

WOMEN'S DISCOVERY OF MEANING AND THEIR HIV TEST RESULTS

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B.S., Kansas State University, 2005

A REPORT

submitted in partial fulfillment of the requirements for the degree

MASTER OF SCIENCE

Department of Family Studies and Human Services
College of Human Ecology

KANSAS STATE UNIVERSITY
Manhattan, Kansas

2008

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Abstract

The risk of HIV infection continues to be high in the United States, with women being one of the most vulnerable populations. Medical tests to determine an HIV-positive diagnosis and to subsequently chart the progression of the disease and the effectiveness of the medications are central to the lives of these women. This paper will focus on how women find meaning in these test results and how these meanings affect the way they view their lives and their relationships. Women are also often in particularly vulnerable positions, and this paper will discuss how they deal with this disproportionate lack of power both before and after HIV infection. It is important to therapists working with these women to have an understanding of how women make meaning of both their HIV test results and power differentials. The implications for therapy include helping the client and her family members understand this new situation and the meanings it has for their lives and relationships.

Table of Contents

| | |
|---|-----|
| Acknowledgements..... | v |
| Dedication..... | vi |
| Introduction..... | vii |
| CHAPTER 1 – Adjustment to Chronic Illness | 1 |
| Adjusting to a Chronic Illness | 1 |
| Women and Chronic Illness | 5 |
| CHAPTER 2 - Medical Knowledge of HIV/AIDS | 8 |
| Acquired Immune Deficiency Syndrome | 8 |
| Viral Load and CD4 Count | 11 |
| CHAPTER 3 - Theoretical Frameworks and HIV/AIDS | 13 |
| Feminist Theory and HIV/AIDS..... | 13 |
| Social Construction, Meaning, and HIV/AIDS..... | 16 |
| CHAPTER 4 - Meaning and Medical Test Results..... | 20 |
| Viral Load and Meaning | 20 |
| Women, Relationships, and Viral Load | 22 |
| CHAPTER 5 - Implications for Therapy | 27 |
| CHAPTER 6 - Conclusion | 32 |
| References | 34 |
| Appendix A - Glossary of Terms | 38 |

Acknowledgements

First, thank you to all my family and friends who have been so supportive of me throughout this process. Specifically, I want to thank my parents who have always been there for me and encouraged me in all aspects of my life. Thank you to my committee members, who have worked with me to complete this project. In particular, I would like to thank my major professor, Candy Russell, for her help and support.

Dedication

I dedicate this to my parents for all of their love and support throughout my education.

Introduction

In the United States today, women are the fastest growing population of those living with HIV/AIDS. Due to the increase in the effectiveness of medications, these women are now living with a chronic disease, rather than a death sentence. Adjustment to this chronic illness requires many changes in not only their day-to-day living, but also in how they view themselves within the context of being HIV-positive.

This paper will focus on women in the United States who are living with HIV/AIDS, how they see themselves as HIV-positive women, and the effects this meaning has on their relationships. Specifically, it will look at how women make meaning of their disease and their changed life within the context of the culturally dominant biomedical model. Currently, medical personnel are seen as the definitive authority on what HIV means and how it affects the body. However, for many people, this is only the beginning, not the end, of finding meaning in HIV. The medical definitions can sometimes even constrain the search for meaning. For instance, the medical information that women are given about their own bodies is often at odds with how the women feel physically. This discontinuity, along with the sheer number of medical tests and medications, force the women to find meaning themselves, by incorporating the medical knowledge, but not being subjugated to it.

In addition to this, men often define medical knowledge. While this has been changing in recent years, women still often find themselves under the care of men within the health field. Therefore, the power differential not only includes the difference between the expert doctor and the patient, but also the cultural power divide between men and women.

The first chapter will contain an overview of the literature on adjustment to chronic illness in general, as well as what this means for women specifically. The next chapter will begin with a summary of the medical understanding and knowledge of HIV/AIDS, as well as a discussion of the relevant medical tests typically administered to follow the disease progression. Chapter Three will focus on the frameworks of both Feminist Theory and Social Construction and how they can each be used as lenses through which to view women's meaning making of HIV/AIDS. The fourth chapter will look at how women find meaning in two common medical

tests and how that meaning then affects their romantic relationships. Chapter Five will focus on the implications this has for therapy and how these themes and concepts can be used effectively in therapy. By obtaining a better understanding of what HIV means to the women living with it, therapists can be in a position to help those women, their family, and friends explore new ways of being. Because the medical field dominates the lives of HIV-positive women, a glossary of relevant medical terms and important concepts is located in Appendix A.

CHAPTER 1 - Adjustment to Chronic Illness

The research focusing on chronic illness encompasses a variety of topics, including how individuals adjust to being chronically ill, as well as how they make meaning of this life-changing development. This “meaning making” includes understanding what a diagnosis of a chronic illness means for the individual’s concept of his or her body and self, as well as how that new self then relates to others and to the cultural environment. The existing cultural environment, far from being a passive backdrop to an individual’s attempt to adjust to and find meaning in a chronic illness, actually provides a set of values and expectations relevant to this process. These expectations have a strong impact on a person’s ability to make meaning of the illness. Any understanding of a woman’s experience with HIV/AIDS must begin with a focus on how individuals adjust to and make meaning of their chronic illness within the context of a social environment.

Adjusting to a Chronic Illness

A diagnosis of a chronic illness brings with it a fundamental shift in how an individual perceives: his or her body, the environment surrounding that body, and important interpersonal relationships. These three different elements influence and are influenced by each other, each one impacting the individual’s ability to change and adjust to the disease.

In order for an individual’s pain to be perceived as legitimate, medical personnel must first provide the diagnosis, and this experience often comes as a relief to the individual. A diagnosis legitimizes the person’s painful symptoms to society, while giving both a name and an explanation to describe what is happening in the individual’s body (Candib, 2004). The employment field also often requires a diagnosis in order to accommodate to the individual’s specific needs, such as sick leave or flexible hours. While a diagnosis is helpful in these situations, it also often carries with it a treatment regimen that will most likely require a drastic change in lifestyle. It often brings the expectation and fear of disease progression and in many cases, possibly a shorter life expectancy. In the particular case of HIV/AIDS, while an HIV-positive diagnosis is no longer the death sentence it once was – provided the individual has access to and can afford the necessary medication – it still carries with it a tremendously strict

treatment regimen and an uncertain future. This is compounded by fears of dealing with the societal stigma, navigating complex interpersonal and romantic relationships, and accepting a body that may feel healthy, but is labeled as ill.

In addition to the practical aspects of treatment and the uncertainty of a chronic illness, the cultural expectations for what it means to be ill also demand that the individual adjust and adapt to their new, ill body. The enormous value that the culture places on having an idyllic body – one that is thin, beautiful and healthy – causes a devaluation of the ill body; it becomes something less than worthwhile (Moss & Dyck, 2002). This idealized body also has a strong sexual component in Western culture, and in the case of HIV/AIDS, this is particularly important to remember. Because HIV is sexually transmitted, the woman is not only seen as less than she once was because of an illness, but also as sexually tainted because of how she may have obtained the disease.

This devaluation leaves the diagnosed individuals attempting to construct meaning within a culture that has decreed their bodies to be less valuable than they once were and less valuable than other healthy bodies. These cultural scripts also convey that an ill body does not have as much to add to society, and ill people are often expected to stop contributing. The adjustment to the illness, as well as to dealing with these negative cultural expectations, is a process that must be lived daily.

The idea of adjustment to chronic illness has been heavily studied. Shelley Taylor (1983) has found that adjustment to a personally threatening event, such as a chronic illness, often revolves around three central themes: a search for meaning; an attempt to regain control or mastery over the event and one's life in general; and an effort to raise the individual's self-esteem. These three themes appear throughout the literature on adjustment to chronic illness.

The idea of meaning making is twofold: it includes an understanding of why the event occurred and a reordering of priorities and attitudes, which individuals believe will lead to more satisfying and meaningful lives (Taylor, 1983). In her study of cancer patients, most participants offered an explanation as to why the cancer occurred, even though medical personnel would agree there is often no "cause" for cancer. Still, Taylor (1983) found that these explanations helped participants adjust positively to their cancer, and allowed them to make changes in their lives that were designed to lead to better health. In the case of HIV/AIDS, of course, individuals will most likely be able to point to a specific behavior, even a specific incident, which led to their

becoming HIV-positive. In this way, meaning making may take the form not of discovering a cause as with other chronic illnesses, but of overcoming any potential self-blame that may come with the diagnosis and reestablishing meaning and purpose in one's life as an HIV-positive individual.

One study found that individuals who were able to discover meaning actually had better adherence to their HIV treatment and medications (Westling, Garcia, & Mann, 2007). This study defined a search for meaning as thoughtful reflection on the event, in this case HIV status, and awareness of the emotions it evokes. This often helps the individual discover a new sense of purpose in his or her life. One participant summarized it best by saying, "...it made me realize how I appreciate life more now than I have in the past and I live one day at a time and try to enjoy each day to the fullest" (Westling, et al., 2007, 631).

However, another study found that patients who emphasized treatment, in this case dialysis, over their daily lives had more severe physical symptoms (Wright & Kirkby, 1999). Taken together, this seems to imply that while meaning making helps with treatment management, allowing the medication management to become more important than living life is also detrimental to health. The second half of Taylor's description of meaning making, the understanding and reordering of priorities and attitudes, leads directly into treatment adherence.

The second theme, mastery, includes gaining a feeling of control over the event by taking active steps towards a healthier future. One study found that this belief in control was positively related to beneficial physical effects (Taylor, 1983). In the course of HIV/AIDS treatment, the individual is required to subscribe to a tightly scripted and very controlled regimen of treatment, including taking medications at strictly prescribed times and with certain dietary restrictions. Adverse side effects are also extremely common and unpleasant. Many in the medical community as well as the patients themselves see this treatment program as exceptionally hard to maintain, so while a sense of mastery is important medically, it may also be quite difficult to achieve (Westling, et al., 2007).

Taylor's (1983) third theme is an effort to enhance and restore self-esteem. In her research, she discovered that this often involves the individuals creating illusions about their disease. However, these are not harmful and are actually beneficial to the process of adjustment. For example, Taylor (1983) found that individuals would often make social comparisons to those who are struggling, leading them to conclude that they are doing as well, if not better, than others

in similar situations. This allows individuals with chronic illnesses to feel that they really are not as bad off as they could potentially be. While for some this may statistically be an illusion, it seems to lead to better adjustment and enhanced self-esteem. Individuals use these illusions as resources and they become very helpful in learning to cope. “In the case of life-threatening illness, these resources may act as buffers against the reality of advancing disease and death to the point that people face such experiences not only with psychological benefits but also with more resilient physical resources as well” (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000, 106).

This third theme of enhanced self-esteem again ties into the previous two. If a woman is able to make meaning of her HIV diagnosis and feel as though she has mastery and control over her medication and therefore the trajectory of the disease, as well as a sense of being better off than others in her situation, her self-esteem is likely to increase.

Adjustment to a chronic illness involves many aspects, and these three themes are useful in understanding this complex idea. An HIV-positive diagnosis is a life-threatening and life-changing event. This is true not only for the diagnosed individual, but also for anyone connected to her, such as family members, friends, coworkers, and especially current and former sexual partners. All of these people are affected by the changes that HIV brings to her life.

The diagnosis can potentially lead to another dramatic change in the illness status: the transition from simply being HIV- positive to being diagnosed with AIDS, which occurs when the individual’s CD4 count drops below two hundred. The concept of adjustment is useful at these two distinct junctures in the case of HIV/AIDS. While adjustment and meaning making are never truly “complete,” these two distinct statuses of the disease will likely cause two different evaluations of the body, self, and relationships.

The social environment cannot be ignored when discussing how individuals cope with chronic illness. Gaining mastery, finding meaning, and restoring self-esteem are all accomplished within the context of the culture. The culture defines what “knowledge” is and how this information should be used. Those in power create and disseminate certain types of knowledge and give them preferential status. Other kinds of knowledge are “subjugated,” and are reduced in availability to “alternative” outlets. When this occurs, people do not see them as worthwhile or true. Still other ideas are diminished by a lack of media space or other resources (Dervin, 1989, 67). Therefore, chronically ill individuals are left with only a limited number of

ways to view both themselves and the disease. This applies not only to the acceptable ways of viewing the disease itself, i.e. within the biomedical model, but the dominant society has also created many scripts for behaviors that it expects will be adhered to by those with chronic illness.

The most common script comes from the biomedical model, which so permeates our society that it is almost universally accepted that until a diagnosis is given by a qualified professional, an individual's suffering is not legitimized or accepted as "real." Once a diagnosis of being HIV-positive is given, the individual's many different illnesses and complaints suddenly are brought into focus by that one diagnosis (Candib, 2004). However, a diagnosis of HIV brings with it cultural scripts and expectations regarding this virus that are very strongly written.

When an individual is diagnosed, the body becomes culturally inscribed with a "text" or a story, which tells those in the society how to think about the ill person, as well as how the individual herself is to behave and think (Dyck, 2002). In her study, Isabel Dyck (2002) found that the women diagnosed with the illness, as well as their friends and family members, came to understand and react to their bodies as something that was "diseased." The dominant social narratives, whatever they may be, have profound impacts on how the individuals will make meaning of the illness and gain mastery over their lives. In many cases it may become necessary for those with a chronic illness to step outside of these cultural narratives and to construct new, more appropriate ones.

Women and Chronic Illness

Before understanding women's experiences with chronic illness, it is first necessary to know who defines the field of "women's health." That definition impacts the way the medical community cares for women (Dan, 2003). Many times, it is not the women who are defining themselves, but society and, more commonly, men. Therefore, it is important to appreciate how women themselves view their bodies and their illnesses and how they make meaning for themselves. Many studies have dealt exclusively with how women cope with and adjust to chronic illness. By focusing on women, it becomes possible to deconstruct the coping strategies of women, as well as understand how the dominant social narratives and gender constructions affect women who have been diagnosed with a chronic illness.

Women diagnosed with a chronic illness not only contend with the physical symptoms of the disease, which were most likely present before the diagnosis, but also with the destabilization

of the notion of a healthy body, which is often taken for granted, especially among younger women (Moss & Dyck, 2002). The data from 2004 shows that cases of HIV/AIDS occur in all age groups, but they are most prevalent for those individuals between the ages of thirty-five and forty-five. Seventeen percent of the HIV/AIDS cases occurred among people in the 35 to 39 year age category, while 21% of AIDS cases occurred among those between the ages of 40 and 44 years (Centers for Disease Control and Prevention, 2006). Women in these age groups must contend with the idea of being sick at a time in their lives when society tells them they should be healthy. American culture often correlates illness with old age, and having the healthy body taken away at a younger age may be particularly difficult for these women.

The diagnosis of HIV/AIDS has taken away the notion of a healthy body at a time when the women may not necessarily be feeling ill. However, by giving the HIV-positive diagnosis, the medical community has marked their bodies as “deviant” from the norm (Dyck, 2002). A diagnosis of HIV/AIDS carries with it the stigma of how the virus was contracted, as well as the cultural expectations of what it means to be HIV-positive. Society has inscribed the women’s bodies with a narrative that they are HIV-positive, and this comes with much more weight attached to it than just the physical symptoms of the disease. However, these cultural narratives about what it means to have HIV/AIDS are only the beginning of the story. It is left to the women to find new meaning and mastery in their lives. “These inscriptions are incomplete, and contradictory, forming borders that are thus permeable, fluctuating, and fluid, leaving space for competing readings of ill bodies. Because they exist within these borders of illness, women are able to resist dominant readings of ill bodies, and engage in practices that redefine the parameters through which their own bodies can be defined” (Moss & Dyck, 2002, 171). By resisting the dominant cultural narratives, women can begin to experience their illnesses in new ways.

One study focused entirely on how chronically ill women experienced symptoms and pain management. This study found that women often measured their health by monitoring how well they were able to meet their home and family responsibilities. They also focused on their subjective levels of fatigue at these daily tasks. Women reported greater symptom distress. In contrast, men focused more on their caregiver’s instructions as an indication of general health and reported less pain overall (O’Neill & Morrow, 2001).

This idea points to the social narrative of women as the homemakers and caretakers for their children. If they are unable to meet these demands, women perceived themselves to be in

poorer health than a man who could not complete the same tasks. The greater symptom distress, as well as the women's self-monitoring of their bodies, indicated a greater perception of the body in general.

O'Neill and Morrow (2001) also found that in general, women are more likely to use confrontive coping strategies rather than avoidance strategies. Confrontive strategies include positive reappraisal, distancing, and seeking spiritual guidance. While these are positive implications for women, it must be noted that these types of coping strategies and meaning making are easier for women of greater economic means to accomplish. When women live in poverty, their focus must be on economic survival for themselves and their families, before they can find meaning in their illness and use positive appraisal to refocus their life priorities. While physical survival is a much more immediate and pressing need for women living at or beneath the poverty line, nearly all the women in this study expressed a significant amount of distress about being able to access the necessary resources (O'Neill & Morrow, 2001).

A final element that women with chronic illnesses must contend with is the day-to-day fluidity of their lives. It becomes difficult to make plans because there is always an uncertainty regarding the body, which cannot be anticipated (Dyck, 2002). This is especially difficult when women measure their health in accordance with how much they can accomplish around the home and for their children. This inability to make firm plans can significantly impact the relationship these women have with their children. Soccer games, school plays, and piano recitals all become soft plans, in expectation of the days the women find their bodies unable to perform as they had hoped.

All of these elements of living with a chronic illness affect women significantly in all aspects of their lives. In the case of HIV/AIDS, women are the fastest growing segment of the population to acquire the virus. Between 2000 and 2004, the number of AIDS cases in the United States increased 10% among females and only 7% among males (National Institute of Allergy and Infectious Diseases, 2006). Because of this increase among women, it is important to understand how these women adjust to an HIV/AIDS diagnosis and how they find meaning in a life changed forever by this virus.

CHAPTER 2 - Medical Knowledge of HIV/AIDS

In the United States today, the medical community is responsible for providing the majority of the understanding and knowledge of HIV/AIDS. Because the biomedical model is extremely important in Western culture, any diagnosis of HIV comes from and then is filtered through this model. When a woman learns she is HIV-positive, the medical knowledge and the views of her doctors and nurses become central to her life. Any meaning or narrative she creates for her life, as an HIV-positive woman, is built on and around the medical understanding of HIV. Her life now includes a variety of medications, frequent visits to the doctor, and numerous medical tests.

Chapter Two will provide the reader with an overview of the medical understanding and knowledge of HIV/AIDS, as well as the typical progress of the disease. It will also include an explanation of the two most common medical tests designed to chart HIV progression: the viral load test and the CD4 count.

Acquired Immune Deficiency Syndrome

Acquired Immune Deficiency Syndrome (AIDS) was first seen by doctors in 1981 and named in 1982, but it was not until 1984 that the human immunodeficiency virus (HIV) was discovered and shown to be the cause of AIDS (National Institutes of Health, 2001). While it is difficult to determine the number of people living with HIV, in 2005, it was estimated there were 900,000 Americans living with HIV, with 40,000 more people becoming infected every year (Berry & Hunt, 2005). Although AIDS affects people from all races and socioeconomic backgrounds, people of color have higher rates of HIV than White people (Berry & Hunt, 2005). By understanding the demographics of who is at risk, it becomes clear that HIV/AIDS must be understood in the context of this unequal risk factor. Without this important element, any discussion of AIDS would be missing a crucial piece. This disproportionate vulnerability is also seen after HIV infection, as many people find themselves unable to afford the life-saving medications.

However, before these differences can be understood and appreciated, the physical course of AIDS must be explained. The course of the disease varies greatly from person to person. A variety of factors can affect the reproduction of the virus and influence how well the body's immune system responds to opportunistic infections. "Opportunistic infection" is the term doctors apply to a disease that takes advantage of a weakened immune system, such as tuberculosis or pneumonia. Due to the wide variability in individuals' immune functioning and their ability to fight opportunistic infections, the course of HIV/AIDS is unique to each person. In order to understand how individuals make meaning of an HIV-positive diagnosis and the distinctive course their disease takes, it is necessary to have a basic knowledge of the general course of the disease.

After an individual has been infected by the HIV virus, it may take anywhere from three weeks to three months for an HIV test to show a positive result. An individual who is HIV-positive, or seropositive ("sero" meaning "viral"), may be symptomatic or asymptomatic; this depends several factors, including immune health and the presence or absence of opportunistic infections.

Throughout the treatment for HIV infection, medical personnel routinely check the person's viral load, which is the amount of HIV in the blood, as well as the CD4 count - the level of white blood cells. These cells are necessary to an effectively functioning immune system. In general, as an individual's viral load increases, the CD4 count decreases, resulting in a possible increase in physical symptoms or infections.

The diagnosis of AIDS is only given if there are specific AIDS-defining diseases, which are the most severe opportunistic infections, or a CD4 count of less than two hundred. For comparison, healthy adults have a CD4 count of more than one thousand. This diagnosis of AIDS will remain with the individual, regardless of any future CD4 counts higher than two hundred (Berry & Hunt, 2005). Without medication, the clinical course of development from HIV infection to a diagnosis of AIDS can be anywhere from two to ten years (Arnaout, Lloyd, O'Brien, Goedert, Leonard, & Nowak, 1999). However, today there are many treatment regimens for HIV/AIDS, which are designed to control the ability of HIV to replicate, thus increasing this time frame. As one study stated, the goal of these medications is to "maintain immune competence and forestall irreversible immunological deterioration, to allow greater quality of life without evolution to AIDS or death" (Piroth, et al., 2004, 597).

Highly active antiretroviral therapy (HAART) first became available in 1996. This treatment usually includes three different antiretroviral medications in combination, often called the AIDS “cocktail.” The regimen is usually very precise, and strict adherence is necessary for success (Wynn, et al., 2004). There are four classes of medications that comprise HAART, with the most common being protease inhibitors. These particular drugs function by stopping the cell’s ability to cleave proteins into active viral particles, thus they keep the virus from replicating (Wynn, et al., 2004). This will forestall the progress of the infection. More recently, these medications are sometimes referred to as simply “Antiretroviral Therapy” (ART) or “combination therapy” (Berry & Hunt, 2005).

The different antiretroviral medications that comprise HAART often have many adverse side effects. For example, side effects of protease inhibitors include gastrointestinal disruptions, such as nausea and vomiting; dysfunctions of lipid and glucose metabolism, which leads to fat redistribution, often around the neck area; sexual dysfunction; liver toxicity; and an increased risk of bleeding (Wynn, et al., 2004). Because of these painful side effects and the strict rules that accompany the taking of HAART, adherence to the medication treatment is extremely difficult and often adherence rates are very low (Berry & Hunt, 2005). Much of the research in this area aims to find ways to increase adherence.

Although HAART heralded a new phase in the AIDS epidemic, one drawback is that there is now some evidence that antiretroviral medications may be contributing to the transmission of drug resistance forms of HIV (Catz, Meredith, & Mundy, 2001). This is most often the case when two seropositive individuals engage in unprotected sex and transmit different viral strains to each other. The final result of this development on HIV/AIDS management is still unknown.

While these drugs have very unpleasant side effects, they have also managed to transform HIV from an absolute death sentence to a more manageable chronic illness. However, these antiretroviral medications are mostly available in Western countries. Even when accessible, they are still very expensive, and many people are unable to afford them. Rosengarten (2007) stated, “It is possible that ‘the will’ necessary for critique [of HIV] has been replaced by a certain complacency in the West about drugs and, perhaps, even by a shame of having them in light of the millions more who will die without them” (207). Even with these new medications, it is

vitaly important to not become complacent or to forget the large numbers of people without access to the medicine. A diagnosis of HIV is still a tremendously life changing event.

Viral Load and CD4 Count

The combined therapies used to treat HIV typically contain protease inhibitors and nonnucleoside reverse transcriptase inhibitors, which act to suppress the viral loads in the body to undetectable levels. This then leads to improved immune functions (Catz, et al., 2001). The viral load is simply the amount of HIV present in the bloodstream, and measuring this amount is useful in medical circles to determine both the prognosis of the infected individual and to monitor the effectiveness of medications (Ho, 1996). The goal is to keep the virus at undetectable or near undetectable levels in order to maintain the immune system.

The second way to quantify the progress of the disease is to observe the individual's CD4 count, which is the amount of white blood cells in the body. For a given seroconversion (the time of HIV infection) CD4 count, a higher viral load is associated with faster decline and a shorter predicted survival time. However, even for a given viral load, a higher seroconversion CD4 count does not always change predicted survival time (Arnaout, et al., 1999). Because of the many factors influencing viral load and disease progression, a high viral load test result can lead to many differing feelings, thoughts, and meanings for the individual.

Although the viral load is considered to be one of the defining ways of measuring the disease status, viral load cannot be felt in the body (Moore, Candlin, & Plum, 2001). This leads to a very probable disconnect between the physical feeling of well being and the medical test results. By placing almost all indications of disease status on the viral load, the individual herself loses the ability to make personal claims as to the state of her own health.

While medications can sometimes cause the viral load to be so low as to be undetectable, HIV is always there. There have been no medications discovered that can "cure" HIV infection or AIDS. "Viral load can go up and down, but it can not go away" (Moore, et al., 2001, 430). This may cause difficulty in finding meaning in an undetectable viral load. At that point, the individual is as close as she will ever be to being "healthy" again, although even at that time, she may still feel particularly unwell, due to the medication side effects.

CD4 counts and viral loads are two ways of quantifying HIV and determining the disease status. Therefore, the meaning that an individual attach to her test results is incredibly important to her overall identity as an HIV-infected person. These meanings can be very different depending on the circumstances, as well as the individual. “Because viral load is so central to clinical activity, but also because it is by no means an unequivocal symbol of progress and hope, the success of doctors’ and patients’ efforts in planning and implementing HIV health care hangs on a shared understanding of what it means” (Moore, et al., 2001, 429).

Because a woman who is diagnosed with HIV must deal with a variety of medical tests and views, it is important to have a working knowledge of what types of information she is receiving from her doctors. After understanding this, it is possible to move forward and to discover how she then incorporates this knowledge into her overall search for new meaning in her life.

CHAPTER 3 - Theoretical Frameworks and HIV/AIDS

There are many instances, both before and after an HIV diagnosis, that women may find themselves in vulnerable positions, where their control and power over themselves and their bodies are limited. This type of vulnerability combined with their search for meanings and control as HIV-positive individuals are best exemplified by the theoretical frameworks of Feminist Theory and Social Construction. Chapter Three will offer an overview of these two theories and how they function as lenses through which to view women and HIV/AIDS.

Feminist Theory and HIV/AIDS

Feminist theory makes strong use of the “both/and” phenomenon (Lloyd, Few, & Allen, 2007). Rather than focusing on an “either/or” dichotomy, feminist theory seems to understand multiple influences on a single event. This leads to intersectionality, which proposes that power and meaning are constructed through the intersection of race, gender, and class. Each of these elements combines and influences each other, and all must be incorporated into any understanding of gender, power, and identity in modern society.

However, the dual idea of feminist theory and intersectionality does not pull apart identity into the separate aspects of gender, race, and class. Instead, intersectionality can be used to understand how each of these subjective elements and experiences affects each other and, in turn, influences women’s behaviors and their life paths (Lloyd, et al., 2007). This idea is especially important to any understanding of HIV because each of these three elements has an effect on both the risk factor for HIV contraction and on the way women make meaning of the virus after infection.

Feminist theory also emphasizes power differentials and vulnerabilities caused by society. One article stated, “Women and other vulnerable populations continue to be disproportionately affected by the HIV/AIDS epidemic” (Wyatt, Myers & Loeb, 2004, 401). People in oppressive circumstances often do not have access to information regarding HIV prevention or the methods required to protect themselves. Because of this cultural oppression,

feminist theory and social construction together help seropositive women to make sense not only of themselves, but also of the society around them, all within the context of HIV.

Before even becoming infected with HIV, women typically have less control over their sexual relationships and the behavior of their sexual partners than men do. The increased risk of HIV for heterosexual women must be recognized within the context of this sexual power differential. Without complete control over their bodies and their sexualities, women are at risk of contracting multiple sexually transmitted diseases, including HIV. “AIDS prevention campaigns to date fail women by urging prevention methods that women often have little or no power to apply, namely condoms, abstinence, and mutual fidelity” (Tallis, 2000, 65). Many of the advertised ways of protecting oneself from HIV necessitate the male partner’s cooperation. Without the means to care for themselves, women have become disproportionately targeted by HIV.

There are other variables that interact with this concept of female sexual oppression. For example, “Black feminism” is a theoretical framework that recognizes that systems of power maintain socially constructed categories of race, class, and gender. This theory understands that HIV prevention and meaning making must take into account the unique experiences of women in today’s culture, and especially the many controlling images that are constructed for poor African-American women in particular (Gentry, Elifson, & Sterk, 2005). The wide discrepancy between the economic classes, which often runs along racial and gender lines, affects the way HIV impacts women’s lives. “Economic, relationship, lifestyle, and immigration factors, along with substance abuse and risky relationships increase risk for HIV transmission and disease progression” (Wyatt, et al., 2004, 401). It is not possible to solely focus on women and HIV without acknowledging the myriad of other forces affecting their lives today. For example, HIV-positive women are at high risk for sexual and physical violence, and the fear of not finding another accepting partner makes leaving an abusive relationship even more difficult (Gurevich, Mathieson, Bower, & Dhayanandhan, 2007). Women in general are at risk for relationship violence, but the disclosure of a diagnosis of HIV increases this risk substantially.

Women’s inequality in economics in part increases their vulnerability to HIV. However, becoming infected with the virus in turn makes them poorer, because they generally have less access to health care and are expected to carry the burden of care giving (Tallis, 2000). These outside cultural considerations affect all aspects of the disease. Whether or not the woman has

access to education regarding risk factors, her medical insurance benefits, and her ability to pay for the medications are just some examples of how the combined factors of economics, race, and gender interact to create a unique experience of HIV.

The Black feminist perspective addresses the fact that there are differing social structures, while simultaneously acknowledging the need for action. By addressing both societal issues and personal action, those practicing in this perspective aim to empower African-American women to act to change the oppressive conditions surrounding themselves (Gentry, et al., 2005). One of the themes of dealing with chronic illness is finding control and mastery. This may be particularly difficult for women who have been oppressed throughout their entire lives. Adding an HIV diagnosis to an individual already subjugated by race, gender, or class has the potential to be very destructive, not only physically, but also emotionally. The country is only now beginning to recognize this situation as one with cultural causes, rather than simply individual mistakes. “In the mid-1980s, discrimination and other human rights violations directed towards HIV-infected people and people with AIDS were identified as tragic and counter-productive effects of the pandemic, human rights violations are now recognized to be primordial *root causes* of vulnerability to the epidemic” (Mann & Tarantola, 1998, 8). By understanding that violations against HIV-positive people are not isolated incidents but rather a result of the culture, it becomes possible to address the underlying issues of power and social control.

There are many parts of this culture that negatively view the seropositive person. However, power comes still into play, even within the one context where it would be expected that a seropositive individual would be accepted. While the medical community cannot be faulted for wanting to provide the best possible care for the woman; oftentimes, this zeal can actually take away the control and mastery so necessary to mental survival. The prevailing medical wisdom of HIV treatment is to begin medications as soon as possible in order to minimize viral replication. However, the side effects are sometimes so severe that the individual may want to choose to suspend treatment until absolutely necessary. The medical community often views this choice as illegitimate or wrong, and the patient’s choice of how to best care for herself is removed (Race, McInnes, Wakeford, Kleinhert, McMurchie, Kidd, 2001). The HIV-infected woman becomes powerless once again over her own body. If she does choose to delay treatment, she then must deal with the stress of dealing with the disappointment of doctors, family members and friends – people she looks to for support and help.

HIV also creates an inequality of power during the disclosure process. Revealing her serostatus can sometimes be seen as a loss of power. Until a woman divulges this secret, she is viewed on her other merits, such as personality and intelligence. Once she discloses that she is HIV-positive, she is unable to control the reaction and possible rejection of others. This is true of almost any situation – employment, family, and friends – but it is especially difficult when the valued position of lover is threatened (Gurevich, et al., 2007). After disclosure, a seropositive woman is often seen as damaged or diseased, rather than as an individual person. Not only does the inequality of power as seen through race, gender, and class affect the risk for HIV infection, but it continues to play a large role in the woman’s life with the virus.

Social Construction, Meaning, and HIV/AIDS

“Scholars increasingly recognize that human beings live in socially constructed realities – in worlds of objects whose meaning is indeterminate until ordered in social interaction” (Harris, 2006, 224). This understanding of the world is particularly important when focusing on HIV. There are many “objects” – the virus itself, viral load, CD4 count, medications – to which the woman must attach meaning. Often this meaning is derived by her social interactions, as well as the larger cultural expectations that surround HIV/AIDS.

Through the process of finding meaning for these objects, women also find meaning and identity for themselves. A person’s identity is found through social interaction; it is not automatic (Harris, 2006). This was true before the HIV diagnosis, and it continues to be true after it. However, a woman’s pre-viral identity is forced to change after a diagnosis through her interactions with family, friends, lovers, and society. All these contribute the meaning she ascribes both to the virus, as well as to her identity as a woman living with HIV.

Because of the uncertain nature of an HIV diagnosis, as well as the discontinuity between the medical evidence and physical feelings, women with HIV must find ways to make meaning of the situation. Coming to terms with having HIV requires a great deal of this type of adjustment through meaning making. As discussed in the first chapter, the three themes of adjustment to chronic illness also apply to this diagnosis. The theme of meaning making seems to be particularly relevant, as HIV/AIDS comes not only with a social stigma, but also with the challenge of reconciling physical well-being with medical reports of viral loads and CD4 cell counts.

A large part of living with HIV includes heavy doses of medicine and a life that often must be ordered around their rigid scheduling. All of the clinical medications discussed in the previous chapter can sometimes seem to overtake the individual, keeping her from seeing herself as anything separate from the virus and medical regimen. Therefore, it is important to remember that “at the centre of ART clinical management is a *person* conceived through measures of virus and human immune cells” (Rosengarten, 2004, 215). As medical tests continually read the viral load and the CD4 count, the woman must also continually redefine herself, incorporating the new information about her body into her worldview and sense of self.

Before assessing specifically how viral loads and CD4 counts affect a woman’s ability to find meaning in an HIV-diagnosis, it is helpful to understand that women can construct meanings that are positive or negative. A diagnosis of HIV can lead to both depression and anxiety or to a reappraisal of life and what is truly important. One study found that these two things are inversely correlated. That is, an increase in positive thinking and benefit finding was associated with decreasing levels of depression and anxiety (Updegraff, Taylor, Kemeny, Wyatt, 2002). At the most basic level, finding positive meaning is linked to better mental health.

Many HIV-infected people were also able to find positive meaning through spirituality. One study found that while spirituality and purpose in life were correlated, the relationship between spirituality and general well being were not (Litwinczuk & Groh, 2007). This seems to imply that while spirituality can help individuals find meaning in their lives, it may not be necessary to an overall feeling of well being. Spirituality, then, is a tract that may be helpful for certain women as they search for meaning and purpose in their illness; however, it is not a necessity for such exploration.

Another study found that the best measures of positive changes were education and money. Positive HIV-related changes were operationalized as including several domains of life, including the participant’s views of themselves, their bodies, their social relationships and life priorities. The correlation between these domains and socioeconomic status was especially applicable to social relationships and to an understanding of the self (Updegraff, et al., 2002). These types of positive changes can be seen as meaning making, as they include a reordering of life priorities and a changing view of the self as HIV-positive.

While this study showed that education and money were correlated with these changes, another study reported that positive changes after HIV diagnosis were common, even among

low-socioeconomic patients. Over half of these respondents reported moderate to high levels of “post-traumatic growth,” which was defined as an appreciation of life; a reordering of life priorities, such as spirituality and relationships; and an increase in self-reliance (Milan, 2004). Learning that one is HIV positive can be seen as a traumatic event. Not only does the diagnosis necessitate a drastically altered life style, but it also reduces feelings of invulnerability by destroying previously held assumptions. A traumatic event can disrupt familiar thoughts and assumptions and heighten awareness of life vulnerability. This change in thought patterns allows for an individual to engage in the post-traumatic growth necessary for meaning making and positive life changes to occur (Milan, 2004).

These studies indicate that women from all socio-economic levels are capable of finding meaning in their HIV-diagnosis; however, those struggling with poverty face a much more difficult time in discovering this meaning. These women have less, and sometimes no, access to medications, have fewer community resources, and may lack social support. Without these resources, women tend to focus on physical survival for themselves and for their families in a much more immediate context. Personal growth through meaning making may therefore not occur at the same rate as women with access to more resources. The impact of the social environment influences how women find meaning in an HIV diagnosis.

However, while the environment plays a large role in how and when meaning is constructed, the idea of finding meaning in a chronic illness like HIV seems to be applicable to most women in many diverse situations. Even though women with fewer economic resources may delay meaning making out of necessity, they still report post-traumatic growth following their diagnosis. Another study found that rural women also showed a renewed purpose for living, as well as personal growth and transformation (Mphande-Finn & Sommers-Flanagan, 2007). Therefore, this type of change seems to be part of the HIV experience from the cities all the way to rural settings.

An HIV diagnosis brings a cultural stigma not often found in other chronic illnesses. While the stigma is substantially less than it was in the early years of the HIV epidemic, it still exists to a large extent. Women diagnosed as having the virus must learn how to find meaning in the face of this cultural disgrace. Therefore, meaning making with HIV is not only a reordering of life priorities and finding ways to adjust to medical regime; it is also learning how to react to the stigma of the disease. One study identified three ways in which the stigma was damaging: it

found that African-American women experienced stigma internally as existential despair, socially as shunning, and institutionally as disregard (Buseh & Stevens, 2006). Only by understanding that the impact is both internal and external to the woman can she find meaning.

Finding meaning in HIV means challenging this cultural stigma with positive connotations and personal growth. The same study found that the women almost universally responded to stigma in proactive ways. They took deliberate action to challenge and oppose the external shame inscribed on HIV diagnosis and refused to internalize it; some even becoming advocates for others in the same situation (Buseh & Stevens, 2006). This shows that meaning making is not exclusively an internal mental exercise. It often requires external action, such as challenging the social stigma or prioritizing relationships.

As women tell their story, it becomes obvious that they not only construct their HIV narrative against, but also from, stigma. The cultural stigma is always present, and women often incorporate aspects of it into their own narrative. However, women are also constantly rewriting their narrative to combat the stigma and to change their perception of themselves (Squire, 1999). However, the process of telling the story is never-ending, as there is always a new situation where the serostatus must be disclosed, and each time involves a risk of rejection. However, one study focusing on African-American women has shown that “over time, as they developed capacities to resist stigma, they came to know emancipation from its grip” (Buseh & Stevens, 2006, 15).

Both the lenses of feminist theory and social construction are useful in viewing how seropositive women adjust to their diagnosis, attempt to gain some measure of control over their lives, and find meaning in this complicated world of medical science. Making meaning of an HIV-positive diagnosis is only the first step in adjusting to this chronic illness. The continuing viral load tests and CD4 counts continually give the women new information to incorporate into her understanding of herself and the disease. Women do not stop finding new meanings after accepting their diagnoses. They must continually find ways to incorporate every new test result into their identity.

CHAPTER 4 - Meaning and Medical Test Results

Women diagnosed as HIV-positive will enter a medical world that can be confusing at times. Because HIV requires constant attention, seropositive women will continually participate in medical testing, such as viral load tests and CD4 counts, to determine how the disease is progressing medically. Every new result contains medical meaning for the physician; however, it also has meaning to the women with HIV. Often, the meaning the doctor ascribes to the test may be different from what her physical symptoms seem to be telling her, and she must find ways to incorporate these two conflicting ideas into her identity. For HIV-positive women, test results contribute to meaning in many more ways than simply medically.

Chapter Four will begin by focusing on how women find meaning in their numerous test results. It will continue by addressing how the intellectual exercise of meaning making and adjustment to the different test results affects the lives of these women. In particular, it will focus on how HIV, medical tests, and ascribed meaning impacts how women view and conduct romantic and sexual relationships.

Viral Load and Meaning

“If HIV diagnosis created the possibility of being diagnosed as sick while feeling healthy, viral load testing has created the possibility of being diagnosed as acceptably healthy while feeling very unwell...Often doctors are put in the position of advocating continued therapy – and adherence to abstract and seemingly incongruous indices of health – to patients who are thoroughly demoralized” (Race, et al, 2001, 2). The numerous side effects of HAART make it very difficult for individuals to monitor their own health by their physical well being. They now must rely on the medical community to explain their own bodies to them. This discontinuity between physical symptoms and viral load, which has come to be the measure of health, makes it even more difficult to ascribe meaning to the process. “Interpreting viral load requires the negotiation of a complex web of meanings and discourses” (Moore, et al., 2001, 436). It is necessary to understand these many interacting meanings of how the viral load affects women’s lives.

There are several ways to interpret the meaning of viral load. It can be a property in and of itself, such as blood pressure. It can also be the bearer of important medical information, detailing how well the medication is working or if the patient is in compliance with the treatment regimen. Finally, it can also be an indicator of general health and wellness (Moore, et al., 2001).

With so many different meanings to different people, viral load becomes one of the most important properties of understanding HIV. The objective of medication is an “undetectable viral load,” but achieving this goal can come with unanticipated feelings and emotions. For instance, an undetectable result may lead some people to hope that their HIV infection has been cured (Rosengarten, 2004). While medically this is still impossible, having the virus at such a low count that tests cannot find it in the bloodstream has the potential to invoke strong feelings and hopes. Thus, the individual is left with the mental knowledge that they will always be HIV-positive and an emotional hope that the virus is truly gone for good.

This is but one of the few possible conflicting emotions and meanings women may attach to their viral load. There is often conflict in meaning and interpretation, particularly with medical personnel, when the patient feels ill but the test results show a low viral count (Moore, et al., 2001). This is often due to the many side effects from the combined medications. However, one study found that people with low distress tolerance may be more sensitive to the onset of symptoms and are also more likely to endorse the physical symptoms of HIV (O’Cleirigh, Ironson, & Smits, 2007). This implies that not only do people find meaning from their viral load tests, but also that their mental state of being perhaps influences their physical symptoms. It may then be that those with low distress tolerance who have discovered a high viral count could begin to feel the symptoms that would seem to bring them in line with their test results.

However, patients are more likely than doctors to explore all the different discourses (Moore, et al., 2001). It is therefore necessary that doctors and nurses understand the varied meanings ascribed to viral load counts and be willing to explore some of them with their patients. While adjustment to each new viral count is different, it also depends on how well the person has been able to find meaning in HIV previously. The ability to deal with all the implications of the viral load must be seen in the context of the disease progression. One study found that disease status (i.e. nearing end of life) was not associated with higher levels of posttraumatic growth than earlier disease status (Milan, 2004). This seems to imply that women need the ability to find meaning throughout the disease progression. It becomes a process that is

not necessarily dependent upon each new viral load or CD4 count, but one that incorporates every test result into an already established narrative of HIV. This is not to say that women cannot change their narrative throughout the course of the disease, only that it builds upon itself and women establish new meaning with each new result. Having a more fluid meaning is helpful because it allows the women to change and adapt when necessary; however, it also prevents her from finding an endpoint to her search.

While integration of each result seems to be the ultimate goal, the many possible discourses of the viral load make it necessary that one meaning take precedent over the others as it becomes incorporated into the overall meaning of HIV. “Where viral load and subjective feelings of health point in the same direction, this potential for the signs to contradict each other is veiled...Where viral load and subjective feelings point in opposite directions, appropriating signs from discourse to another will not integrate the discourses they index. In such cases, one discourse must ultimately be privileged over another” (Moore, et al., 2001, 444-445). This final discourse, whatever it may be, is then added to the ongoing illness narrative that the woman is creating for herself.

Women, Relationships, and Viral Load

The meaning that women ascribe to being HIV-positive affects every aspect of their lives, from their understanding of themselves to their connection with the larger cultural community. It also has a strong impact on if and how they form romantic relationships. Finding and maintaining this type of a relationship involves many facets that are not present for HIV-negative women. Disclosure, understanding of safer sexual practices, and the potential long-term consequences of the disease are some of the aspects that must be discussed and understood with her partner as a seropositive woman attempts to find a romantic relationship.

Even before there is the possibility of a sexual encounter, HIV affects a woman’s idea of herself and her sexual appeal. Even if the woman does not want a social interaction to lead to sex, simple flirting is often stopped preemptively due to the internal knowledge that she is HIV-positive. Flirting becomes dangerous in and of itself (Gurevich, et al., 2007). This internal stigma and fear of HIV often impacts every new interaction, regardless of a woman’s intentions for the future of the relationship.

Women who are HIV-positive generally report that the disease has made them feel less interested in sex overall, more fearful of starting and maintaining a romantic relationship, and less physically attractive (Updegraff, et al., 2002). Sexual dysfunctions, such as vaginismus and dyspareunia, are also more commonly reported among HIV-positive women than HIV-negative women (Gurevich, et al., 2007). While some of this may be due to medication side effects, it is just as likely that these dysfunctions are more psychologically based in the woman's anxiety surround sex.

These are large hurdles to overcome, and many women simply choose not to pursue a romantic relationship because of them. For these women, "sex had become too plagued with anxiety, worry, danger and stress to still be pleasurable" (Siegel, Schrimshaw, & Lekas, 2006, 447). These women have integrated their chosen abstinence into the overarching narrative of HIV and the new meaning they now have in their lives. It was easier for them to put this part of their lives aside indefinitely and concentrate on other aspects and find new values, such as non-sexual relationships or advocacy for others in similar situations.

For women that already have a partner or wish to start a new relationship, they must challenge their negative ideas and discover new alternative meanings. With the advent of HAART, the possibility of living much longer lives reintroduced the idea that it would be acceptable to again search for long-term fulfilling relationships. However, one study focused on women in the two different eras of the AIDS epidemic. They found that HIV-positive women reported diminished sexual activity, loss of sexual interest, and decreased feelings of attractiveness both before and after HAART became available (Siegel, et al., 2006). This was corroborated by another study, which discovered that most of the women surveyed did not perceive any changes in their sexual desirability after treatment (Catz, et al., 2001). The idea found here emphasizes that it is the virus and disease itself, not necessarily a shorter life expectancy or the physical symptoms, which contribute to these women feeling sexually undesirable.

While there is some truth to the idea that the medications may be contributing to the loss of sexual interest, the meaning that women attach to their disease is probably more likely to affect how they view themselves in terms of either a long-term or a short-term relationship. The possibility of rejection after disclosure is very high, and women must be secure enough in themselves to risk that possibility. However, one study found that a close and supportive

relationship with either a friend or a romantic partner was associated with higher levels of disclosure (Derlega, Winstead, Green, Servoich, & Elwood, 2002). While it is always an emotional risk to disclose serostatus, it seems that women are likely to take that risk if there is an emotional connection.

An emotional connection within an intimate relationship can be very helpful and supportive to HIV-positive women. However, other women find that there is still a power differential for HIV-positive women involved in these types of relationships. Women's lack of social and economic power within society, along with their emotional resistance to HIV, can be seen as paralleling women's disempowerment in romantic relationships (Squire, 2003). The social and economic inequality affects both how they understand and react to being HIV positive and also how they interact in intimate relationships.

Women often find themselves in the caretaking role, regardless of their HIV status. Because of this expectation for women, they will often take on the responsibility of protecting their partners. This still is true for HIV-positive women, who frequently are in the position of ensuring safer sex. Many of the women reported that men often have a resistance to condom use, even though biologically women are more at risk for transmission in heterosexual relationships (Gurevich, et al., 2007). If the women are to take on primary, or sole, responsibility for condom usage, this places an additional burden on them in romantic and sexual relationships. The relationship is no longer based on equality and mutual support. When this occurs, women may find themselves in positions that are not comforting and supporting, but stressful and emotionally draining.

Women who contracted HIV from long-term romantic partners have additional emotions to understand and integrate into their narrative. In particular, many rural women who contract HIV did so from long-term romantic partners, most especially their husbands. This often leads to feelings of intense betrayal and anger against their partner (Mphande-Finn & Sommers-Flanagan, 2007). Knowing that they have contracted an incurable disease from someone they trusted presents an entirely new set of emotional issues that must be explored. Whether or not to stay with that partner, how to deal with the sexual and emotional betrayal, and learning to trust a romantic partner again are all unique questions of concern for women in this subgroup.

Even for women who are in committed relationships and HIV-positive, fear of transmission sometimes halts all sexual activity (Gurevich, et al., 2007). This can create strain on

the relationship and requires a new understanding of what “safer sex” means and what a “romantic relationship” means. Women and their partners must answer the question, “Can a committed relationship exist without sex?” Regardless of the answer they choose, they must renegotiate the relationship in a way that is mutually satisfying.

Romance is a culturally constructed concept, and particularly in Western countries, the idea of “true love” and “romance” is given a high priority. However, romance has to take place within the limits of the social conditions that sustain both romance and life with HIV. This includes new negotiations with a partner that must be willing to commit not only to the woman, but also to the virus (Squire, 2003). This new requirement makes finding romance even more difficult.

However, once a decision to pursue a sexual and/or romantic relationship is made, viral load becomes an important factor in how women perceive the possibility of sexual transmission. Clinically, an infected partner’s viral load is an important factor for predicting transmission. A higher viral load indicates that the negative partner is more likely to seroconvert than does a lower viral load (Ninger, 2000). However, while effective viral suppression can potentially reduce the risk of HIV transmission, there is still an unknown degree of risk in unsafe sexual encounters, even with the viral load being labeled as “undetectable” (Kalichman, Eaton, Cain, Cherry, Pope, & Kalichman, 2006).

It makes intuitive sense that if the viral load is so low as to be undetectable, then the risk of passing it to one’s partner should be considerably less. In addition to this, when an individual has a higher CD4 count and a lower viral load, she may take this to mean that she is relatively healthy and can have as “normal” a relationship as she would have had before HIV. One study found that women with lower CD4 counts were less likely to engage in high-risk behavior and that recent high risk sexual behavior was associated with lower viral load levels (Catz, et al., 2001). This could be explained with the idea that women who have found meaning in their test results that they are healthy are more likely to take sexual risks, while women who have found that they are ill are more likely to be aware of the fact that they could potentially pass this disease to someone else. However, other studies have found the opposite of this to be true (Kalichman, et al., 2006). If a woman makes a meaning of her viral load count other than that she is “healthy” and it is safe to engage in sexual activities, her behavior will be affected as well.

While the findings are somewhat inconclusive as to exactly how viral load impacts the sexual practices of women, what does seem clear is that how women discover meaning in these test results impacts their romantic relationships. In turn, how their partners also discover meaning may affect the women themselves in how they view their own sexuality.

Understanding how women make meaning and incorporate both the HIV diagnosis as well as subsequent medical tests into their overall identity allows a glimpse into how women adjust to this chronic illness. Women often discover new meaning in their lives post diagnosis, and this often involves a reevaluation of how to decide to navigate romantic and sexual relationships. By looking at these different aspects of their lives, therapists are in a position to help seropositive women on their journey of self-discovery.

CHAPTER 5 - Implications for Therapy

The implications for conducting therapy with HIV-positive women are numerous. These areas include both practical, as well as emotional considerations. The ability to find meaning and mastery amongst the uncertainties of an HIV diagnosis are important for the therapist to address with the client. There are a number of forms that that therapy can take that would be helpful to the woman. For instance, therapy may focus on just the woman herself - both practical and emotional - or it may involve bringing other people into the room.

One area that may be appropriate to address in therapy is the practical side of vocational rehabilitation interventions, such as job accommodation, addressing employment gaps, and discussing when disclosure is appropriate. These may be particularly useful as women learn to live with the chronic illness of HIV (Berry & Hunt, 2005). Because work is a vital part of living, it will most likely be an important topic in the therapy room. It may be necessary to reevaluate how employment will be affected by HIV and, if necessary, how to discuss with potential or current employers the woman's medical needs.

However, there are also emotional and spiritual needs to address. Some studies have also showed the importance of therapy not only in supporting psychological adaptation, but in spiritual adaptation to the HIV diagnosis as well (Litwinczuk & Groh, 2007). This, of course, should be modified according to the individual woman's needs. However, the therapist should be willing to explore spiritual and religious ideas if the client expresses an interest in doing so.

It is also important to allow regular emotional exploration and expression (Mphande-Finn & Sommers-Flanagan, 2007). The idea of being HIV-positive includes a myriad of emotions, which may change from day to day, particularly in the early stages when the discovery of the serostatus is still new. Therapy should provide the woman with a safe place to explore these varied emotions, from guilt to betrayal to anger to fear. Each of these emotions should be given validation and will help the woman find meaning in her diagnosis.

The woman may be in therapy by herself to learn how to have a satisfying romantic relationship in the future. As discussed in the previous chapter, many women find themselves uninterested in sex or feeling sexually undesirable following an HIV-diagnosis "These women need interventions to address these issues and to help them regain a sense of themselves as

appealing, sensual women who can have gratifying, yet safe, relationships with both uninfected and infected partners. They would also likely benefit from guidance concerning how and in what circumstances to share their diagnosis with potential sexual partners to reduce the risks of painful rejection or to endure such rejection without personalizing it as much” (Siegel, et al., 2006, 449). In helping these women to regard themselves as attractive potential partners, therapy can help them to rewrite their narrative of themselves as more sensual and attractive. Alternative scripts for women in this situation may include redefining romance and sex to include a focus on condom use, safer sex practices, and emotional rather than physical closeness. Learning how to incorporate HIV into a romantic relationship is necessary for women who choose to pursue that aspect of their lives.

There are countless circumstances where there may be multiple people in the therapy room. Therapy may take the form of couples counseling to help the woman and her partner navigate sexual closeness. While it is important to understand how to be safe during sex, “too much anxiety can be maladaptive if it results in a fear of physical closeness and any kind of sexual intimacy, even acts that carry no risk of HIV transmission” (Siegel, et al., 2006, 449). The therapist should have a basic understanding of how HIV is transmitted, but it is still good practice to be in consultation with the medical personnel regarding how to help the seronegative partner remain safe or the possible implications of transmitting different viral strains between HIV-positive partners.

Couples counseling is not the only time that others may join the therapy process. Marriage and family therapists have a particularly unique perspective in working with HIV-positive women and their families. Many of these women have children, and it may be appropriate for them to be involved in therapy as well. HIV-positive mothers find themselves in the difficult position of explaining disease to their children. This can be an extremely complicated matter, and therapy can be a useful place to discuss these issues. Children of mothers with HIV provide help and support in numerous ways to their mothers. The most prominent type of care is emotional support, but children are also often responsible for domestic tasks and helping to care for younger siblings (Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005). With this interdependence between mother and children, as well as the potential stress and fear of the children, family therapy could be very helpful in structuring the household and in maintaining a strong bond between the mother and her children.

Women also may need therapy in order to stay connected with their families of origin. It may often be necessary to include an adult woman's parents or siblings in the process. One study, which looked at mothers' responses to learning their adult children were HIV-positive found that they often struggled with feelings of both blame and self-blame (Thompson, 2000). Many of the meaning making strategies, such as redefining life priorities, which are employed by the seropositive women, may also be appropriate for their mothers and other family members. Therapy should also provide a place for all involved to explore these emotions and learn from each other. Therapists can help both the women and their family members come to terms with what it means to be HIV-positive and how they can help and support each other.

There are many important training areas that marriage and family therapists (MFTs) should address if they plan to work with HIV-positive women. Because the medical world can be so complicated, MFTs should have a working knowledge of the medical aspects of the disease and of the terminology used to describe it. Naturally, questions regarding treatment should be left to the physicians, but MFTs need to be aware of how these areas will impact therapy. It will be important for the therapist to have a relationship with the medical community that is independent of the client. Because some women may want to delay treatment or seek alternative help, the therapist may be in the position of helping to support her in an opinion contrary to the medical community. It may be helpful for the therapist to have a prior working relationship with the doctors separate from particular clients. This will help the therapist to be seen as collaborating with medical personnel rather than hampering treatment.

Marriage and family therapists should also be trained in understanding how to deal with the cultural stigma attached to HIV. Providing the client with a nonjudgmental atmosphere is critical to the success of therapy. As previously discussed, it is vital that MFTs working with HIV-positive women be open to bringing loved ones into the therapy situation if necessary to process the changes that HIV brings to the lives of the woman and those surrounding her.

Training also needs to include ethical and legal issues surrounding disclosure to those who are "at risk" for HIV transmission, such as the women's past, current, or potential sexual partners. State laws vary widely regarding this issue, so it is paramount that MFTs receive training in how best to navigate this situation, including consulting legal advice when necessary (Serovich & Mosack, 2000). Even without the legal implications, this is an ethical dilemma for clinicians, and training must focus on how to confront these issues.

There are other areas that were not addressed in this paper, which are important for therapists to have addressed when working with HIV-positive women. It will be necessary for therapists to understand how racial and class differences contribute to the meaning that women make of their HIV. It may be that the women facing different situations will find vastly different meanings in their HIV infection. While briefly addressed in this paper, there needs to be much more discussion of how these different elements affect HIV-positive women.

Another group which requires further study is immigrant women. These women have unique circumstances and may make meaning very differently from women born in the United States. Therapists who are working with this population will need a more thorough understanding of how HIV/AIDS is perceived in their culture and how that perception then affects their meaning making. Immigrants, of course, are not a homogenous group. Depending on their country of origin, they may have vastly different understandings of HIV/AIDS. Therefore, while a discussion of immigrants in general would be helpful, it will also be necessary to focus on specific populations.

This chapter touched on the importance of allowing other people, such as parents, children, and romantic partners into the therapy room. In order to better serve both those loved ones, as well as the women themselves, it will be important to understand how those not directly infected with HIV make meaning of the disease. As MFTs often work with entire families, it would be neglectful not to learn how HIV affects her close family and friends, who may need to be involved in therapy as well. This is particularly important for her children. MFTs will need a basic understanding of how children in all age groups perceive and make meaning of having a mother who is HIV-positive. Again, this will most likely differ according to gender, race, and class. Social construction shows that meaning and identity are derived from social interaction. Therefore, the meaning her loved ones make of her HIV status will have an effect on how she makes meaning for herself.

There are still many questions to be answered regarding how best to help HIV-positive women. However, it seems that the idea of meaning making will be useful in most therapeutic situations. Therefore, regardless of whether or not the woman chooses to pursue a romantic relationship or if she wants to bring in close friends or family, therapy should help her to find new meaning in her life as an HIV-positive woman. The stigma of HIV/AIDS and the physical limitations can combine to cause the woman to feel powerless in her situation. “Steps to

empowerment include building a positive self-image and self confidence, developing the ability to think critically, building up group cohesion, and fostering decision-making and action” (Tallis, 2000, 64). Therapy must help women write the narrative of their lives within the context of the oppression of both women and also of HIV-positive individuals. By empowering them to find mastery and meaning, these women can then move forward with their diagnosis, without being subjugated by the virus.

CHAPTER 6 - Conclusion

Feminist theory and social construction are useful ways to view a woman's experience with HIV/AIDS. The possible discontinuity between physical symptoms and medical evidence, such as viral load and CD4 count, require women to find multiple meanings and to integrate conflicting information into an overall cohesive narrative. The many power differentials both before and after HIV infection and diagnosis strongly influence the women's experiences, as well as their ability to find new meaning in their lives.

Romantic and sexual relationships are extremely difficult to navigate for HIV-positive women. Sex can become so anxiety-ridden that many women choose to forego it altogether. However, for those women who choose to pursue this part of their lives, meaning making becomes especially important. Women must counteract society's views of them as damaged, diseased and unattractive in order to see themselves as worthwhile romantic partners. The meaning that they attach to viral load and CD4 counts can also affect how they then chose to interact in sexual relationships.

As a therapist working with HIV-positive women, these ideas are important to understand. Much of therapy may focus on finding meaning in the face of cultural stigma and internalizations of cultural expectations of how an HIV-positive individual should think and feel. Therapy must help these women to navigate this complex web of emotions, cultural expectations, medical interpretations, and personal meanings. It may be necessary to involve loved ones in therapy. Inviting in romantic partners, parents, siblings, or children can help the women to build support networks and to involve those she cares about in her search for meaning. As an HIV-positive diagnosis affects everyone connected to the woman, it is important to address these issues in therapy. By integrating the many different ideas and meanings into a cohesive narrative, women can find new meaning in their lives and their relationships, as well as positive personal growth, with a renewed sense of purpose.

Feminist theory and social construction were used in this paper to illustrate how women make meaning of an HIV-diagnosis. These two theories work very well together and are effective within this context. However, it is important to also look past these two theories as there are some criticisms regarding their use. For instance, social construction focuses on the

meaning that individuals make through social interaction. HIV-positive women do make meaning through these interactions and especially through societal expectations and understandings of the disease. However, much of the meaning that these women make requires them to move beyond the societal stigma attached to the disease. Staying within the script that society has given them has potential to lead to internalized stigma and self-loathing. Many of the women in the research discussed how they were able to move past this negative societal influence. While it is extremely helpful to have supportive social interactions in order to do this, women are often making meaning themselves against societal expectations.

In addition, much of the research discusses how women make a particular meaning. However, meaning making is not a conclusion, so much as it is a process. As discussed earlier, each new test result must be integrated into the overall narrative. The goal of finding one meaning is not useful or even possible. While it is probable that meaning could remain stable for extended periods of time, it will most likely evolve at some point in the future. Therapists working with HIV-positive women must remember not to view meaning making as the ultimate end goal of therapy, but rather helping the women to understand how they can continue along the path, changing and adapting when needed.

Having a chronic illness like HIV/AIDS requires a fundamental change in both the way life is lived and the way life is viewed. In the United States today, those with chronic illnesses must content with societal views that devalue that individual. “Embracing the vitality of an ill body is not easy; it is merely a way to rethink the ill body so that having chronic illness is no longer marginalizing biomedically, socially, or economically. Having chronic illness could be just another way to be” (Moss & Dyck, 171). This idea may be the final step in helping HIV-positive women to find constructive meanings and benefits in their lives post HIV.

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Appendix A - Glossary of Terms

- CD4 Count – The level of white blood cells in an individual’s blood stream. This is a common test for determining HIV progression.
- Highly Active Retroviral Therapy (HAART) – Medical treatment for HIV/AIDS. It usually includes three or more antiretroviral medications and necessitates a strict adherence to a treatment regimen for success.
- Meaning Making – An individual’s attempt to understand her diagnosis, how it affects her life and her concept of herself, and usually includes a reordering of life priorities and values.
- Sero – Viral.
- Viral Load – A measurement of the amount of HIV in the bloodstream. This is a common test for determining HIV progression. A goal of HAART medications is to lower the viral load count to undetectable levels.