dave gestured as if to indicate that the doctor just can't be bothered).

In addition, doctors who were not up to date on the latest HIV treatment information also denied their clients the ability to make informed decisions since the information could simply not be provided by their physicians, Gloves explained:

> It is just so hard to go to your doctor and open up. Ya know you go in for a wart and you have it removed but to have that one-to-one personal level it's just so hard to develop and I have some really strong needs, I expect, I have really high expectations of what I want from my doctor because I have a life threatening illness and I need his education and his smarts and ability and sometimes they are just not there. Like when I go into the office and say like what are the pros and cons of AZT vs DDI, my doctor looks at me and says I'll have to look it up and that is not the kind of response I need. You're a busy man, I can only see you once

> a month, I need for you to be a least somewhat up on what is happening, like what is the latest HIV treatment.

Disempowering doctors often made decisions on behalf of their clients rather than including the client in the decision-making process. In the following quote from Dave, a blatant disregard for the client's ability to make his own decisions is evidenced.

> At this same hospital I found out they wanted to put me in a private room. They wanted to protect the other patients and make it easier for me. Well, let me make that decision, and well they shouldn't be exposed to AIDS and panic the other patients, and I am saying, "Excuse me, wait a minute here. What if there are three other patients in my room that are uncomfortable with me just because I am gay. Are you going to put me in a separate room, or if I am black, or an injection drug user, they are going to have to deal with it." But no, no, there idea was, "For your own protection, for your own safety, for your own comfort, we will put you in a separate room." I said, "No you won't."

Physicians disempowered their clients by withholding information regarding treatment issues, thereby denying the client the opportunity to be involved in their health care. By making decision for their clients rather than with them, doctors maintained the unbalanced, hierarchical relationship and the men are left feeling disempowered.

SOCIAL ACTION: MEDICAL STUDENTS' TALK

An integral part of my thesis is the social action component. It was my desire to present the findings of my study to medical students in order for the students to have the opportunity to gain valuable insight into the experiences of gay men living with HIV. On October 24, 1994, I presented the findings of my study to medical students enroled in a course on the psychosocial aspects of living with HIV at the University of Western Ontario. I was part of a panel that consisted of Dr. Gary Gibson, who was the course instructor and my friend Bill who was HIV positive at the time of our talk. Below I present an outline of my talk.

My Talk

The Psychosocial Issues of Living with HIV: The Doctor-Client Relationship and Gay Men Living with HIV

The men I interviewed described compassion in terms of a people skill, something that you needed to have to be a good physician. As one of my participants said... *The first time, I went to see him he poked at me for about half an hour but then he took half an hour to almost 45 minutes with me and however long I wanted to stay that was fine, ya know like I just got the impression that he was not there to make the money he was there to make a difference.*

Included in compassion are characteristics such as caring, understanding and acceptance. Accepting the person living with HIV infection for whom he is, a person who just happens to be ill. Compassion can be seen clearly in the following quote. *But that person was the first doctor to touch me without rubber gloves. I felt like just this awful thing that should be swept under the carpet and never touched again. But she was really nice very caring, very sensitive. She had the right people qualities to deal with the issues around HIV.*

Speaking about rubber glove wearing. I don't think they realize what they are doing, what they are saying. I mean actions always speak louder than words and being HIV positive makes you more sensitive to whats happening around you.

Collaboration as described by the men I interviewed came out as a willingness of the patient to work with his physician in terms of health care planning. *It is a human need to have knowledge of what it is that is going on inside you.* I think that quote refers to the patient needing to have information shared with them.

Each time I go he says you know your counts are below 500 you should really consider AZT and yet he doesn't offer me any more information about AZT and he knows that my instincts inside me say I just don't want it.

All of the men I interviewed talked about wanted to be key people in the decision-making process, in fact they believed that the ultimately decisions were theirs to make. *Well he tells me the pros and cons and tells me that it is entirely my decision. I have the choice of taking the medication and dealing with the side effects and maybe prolonging my life for six months and being miserable, or not taking it and feeling fine. It may not give me those six months but that is the chance you have to take. And it is my choice because it is my life.*

The people I interviewed realized how difficult it can be for a physician...*Doctors do not have an easy life, there is no way that they can keep on top of everything that is going on cancer, HIV...and I think they can learn a lot from the people who are intuitive enough and energetic enough and intelligent enough to go and find the answers for themselves. The information can be shared in both directions.* The client is looking for a relationship that is based on collaboration and sharing of information, decision-making and control.

In a study by Taylor, Helgesen, Reed and Skokan, in 1991, gay men living with HIV were asked about their ability to exert control over the disease itself, their daily symptoms and their treatment. The men were also asked about the perceptions that others, such as doctors, could exert some control over the disease. The authors found that perceptions of personal control were associated with better adjustment to HIV. Interestingly the authors also found that men who perceived that others could exert control over their disease were more poorly adjusted. The authors suggested that due to issues of prejudice by the heterosexual community toward gay men, the lack of response initially, to AIDS by the health care community and homophobia it may be difficult for gay men to benefit from the belief that others can exert control over their disease.

HIV positive people and particularly gay men seem to take control over the course of their treatment. And I think that is because there are not that many doctors that are up on the latest issues of HIV and AIDS. Gay men pick up all the literature themselves because they are pretty much in tune with taking care of themselves to start off with and this is just one more aspect, so they go out and do it for themselves.

HIV is illness that the person cannot control, they do not know when it will really hit them so reading and staying on top of things that is the only control that the person living with HIV has.

The issues of confidentiality for people living with HIV infection are enormous. Therefore, it is not surprising that the men I interviewed talked about the issue of trust in the relationship.

I mean it's not like I'm seeing a doctor, it's like every two months I go to see, well a friend. I can say anything I want to him and I know that is where it is going to stay.

It is just so hard to go to your doctor and open up. Ya know you go in for a wart and you have it removed but to have that one-to-one on a personal level, it's just so hard to develop.

Responses to the Presentation

At the conclusion of my talk, the students and I had some discussion about what I had presented. The first thing the students asked me to explain was my use of the word "client". I explained that for me the word patient had a negative connotation which suggested someone who had less power than the physician. I said that my preference for the word "client" centred around the fact that this word seems to connote equality within the relationship. One female resident shared with me her thoughts which were that the word client made it sound like I was describing a business relationship and she assured me that, "This is not a business relationship." I queried her as to whether she got paid for providing a service, to which she angrily replied that, her profession was different from other professions.

The next topic which the students questioned me about was whether I was advocating that all doctors not wear rubber gloves so that the "patient", this was their word choice, would feel better. I must admit that I was a bit overwhelmed by this question and was thankful of Dr. Gibson when he intervened and assured the residents that I was not advocating anything but merely sharing the experiences of the gay men living with HIV whom I had interviewed.

Finally, the students explained to me that they could not be friends with each and every one of their patients. I explained that I did not think it was necessary for them to be friends with their patients, but that perhaps they could engage in behaviours that made their clients feel like they were friends.

After my talk Bill spoke about what it felt like for him to live with HIV including his personal struggles. His talk was very eloquent and moving. I was struck at the time by the fact that when one of the residents wanted to know what Bill's last blood count was the resident asked Dr. Gibson the question. I think I agree with Gloves, "actions always speak louder than words."

At the end of all presentations and discussion I handed out an evaluation form. My intention was to obtain feedback regarding my talk, however, some of the residents evaluated the whole panel session. In this next section I present some of the comments written on the evaluation forms.

Question 1. Briefly tell us what you learned from today's workshop.

~ reinforced basic principles

~ confirmation of what already knew but enabled a good synopsis and pattern

~ minimal

~ The concepts were not new ones, they are part of the person-centred method format we have been taught. Feedback from patient was informative.

~ the personal issues of living with HIV

~ HIV people want to feel like human beings

Question 2. What part was the most informative? Why?

~ patients' feedback

~ Bill's discussion of dealing with the issue surrounding HIV

~ Talk by Bill, useful to hear firsthand experience

~ being friend may be okay, Bill being so open

Question 3. What part was the least informative? Why?

~ General issues re: doctor-patient relationship, these issues have been ingrained into us throughout our residency

Upon reflection of my experience with the medical students at the University of Western Ontario I realised that my approach to the presentation may have been construed as confrontational. It was the purpose of my talk to convey to these students what I had learned from the gay men living with HIV who participated in my study. However, I think perhaps that the students thought that I was there to tell them how to do their job. At best I experienced ambivalence from the residents and at the worst I experienced a lack of respect and a hint of hostility. I realise now that I highlighted mostly the negative experiences of the men in my study and that these negative experiences may have made the students feel defensive. If there were to be a next time, I would focus on both the positive and negative experiences of the men, and I would attempt to engage the residents in further discussions about the relevant issues. Despite the somewhat negative reaction of the residents to my talk, I do not believe that this talk had no impact on the residents, as it seemed to me from their often emotion-laden responses that I piqued their interest on several of the topics I discussed.

CHAPTER 4

DISCUSSION

Unlike the body of literature which I reviewed related to the doctor-client relationship and gay men living with HIV, my study was completely exploratory. At the beginning of each interview I simply asked each man to tell me about his relationship with his physician. Each man told his story in his own unique way. Through this technique I learned a great deal about the doctor-client relationship. The experiences described by the men are both negative and positive. For me, two key themes emerged from the narrative analysis process. These two themes, as identified in the community narrative, are connection versus disconnection and empowerment versus disempowerment.

Within these two themes I understood how the men described both positive and negative experiences they had with their physicians. On the positive side, the men discussed physicians who took the time to sit and talk with them and who willingly shared treatment information and options with them. The men also described physicians who engaged in shared decision-making and respected the clients decision-making ability. In addition, the men described physicians who treated the client as a human being who happened to be ill, thereby appreciating the emotional aspects of the disease. Lastly, the men valued physicians who were willing to have physical contact with the client. Conversely, the men discussed physicians who did not interact with their clients and who addressed only the medical aspects concerning the client. Also on the negative side, the men described physicians who did not share treatment information and options with clients, who therefore denied clients the opportunity to be involved and have control over their health care. Finally, the men talked about physicians who often made decisions for their clients rather than with them, and physicians who discriminated against their clients treating them as if there were not a human component to the disease.

All the men I interviewed experienced some sense of loss: loss of relationships, loss of jobs, and the loss of less concrete things such as independence, pride, and dignity. Three of the men in my thesis experienced loss of life due to their illness. The lines "I'm growing tired and time stands still before me and Frozen here on the ladder of my life" from Elton John's song "Don't Let the Sun Go Down On Me" highlight for me the tragedy of a life which has ended prematurely due to AIDS. However, as Dave clearly states, "This is a disease of losses, there are so many things that we lose, and the big one is loss of control..." Specifically with respect to the doctor-client relationship, the men lost control of the decision-making process. Control over decisions about health care treatment was taken away from the men by doctors who did not openly discuss all treatment options or provide adequate information about the benefits and side effects of medication, thereby preventing the client from being able to make an informed decision. Other decisions over which the men had little or no control included choosing: to have a resident present during a visit, to be put in a private room, to have an AIDS test, and with which doctor to work.

Researchers in the area of control and psychological adjustment to illness have found a strong link between positive psychological adjustment to an illness and feelings of having personal control over the day-to-day symptoms and course of an illness (Taylor et al., 1991; Thompson & Spacapan , 1991). Interestingly, there is also research that suggests that for gay men living with HIV belief that medical professionals have control over the course of their health care treatment is associated with negative psychological adjustment to the illness (Reed et al., 1993). In addition to being linked to positive adjustment to an illness, feelings of control have been found to be associated with better health outcomes (Thompson & Spacapan, 1991). It is believed that feelings of personal control may moderate a person's physiological response to stress, resulting in fewer adverse effects on the immune system (Lord & Farlow, 1990). In light of these research findings and from the personal experiences of the men, I believe it is imperative that within the doctor-client relationship steps are taken to ensure that control of health care issues remain in the hands of the client. Loss of control over decision-making undermines the values of self determination and collaboration and participation. Since ultimately health care decisions affect the life of the client, clients must be consulted on each issue, and it must be the client who makes the decisions in the relationship. It may be that for some clients, they would prefer to be consulted on issues but have the doctor make the decision. From my perspective, as long as it is the client's decision that the doctor be the primary decision-maker, the value of self-determination is still being respected.

Several of the men I interviewed described experiences of discrimination in the form of AIDSphobia and homophobia. This experience of discrimination seems to be encapsulated by the line from Elton John's song "Don't discard me just because you think I mean you harm." The words highlight for me the significance of the participants' experience of stigmatization. For instance, Moss' story of how he learned that he was HIV positive, in my opinion, is an example of discrimination. I find it difficult to imagine a doctor informing a client that he/she has cancer in the same abrupt, non-caring manner that Moss reported. What I also find difficult is to identify which type of discrimination Moss may have experienced. The reality is that gay men who are living with HIV are stigmatised both as homosexuals and as diseased persons (Cadwell, 1991;

Fineberg, 1988).

In a study that investigated AIDS anxiety among health care professionals, almost half of the respondents reported feeling angry at the homosexual population for the AIDS epidemic, while 18% of the doctors and 33% of the nurses agreed that homosexual men who were HIV positive had only themselves to blame (Wallack, 1989). Abby Wilkerson (1994) shares findings from a Health Department Study which indicates that 21% of 241 HIV positive people could not find a dentist willing to treat them. Both of these studies confirm and validate the experiences of the men in this study. It is not the case that these men are overly sensitive or have negative attitudes, their experiences are real; some or many doctors, nurses, and dentists do discriminate against HIV positive gay men. Health professionals must confront both their fear of AIDS and their attitudes towards homosexuality, if healthy doctor-client relationships are to flourish. It is neither fair nor ethical for a physician to display his/her fear by refusing to provide treatment or treating the client as if he/she was an object. It is imperative that doctors do not engage in behaviours that may be discriminatory to clients, because discrimination undermines the value of human diversity. Doctors must also be careful not to make assumptions about clients based upon stereotypes. Each person is an individual and therefore should be treated as such.

Another aspect of discrimination against men living with HIV is dehumanization. This is the practice of divesting or depriving someone of human characteristics (Webster's Dictionary, 1988). In the song by Elton John "Don't Let The Sun Go Down On Me", the line "But these cuts I have oh, they need love to help them heal" seems to me to highlight the need for acceptance and unconditional positive regard that the men need and deserve from health professionals. These interpersonal qualities were glaringly absent in some of the relationships these men had with their physicians and thankfully present in others. With respect to the men in this study, they experienced dehumanization at the hands of residents whose personal curiosity led them to disregard the personal feelings of the client and doctors who only dealt with the medical aspects of their clients. In a recent study (Foley & Fahs, 1994), interviews with HIV positive clients revealed that hospital health professionals were engaging in depersonalising behaviours, such as referring to their clients as "the AIDS patient." The authors conclude that health care professionals need to develop increased sensitivity to clients' perspectives of their circumstances. Cherry and Smith (1993) also describe the loneliness gay men living with HIV experience at the hands of physicians who ignored the emotions associated with learning one is HIV positive and referred to the men in judmental language, such as "the AIDS victim".

The reality is that this lack of sensitivity experienced by the men badly damages any type of emotional bond that may occur between client and doctor. AIDS is not just a physical illness, it is also an extremely emotional one, and insensitivity simply compounds the emotional pain (McConochie, 1994). Dehumanising treatment undermines the value of caring and compassion. Care within the doctor-client relationship involves much more than the treatment of physical illness. It involves caring and compassion being expressed for the emotional and physical well-being of the individual. By treating individuals as if they were objects and therefore devoid of all emotions, the doctor is providing inadequate care, care that may in fact lead to distress and therefore increased risk of illness. I concur with Cherry and Smith (1993) who investigated the psychosocial dimensions of HIV disease and concluded that, for caregiving to be effective, it must consist of care that treats people with AIDS as total human beings who happen to be ill.

Similar to the study by Crossley (1998), the men in this thesis also rejected the sick role.

None of the men placed sole responsibility for their health care and the decision-making process in the hands of the doctor. Most of the men chose to engage in shared decision-making with their physicians. The men listened to the physicians' suggestions with respect to treatment options and shared their own opinions with the doctor and ultimately made their own informed decision. It was not the case for any of these men that they simply accepted the doctor's authority. All of the men challenged their physicians and demanded that their doctors share treatment information and options with them. The extent to which they challenged their doctor varied among the men, however, each man in his own way sculpted the doctor-client relationship to suit his needs. The difficulty in this process arose when doctors did not allow enough time during appointments for questions or were not up to date on the latest HIV/AIDS treatment issues.

The study by Wong-Wylie and Jevne (1997), in my opinion, mirrors most closely the present findings. In their study the authors asked people living with HIV/AIDS to describe hope-enhancing and hope-diminishing interactions that took place between themselves and their physician. Within the hope-enhancing category the participants identified being known as a human, connecting, and informing as some of the behaviours their doctors engaged in that enhanced their hope. Conversely, within the hope-diminishing category participants identified being known as a patient, disconnecting, and poorly informing as some of the behaviours engaged in by their physician that diminshed their hope. The title of Elton John's song "Don't Let the Sun Go Down On Me" captures for me the essence of the crucial nature of hope and its role in the healing process for men living with HIV. The men in my study experienced behaviours within both these categories, although the men did not explicitly identify them as such. In my study I did not ask the men to identify hope-enhancing or hope-diminishing interactions directly. However, through the openness of the questioning and the duration of the interviews I elicited comparable data.

Having summarised the experiences of the men within the themes of loss of control, discrimination, and dehumanisation, I would now like to identify what the men deem as appropriate guidelines for physicians. I am not intending these guidelines as a didactic mandate for physicians, because my qualitative study included only six participants and therefore is not generalizable. Nonetheless, this list has value in that it stems indirectly from the men's wishes of how they want their docor to work with them in the healing relationship.

Recommendations for a Healing Relationship

1. Do...recognize my ability to make my own decisions.
2. Do...respect the decisions I have made.
3. Do...treat me with respect.
4. Do...treat me as a person who happens to be ill.
5. Do...appreciate that I have feelings.
6. Do...admit your fears.
7. Don't...expect me to feel immediately comfortable with you.
8. Don't...treat me like a disease.
9. Don't...make decisions for me.
10. Don't...push medication on me.
11. Don't...use technical language.
12. Don't...ignore my feelings.

13. Don't...discriminate against me.

In addition to naming recommendations for doctors, the men also identified several qualities that they would like their physician to possess. These qualities include being willing to spend as much time with the client as needed, sitting and talking, being caring and compassionate, and being open and honest. Gloves also described many attributes that he considered important for his doctor to have. I include the qualities he specified in this list, because I believe that they are representative of the physicians' attributes desired by each man.

Qualities

1. Be willing to spend as much time with me as I need.
2. Be willing to sit and talk with me.
3. Be caring and compassionate.
4. Be open and honest.
5. Be willing to provide me with emotional support.
6. Be current with respect to the latest treatment issues.
7. Be accepting.
8. Be sensitive to the fact that I am gay and HIV positive.

Strengths and Weaknesses of the study

One of the strengths of this study is that I chose to use narrative analysis as the methodological approach. Narrative analysis allows the voices of oppressed groups to be heard;

specifically, the voices of clients, gay men and HIV positive men are heard in this study. An additional strength of this study is that I believe participation in it was an empowering experience for the men. I provided each man with a copy of his transcript and asked his permission to include his interview in my thesis, prior to which I deleted any information the participant said he did not want included. I also shared with as many participants as I could my interpretation of their stories and incorporated their thoughts in my thesis.

One weakness of this study is the fact that it only includes the stories of six men, therefore limiting the transferability of my findings to other samples. Another weakness is that I chose to focus on only one aspect of the lives of gay men living with HIV, that is, their relationship with their physician. This meant that portions of their interviews that did not relate to the doctor-client relationship were not included in this study.

I would like to conclude this section of the discussion by sharing some of my thoughts for future research. An article by Zimmerman and Rappaport (1988) provided me with one idea for future research. The authors studied the relationship between empowerment and participation in community activities. It would be interesting to investigate whether people living with HIV who have empowering doctor-client relationships participate in the fight against AIDS more so than their non-empowered counterparts. Directly related to my study would be a study which determined if men who have empowering doctor-client relationships have better health outcomes. The results of such a study could help researchers and health professionals understand the role of the doctor-client relationship with respect to the physicial health of persons living with HIV. It would also interesting to do a qualitative study which looks at the experiences of women living with HIV. It may be that women's stories and experiences are different than the experiences of men. Finally, I believe it would be worthwhile to investigate the positive aspects associated with being HIV positive. Schwartzberg (1993) interviewed gay men living with HIV to discover how the men ascribed meaning to AIDS and their HIV infection. His study revealed that 74% of the participants spoke of ways in which their HIV infection had led to some sense of personal growth. More qualitative studies in this area could help others understand more fully the experiences of persons living with HIV.

MY PERSONAL JOURNEY

I began this thesis in 1994 and finally completed it in 1999. The past five years spent working on this thesis have been for me both the best of times and the worst of times. The best times occurred during the many hours I spent with the six gay men living with HIV who participated in this study. The worst time occurred during the many hours I spent alone with the mens' words and my personal feelings of sadness.

Having the person with whom you intended co-authoring your thesis die before its completion has a huge impact. I say this in a third party manner because it is only recently that I have come to realise just how true that statement is. When I set out to do this research, it was with the naivety of someone who had not much experience with death and dying. I had no idea what lay ahead. Yes, I knew that my dear friend was HIV positive but the thought of him dying did not ever enter my head. I was not prepared for the emotional havoc his death would wreak on me. But then again can anyone truly prepare emotionally for the death of a loved one? Not only did I watch Bill struggle through the last months of his life, I also changed both our lives when our paths crossed, through what I consider fate, on July 15, 1994.

The following is an excerpt from my journal which I share here, because I believe it will give the reader valuable insight into my personal struggles to complete this thesis.

On the morning of Friday, July 15, 1994 at 10:22am I called Gmelin's (the flower shop where both Bill and I worked) to speak to Bill about writing me a reference letter for a job that I am applying for at ACCKWA. I was told that he was not at work and that he had not called in sick. I hung up the phone after pausing to think about this and tried to get on with the rest of my morning. I couldn't. At 10:45am I called back to Gmelin's and asked if anyone had tried to contact Bill. The reply I got was that someone had called and had got Bill's answering machine. I said that I was going to go and check and that I would call Gmelin's back.

I ran upstairs and got dressed - pausing to think about whether I should iron my shirt or not - and told Mark (my husband) that I was going to check on Bill. I think in my heart I knew something was wrong, but I still had to go by myself as I wanted to maintain a sense of dignity for Bill as I know how private of a person he is.

I walked over to his house and began by knocking on his front door. I got no answer, I then walked around to the back door where I knocked again and actually tried the door. Nothing. I ran around to the side of Bill's house and tried to jump up and see if I could see anything in his dining room window. I couldn't. I was too short. I came back up to the front porch and tried to look in the living room window but with the blinds at the angle they were I couldn't see anything. It was then that I heard the loud music coming from inside the house. I put my ear up to the window and could hear how very loud it was. I stared to get a little bit panicky and set off running for my house to get Mark. As I approached the corner of the street I remembered that I had not tried the front door so I turned around, ran back and tried the front door. It was open. I walked into the house not knowing exactly what I was to do and went into the living room.

There on the floor I found Bill. He was wrapped in his white bathrobe with his head tilted back, as a pillow was lodged underneath his upper back and his eyes were wide open. He was making gurgling noises and I knew he was not just asleep. He was incredibly white, almost grey and he was stone cold. I sat down on the floor beside Bill squeezed his hand and yelled "Bill, Bill, I don't know what to do, what should I do?" You see I knew that this was Bill's attempt on his life and I knew that he really did want to die, I needed some time to think but I couldn't. I ran into the kitchen and found the empty pill bottles Bill had left out, I also noticed that all his bills were sitting on the counter. In the living room Bill had left a manilla envelope with his mother's name on it and inside were his funeral arrangements. He also left his album of Mozart's "Requiem" - since this was what he wanted played at his funeral. I stood in Bill's living jumping up and down, crying, and shaking my hands asking Bill what to do... "I don't know what to do, what should I do???". Eventually I decided that I could not let him die and I set off running for my house to get Mark.

I ran home, flew in the front door and yelled "I just can't let him die.. I just can't." Mark and I and Stuart (our house guest) started trotting towards Bill's house and then we started running. We went in through the front door and as soon as I stopped and listened for a minute I knew that I could not hear Bill breathing anymore. I screamed "Oh God he's not breathing" *and Mark ran over to him to see if he could get him to wake up and come around. Mark sat there calling his name and asking Bill to wake up. He then told me to call the ambulance as Mark could not detect a pulse.*

I ran around the kitchen looking for the phone and Mark joined me in the search and found the phone. He called for the fire and ambulance and told them that we had a male who was HIV positive with no vital signs. I started to cry even more as I didn't know whether I had done the right thing or not. Stuart turned the music off and the house was silent. We waited for the fire truck and I ran outside to meet them. They took Bill away in the ambulance and we all quietly walked home. I had many regrets as I waited for the ambulance to arrive as I debated if I had done the right thing.

Finally on Thursday August 11th I got to speak to Bill about all the things I had been feeling. It seemed really incredible to be speaking about death with someone who you wish had got his wish and had died. We laughed and we cried. I read Bill a poem which is written by a man who watched his partner die and I discussed with Bill how I felt I did have a choice in terms of saving his life. Everyone tells me I had no choice in that I could not have just walked out of the house and left Bill there, however I believe I did have a choice to just sit down with Bill and to wait for the end to come but I was not that brave.

I think, actually I know, that I lost myself in this thesis and became completely overwhelmed by my strong desire to preserve every single word each man had shared with me. It became a compulsion with me that I keep the interviews in their entirety even though I had obtained much more information than just stories about the doctor-client relationship. I struggled internally with thoughts like, "Who was I to decide what part of their interview became a part of my thesis and what part got discarded?" and "These men are dying, how can I possibly not consider every word important?" I was stuck. I remained stuck for approximately two years and agonized daily over the guilt I felt not working on my thesis. Finally I realised that if I kept all of the mens' words the potential existed that I would not finish my thesis and their powerful, moving stories would not be shared with anyone. I had to be reminded that I was not writing a eulogy for each man and so I began the second phase of this thesis in 1997 - the creation of a thesis which was respectful of each man and also an academic contribution. I believe I met my goal.

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Appendix A

CONSENT FORM

My name is Adele Parkinson-Heyes and I am currently a second year student in the Community Psychology programme at Wilfrid Laurier University. I believe (insert name of contact person) told you a bit about my study and asked you if you would be willing to participate. I would like to take some time to tell you a little bit more about my study, is now an okay time? (If no, I will arrange for a better time, if yes I will proceed).

My advisor, Dr. Steve Chris and I are exploring the relationship between gay men living with HIV disease and their physicians. We are interested in learning more about how decisions are made in this relationship, the friendship which may exist between the doctor and the patient, and what the patient expects from his physician.

I am hoping to interview approximately 8 gay men living with HIV disease. There will be two interviews, with the first one lasting approximately 1.5 to 2 hours and the second one being approximately 1 hour. During the first interview I will be asking you to tell me about the relationship you have with your physician. I may ask some specific questions as the interview progresses but mostly I will simply listen. I will be taping each of the interviews and then transcribing them. Prior to the second interview I will give you a copy of your interview for you to look at. During our second interview I will ask you if there is anything you wish to add, delete or change about the information you gave me during our first interview. I may also ask a few more questions to clarify anything I may not have understood. I will also ask your permission to use any quotes from the interview in my thesis - these of course would be anonymously.

In order to ensure confidentiality of any information you provide me I will be keeping all information, such as your name and telephone number, the disk with the interviews on it and a copy of the transcription in a locked cabinet. After I have transcribed the interview I will be erasing the tape. You should also be aware that I only know your first name and that I will not be asking for any other information about you. I will also not have your name on any of the interviews. I will be the only person to listen to the tapes and only myself and my advisor, Dr. Steve Chris, will look at the transcribed interviews, however he will not know whose interview it is.

Your participation is completely voluntary and you may choose to not participate. If you do choose to participate you will be given the opportunity to disallow any part or all of your interview to be included in my thesis. You may also allow your interview to be included in my thesis but not any quotes, that is okay too.

Does this sound like something in which you might like to be involved? If yes, I will set up a time and place for the interview. If no, I will thank the person for their time.