

Women and AIDS: A Spiritual Journey

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Acknowledgements

"Nothing seems really to matter, that's the charm of it. Whether you get away, whether you don't, whether you arrive at your destination or whether you reach somewhere else, or whether you never get anywhere at all, you're always busy and you never do anything in particular, and when you've done it there's always something else to do . . . "

-THE WATER RAT, from *The Wind In The Willows*

Life is about journeys, and journeying is what makes life the colorful and vibrant experience that it is. My thesis, although about a topic very important to me, is not so much simply the culmination of a year's research, as it is the culmination of twenty-two years of journeying- sometimes thoughtfully and often spontaneously, but always done in appreciation of all that surrounds me. I gratefully thank all of those individuals who helped with interviews, materials, and personal stories - you are what made the experience so unforgettable!

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I. Introductory Reflections

Only recently has American culture recognized the need for an affirmation of the reaction to death - grief. Elizabeth Kubler-Ross' work, On Death and Dying, began a movement which encouraged grief and its stages as legitimate and necessary to the process of life. In the 1970's the Hospice movement began to gain momentum, and by the late eighties topics such as "euthanasia" and "Living Will" became dinner-table conversation. Books, tapes, retreats and self-help groups surrounding the topic of grief are now normal occurrences, as are widely-held beliefs in "near-death experiences", and visitations with the dead. The act of grieving is commonly accepted, and indeed, expected when a loved one dies.

What if the scenario were to be changed, however, and it is not a loved one's death that is to be mourned, but my own? As a woman, a traditional provider and care-taker, how would I go about preparing to die . . . ?

Some time of repose, that is all I would request, some time to collect, to understand, to ready myself, some time to heal. The difference is, I suppose, in the use of the word "heal". To heal myself when I am terminally ill is much different than to heal myself from a winter cold or a time of great emotional stress. A time to grieve, a time to heal, a time for the world to

settle itself around me and a time to catch my breath - for the whirling to stop. What is important is to be allowed my own time to mourn And to decide that what is ultimately needed in healing is to slowly withdraw my identity as mother, daughter, sister, and grandmother, and to reenter the universe as a very different and very independent being.

Women who sense that they are dying, women who know that they are dying begin to make arrangements, mental and emotional arrangements, arrangements of the heart. They begin to see God in a new light and it is only under this illumination that healing can, finally, come

Women living with Acquired Immune Deficiency Syndrome - AIDS - have yet another version of this tale. They constitute a minority of minorities, and yet they are quickly growing in number. These women must deal with the AIDS virus in a unique way: they are faced with biological, cultural, social and emotional problems which men in identical circumstances do not have to face. The plight of women living with the virus is a complex one that cannot be pinpointed to merely one, pivotal factor - it encompasses a variety of unique issues and situations which are at once both interrelated and distinct in their severity. Underlying all of the discrimination, the marginalization, and the inequalities, however, is a crisis of faith.

At the close of the twentieth century, still the virtual advent of the AIDS epidemic, more and more women are discovering solace and a place of peace within their own unique sense of spirituality; after finding that the world is not ready to help them, they are finding the help and strength they both need and deserve, in God. Ironically, for many of these women who began as prostitutes and drug addicts, who were involved in sexually abusive or co-dependent relationships, or who, due to their cultural background have an already marginalized status, AIDS has given them a way out. They have found new hope and freedom in life amidst the societal repression and discrimination that comes with AIDS. Ironic, too, is the fact that despite the negative feedback and lack of support from mainstream religious groups, it is the AIDS pandemic which has brought many women a spiritual awakening - it has brought them closer to God and thus strengthened and enriched their spirituality. JB Coles, an HIV positive Sioux Indian woman who began her new life only after finding out that she had contracted the AIDS virus, writes about this phenomenon in her poem, "LIVE":

You Selfish Bastard . . .
. . . let me help you live!" he yelled.
The words kept ringing in my ears.
"Let me help you live!"
I'd never tried that before - life
It was always death and destruction.
Now, for the first time, I'm doing

Something I've Never Done Before.

Most of my "Friends" have left me, But
those who have stayed have truly Been
my life line.

Not only "sharing" my Dis-ease With
them, but life through AIDS.

(By the Way, it means And I Deserve Serenity)

More often times than not, in the midst of my anger,
frustration, fear and depression, I'm gently
reminded of why I'm alive, even though it's
hard for me to put into words - I feel it in my heart.

To be Native, Female and an Alcoholic/
Addict was bad enough - Now I have

AIDS. "How much further Down the Ladder

Can I get?" Yeah, there's no way but up.

I hope for life and all its riches

I live for me and my dog POOH

I pray for Peace and Love

I Do my best to see the bright side

I Grab for the Gusto

My Mother gave me life, but God gave
me Wings, not AIDS.

To Stand Strong and trust in God,

Follow the promptings Within, not Without.

The World is full of Doom and Gloom. I

need not be that way. Living in the Moment
is living Life. One day at a time.

I shall not die with regrets -

I shall not die in debt -

I shall not die alone -

I will merely pass through a

doorway of such love (Coles 79, 80).

The evolution of JB's faith is easy to glimpse through her work, as is the fact that through her faith in God she has discovered a well-spring of strength within herself. Although she is only one woman, her experience is indicative of the countless numbers of women living with AIDS. God has given JB her time to grieve, and thus an opportunity for her time to heal.

II. The AIDS Crisis

AIDS. AIDS. I keep saying it over and over in my head. I'm scared. Why? Because people actually die from this disease. I'm frustrated. Why can't they find a cure? While scientists are in their lab coats working on O.J. Simpson's DNA samples, people are dying from AIDS.

My cousin died of AIDS and, although I never knew him, I don't ever want to think of AIDS in my family. It's too scary. It's too dangerous. It's too common.

I've got many questions that no one can answer. Why are people ashamed of AIDS? Nobody wants AIDS. To many people, it's a disease that is just heard about on TV and in the newspapers until it strikes close to home. Why are people with AIDS treated like outcasts? Unless you're famous, nobody really cares if you have AIDS or not.

I just pray to God that I never get AIDS.

But, God forbid, if I do, I'll hold my head up high and tell the world that Alexandra Backis will die with dignity.

With AIDS.

These words were written by Alexandra Backis, a ten-year-old girl from the Chicago area, as a reflection on the AIDS crisis (Daughters of Sarah 1).

Although Alexandra's voice is young, she speaks with a force that represents the quickly growing number of individuals who are eager to put an end to the labeled risk groups and victimized stereotypes in order to see the faces of those individuals who are living with AIDS, and in order to reach out hands

and hearts to those who are hurting and most need support.

The tone of Alexandra's voice, however, is a recent addition to the AIDS equation. Once fearful and filled with distrust, American society has shown a new face to the virus - that of compassion and hope. This perspective is relatively new not only as a popular public outlook, but also to the media surrounding the virus. HIV positive individuals such as Rock Hudson, Earvin "Magic" Johnson, Ryan White, and Elizabeth Glaser have campaigned personally against public ignorance, helping too, to heighten both public awareness and compassion. Resource networks such as ACT UP and the National AIDS Hotline have sprung up with the latest news regarding treatment methods; counselors on duty 24 hours a day, newsletters like "Positively Aware" and "Body Positive" help to update individuals who are HIV positive; and humanitarian efforts, such as the Names Project and AIDS Memorial Quilt, have provided not only a means by which to educate the general public and to raise money to benefit AIDS-related research, but also a medium through which families and friends can mourn and memorialize their loved ones.

Through the positive efforts of groups and individuals such as these, the struggle to view the epidemic with care and compassion has already come a long way from its first days in the early eighties. There is still much more to

be accomplished, however, and to fully understand the significance of the crisis, as well as to understand the plight that many face, especially women who are infected, it is first necessary to trace the steps of the disease, both epidemiologically and in the mind of the public.

AIDS is the acronym for Acquired Immune Deficiency Syndrome, a virus which attacks one type of white blood cells in the immune system and allows for a variety of diseases, against which the human body normally has a defense, to manifest themselves in the infected individual. The virus which leads to AIDS is termed HIV, or the Human Immunodeficiency Virus.

An individual who tests HIV positive has contracted the HIV disease but may live for up to ten years with no visible symptoms; this condition is known as asymptomatic. During this period, most persons are not even aware that they are carrying the virus in them, thus if they engage in risk behaviors they are unknowingly spreading the disease to other individuals who are unaware of the danger, and the pattern is repeated. Eventually, an HIV positive asymptomatic individual will begin to show symptoms which may either be flu-like in nature, indicating a move to an HIV positive symptomatic condition, or they will develop one or more secondary diseases termed "opportunistic", which indicates a development into full-blown AIDS.

Opportunistic infections are those which take advantage of the weakened immune system, and in the case of those infected with AIDS, are as painful as they are debilitating. Two of the most common opportunistic diseases are pneumocystis carinii pneumonia, or PCP, and Kaposi's sarcoma, or KS, which is a form of cancer. Initially, it was believed that an HIV positive individual would always develop AIDS within a few years of their HIV positive status. Now, however, with the help of current medical knowledge and a positive outlook, persons with an HIV positive status are living longer and fuller lives without developing AIDS.

Because HIV attacks the immune system, it must reach an individual's blood stream in order to infect them; therefore, it can only be spread through body fluids which in some way come into contact with the blood stream. These fluids include semen, vaginal secretions, breast milk, and blood itself. Obviously, then, the activities which leave an individual at risk are not numerous, but they are an almost certain means of getting infected; they include engaging in sexual intercourse, anal sex, or oral sex with an infected individual, sharing an IV for intravenous drug use, and possibly breast feeding and childbirth.

Epidemiologists have mapped out three distinct patterns throughout the world to identify the means by which the virus is spreading, and with the

hope of being able to curtail its growth in the future. Pattern type I includes the United States, Canada, New Zealand, some Central American countries, some western European countries, and some countries in southern Africa. This pattern is made up of mostly males, and began by contact between homosexual men and between IV drug users. There are very few transmissions perinatally, or during pregnancy and delivery. The type II pattern is prevalent in most of the Caribbean and in many central, eastern, and in some countries in southern Africa, and has an approximately equal number of male and females who are infected. Also equal, in this pattern, is the number of transmissions through sexual contact, from male to female and from female to male. Perinatal passing of HIV/AIDS is common as well. Pattern type III includes countries such as those in eastern Europe, northern Africa, most of Asia, and the Middle East, where there have been very few AIDS cases as of yet, and thus no definitive epidemiological patterns.

AIDS has been proclaimed the world's fastest-spreading epidemic by the World Health Organization (WHO). Globally, by December 31, 1994, 1,025,073 cases of AIDS had been reported, but WHO estimates that the actual number was closer to 4.5 million infected persons. As has been previously stated, due to the long period of infection when HIV lies asymptomatic in its host, many persons have been infected and gone on to infect others without

either individual's knowledge. This has resulted in a phenomenon which is best described in terms of a metaphor, and easily explains why the amount of those persons infected rises so rapidly in the matter of only a few years, and why the estimated numbers are so high in comparison with the actual numbers of cases reported. If the number of cases officially documented is represented by the tip of an iceberg - that portion which rises out of the water - then the number of infected individuals who do not yet know is represented by that portion directly under the ocean's surface, and those individuals who are HIV positive is represented by the iceberg further down, where it continues to widen. The largest portion of those infected, then, is by far yet undiscovered, as is the part of an iceberg which is under water. Those individuals may not show any signs of being infected for at least another decade, if not more. The estimated numbers, therefore, are the numbers which are truly indicative of the spread of HIV/AIDS throughout the world.

In 1994, WHO estimated that 13-15 million individuals had contracted HIV, and that by the year 2000 the total number of HIV infections in men, women and children across the globe will exceed 30 million and possibly grow as high as 40 million. As of February 25, 1995, WHO estimated, over 3 million people had died from AIDS worldwide. The United States Center for

Disease Control, or CDC, had 475,899 AIDS cases reported to them by June 30, 1995, and by this same date had had 294,473 AIDS-related deaths. Currently, AIDS is the leading cause of death for people ages 24-44 in the United States, and one in every 250 Americans is infected with HIV.

The CDC first identified and labeled AIDS in the United States in 1981, when the disease was observed and tracked in a group of gay men. A diagnosis of AIDS is made only after the symptoms meet the conditions set forth by the CDC, which are based according to the type of opportunistic infections the first individuals - those few gay men - displayed. This definition has changed little since the early eighties, even though the face of the disease has changed immensely to include women, who now comprise the fastest growing number of newly HIV-infected individuals, a group who for their own unique reasons, requires their own unique definition.

Before closing in on the specifics of women, however, it is necessary to follow the development of the moral stigma attached to AIDS, a stigma which, notably, is found only in those countries with pattern type I transmissions, traditionally homosexual in form; ironically, it is these countries too who have the most readily available capabilities for support of those who are HIV infected and living with AIDS, through medical research and funding.

Susan Sontag, in her book, AIDS and its Metaphors, has attempted to trace the negative stigma surrounding the AIDS virus through following the development of the fear of disease in the middle class mind. She succeeds in identifying reasons underlying prejudice against those individuals who are living with HIV/AIDS, and in so doing, affords insight into the negative religious preconceptions which are associated with the virus.

Sontag asserts that as society became more stratified, as in the middle ages, illness was associated more and more with sinners and with the poor, those persons who were unable to be reliably productive or emotionally self-controlled. This invariably led to the "adoption of middle class values" with which, it is not surprising, health itself would become identified (54). In more contemporary times, the need secular culture has had to blame and punish through the imagery of a disease has been frustrated by modern biological knowledge. The only opportunity left for moralizing about epidemics was, and still is, present in sexually transmitted diseases (56).

The last few centuries have put more emphasis on the total freedom of the human being in all decisions, which in many instances has meant "personal fulfillment", and in the case of the HIV infection, specifically personal choices in fringe and illicit activities. AIDS has debunked the movement toward total freedom in favor of self-interest, and moved popular

culture into a moral position, one reminiscent of the stance taken in the middle ages. Thus:

The unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency - addictions to chemicals that are illegal and to sex regarded as deviant (25).

AIDS is understood in a premodern way, as a disease incurred by people both as individuals and as members of a "risk group" - that . . . category which also revives the archaic idea of a tainted community that illness [or God] has judged (46).

In social practices reminiscent of constraints on lepers in the Old Testament, persons living with AIDS have been ostracized and judged as if by God. The very nature of the AIDS virus has posed a threat to the moral norms of communities throughout the United States. Not only is AIDS primarily spread through means which, to many Americans, are ethically questionable, but its degree of communicability through blood has also left those same Americans wondering how safe it is for them to trust others, or to help out their needy neighbor. In addition, AIDS is deadly in the worst possible way: it not only kills the body slowly and painfully, but also dehumanizes the person, horrifyingly deforming the face and spirit of the individual infected and almost always isolating them through unjust bias and hate within their community (Sontag 38). Sontag continues by distinguishing between the mind and the face, an important distinction in

understanding how the AIDS virus affects social perceptions:

Physical beauty and physical ruin continue to be very, very important to our society; although we may separate the mind and body, we do not separate the face and the body . . . all the debunking of the Cartesian separation of mind and body by modern philosophy and modern science has not reduced by one iota this culture's conviction of the separation of face and body, which influences every aspect of . . . life (39).

Horrifying too, is the fact that AIDS is spread by those fluids which also hold within them life itself. With AIDS, blood, sexual fluids, and breast milk - the very carriers of human life - are the contaminants (73). This fact only works to reinforce the already-present American moralism regarding sex, and has the "unhappy effect" of further alienating those individuals infected, and branding them as immoral (73).

The religious community picked up on this from the beginning; as John Fortunato, a gay Episcopal priest, asserts, communities are so threatened by gay people because gay people represent people who enjoy sexuality and find pleasure in sensuality - the antithesis of the Western church's excuse of limiting sexual acts to the intent of procreation (Fortunato 80). Homosexual relationships are innately such that they can never lead to biological procreation. Thus not only does homosexuality flaunt the very physical joy of sex in the face of Christian Western culture's fear, it also symbolizes an

absence of the eternal - mortality. Fortunato continues:

And now we who are gay, who at some subliminal level already intimate death to people, now we have been linked in the public's mind with a frightening, most deadly disease. It is a deadly combination. It made us expedient scapegoats, because we and AIDS, and especially the synergistic combination, remind a society bulwarked against death of their inevitable ends (81).

It is important to acknowledge that while AIDS the virus is purely physical, the associated discrimination and hate is easier to pass and easier to contract: therein lies a significant social problem with the true nature of the disease. Persons who are HIV positive need emotional and spiritual support just as badly as they need health-related support. These individuals know that death is inevitable; and like any person who is faced with the reality of a fatal disease, they are eager to begin to right the side of their lives which is often neglected until the end - most commonly, the spiritual side.

Women, who have traditionally taken on the role of the caregiver, and who are often faced with a sense of emptiness within their spiritual lives, are hard-pressed as members of this crisis to find the support that they require among their communities.

III. Women - the "Second Wave"

From the early eighties, when women were a virtually unknown entity in the AIDS equation, to the present, when women constitute the fastest growing newly infected population, it has become increasingly apparent that AIDS affects women in a very different manner than it infects men. Equally apparent is the fact that the world was and continues to be unprepared to deal with the newest factor in the equation.

In the beginning of the AIDS epidemic, women acted as the care givers for their sons, husbands, lovers, friends, and patients who had contracted the virus. They were seen only as instigators of service organizations, often the faceless force behind the gay community, supporting bisexual and unfaithful husbands, homosexual sons and gay friends despite prejudice from religious and social circles. Within ten years, however, that situation has turned and women have become representative of the "second wave" of infected, and the question continues to remain: who will care for the caregivers (Grover 147)? Women have no one to care for them, and as many have been infected by lovers or husbands, after their partner dies it is they who are left alone in a society which is already suspicious of their positive status.

In the case of women infected with HIV/AIDS, the stigmatization

associated with the disease is only heightened by the fact that they are women, and as such are already marginalized as members of society around the world, and in the health care community. Medical and research fields are decidedly androcentric, either assuming that HIV/AIDS will act itself out in the same way in females as in males, or simply ignoring the female half of the population altogether. This androcentrism is still reflected in the CDC's definition of AIDS, and international governmental policies regarding AIDS research, rights, and treatment.

In the early eighties, when AIDS first appeared on the American scene, it was observed in and thus attributed to gay men and to drug addicts only. Women, therefore, were not considered vulnerable, and for a short time it was even postulated that they could not become infected. From those early circumstances arose the CDC's definition of AIDS, which is used to allow patients officially diagnosed to receive health and monetary benefits, treatments and proper medical care. Unfortunately, women, in comparison to men, often contract different opportunistic infections, which are not included in the CDC's definition and leave many women out of the statistical picture altogether. The initial definition included opportunistic infections which males manifested, and although this was revised in 1987 to include some of the unique infections women manifest, the new definition was by no

means exhaustive.

For example, one study reported that for one-third of the HIV positive population of women, the first sign that a woman is infected is in the form of a severe vaginal yeast infection which is highly resistant to being cured (Girvan 1). While yeast infections of the esophagus, trachea, bronchi and lungs appear on the CDC's definition, vaginal yeast infections do not, thus many HIV positive women go undetected. Yeast infections, however, only constitute a small portion of the opportunistic infections of women that are left out of the definition. AIDS, as defined by the CDC, does not include increased evidence of pelvic inflammatory disease, abnormal PAP smears and cervical cancer, and an increased rate of respiratory diseases. As opposed to males, infected females also display an increased rate of recurrent bacterial pneumonia, often contract cervical cancer and pulmonary tuberculosis, and do not contract Kaposi Sarcoma, as do infected males (Girvan 3). In females, the most prevalent infection is a yeast infection of the esophagus, whereas in males it is pneumocystis carinii pneumonia.

Studies have also shown that since AIDS is a sexually transmitted disease, women naturally have a greater biological vulnerability to HIV/AIDS than men. The rate of male-to-female transmissions of some sexually transmitted diseases is at least 15% higher than female-to-male transmissions,

and this statistic appears to be no different when dealing with the AIDS virus. Research in many countries has shown that male-to-female transmission of the virus is up to 24 times as efficient as a female-to-male contraction. There have been various reasons postulated for this number, and the proposed major factors include the fact that females have a larger mucosal surface area which is exposed to the virus, and the fact that there is a greater amount of viral inoculum present in semen as compared to vaginal secretions (Criss 20). Young females, whose bodies do not yet produce large amounts of vaginal mucous, are more vulnerable than more mature women, whose bodies naturally produce enough to make a natural barrier to HIV (Women and AIDS 4). In addition to these difficulties, women also have to deal with another biological issue, pregnancy.

Not only must HIV positive women deal with what will happen to their children when they die, but they also must struggle with whether or not to become pregnant; although over 1.5 million infants have been infected through their mothers, HIV positive individuals are living longer and longer, and a woman can lead a happy and productive life, even giving birth to one or more children with a fairly good chance of not transmitting the virus to the child (Women and AIDS 5). A 1992 American study suggests that between 25% and 30% of children born to positive mothers will be positive

themselves; a 1993 study suggests that that rate is much lower - about 8%; a 1993 study done in Europe, however, labels that percentage as 14% (womansource HIV 12). Once a woman has given birth to her child, it can take up to 18 months before the woman will know if her child is HIV positive. The newest techniques employ methods which could shorten that period drastically, allowing the mother to know the child's HIV status often as little as 2 weeks after birth (womansource HIV 13). The decision to give birth is a hard one, and one for which there are no easy answers. Many times women are condemned for wanting to give birth to a child and thus to endanger its life in such a way. This is only heightened by the perspective in some poorer countries that children are necessary to continue the bloodline of the family. Conversely, a woman who desires an abortion to terminate her pregnancy will often be unable to locate a safe means by which to do this, and a woman who wants some means of contraception with which to avoid pregnancy altogether, often finds that contraception is inaccessible to her. Even if she is able to access a means of birth control, she may still be in danger; there have been very limited studies done on the effects of oral contraceptives on women testing positive, and taken in conjunction with drugs which lessen the pain of HIV.

Transmission in women is currently still very much a matter of

speculation. In 1988, 44% of women testing positive couldn't identify their risk behavior, asserting that they had only had sex with heterosexual men who claimed that they had tested negative. This statistic is puzzling, until it is viewed in light of the results of a 1990 study, which reported that a high percentage - 35% - of men asked would lie about their HIV status, and an even scarier statistic - 20% of those men - had already lied about their HIV status (Girvan 2). In addition to this discrepancy in data, women have a 9% rate of unknown transmission, which is over twice that of the rate for unknown transmissions in men (Denenberg 3). Transmissions from female-to-female are virtually unresearched, and the CDC's category for homosexual/bisexual transmissions does not include women. Statistics have also shown that once contracting the disease, women die more quickly than men. There is no known biological explanation for this. Clear from these statistics, then, is the fact that there is still much to be learned not only regarding HIV/AIDS transmission in women, but also regarding the actual physiological affects the disease has on females.

Women have again, therefore, been left out of the equation, and the inequalities have caused both the loss of lives, and the loss of quality of life for many women living with the virus. This situation is elucidated by Risa Denenberg, a contributor and editor to a book regarding women and HIV:

Since the CDC definition for AIDS was developed from observations of men, women often die from opportunistic infection before they are even considered eligible for an actual AIDS diagnosis. Women are thus excluded from the total statistical picture. They not only won't get counted, they also won't get treated; they won't qualify for health benefits, child care, rent subsidies, or other support services. Statistics, in other words, only count women who already fit into the CDC's narrow definition for AIDS; all the other women just remain invisible. Many women (and of course there are no statistics for this) are diagnosed with HIV infection only after they have died (Denenberg 4).

The actual statistical numbers currently surrounding infected women speak for themselves; women are a quickly growing entity in regards to the AIDS crisis, and an entity that neither the medical community, nor individuals are quite ready for. One in four newly infected Americans is female, and according to the February 1993 edition of "HIV/AIDS Surveillance" - just three years ago - women made up 11% of all AIDS cases, and 13% of all newly reported AIDS cases (womansource HIV 5). Now, however, WHO estimates that almost half of all newly infected adults are female (Women and AIDS 1). In 1994 alone, more than one million women were infected worldwide, and by the year 2000, over 14 million will have been infected, and approximately four million of them will have already died

(Women and AIDS 1). By 1992, AIDS was the leading cause of death for females ages 25-44 in major cities (Girvan 2).

Women constitute an extreme minority in the face of the AIDS crisis. Truthfully, those who are most likely to be infected are not only those who, for cultural, educational, legal and economic reasons, are least likely to be able to seek emotional help, but also those who already make up parts of what is considered among the least advantaged groups in society (Cochran, et al 526). Fifty-three percent of AIDS cases in females are African-American, 25% are white, 21% are Hispanic, and the percentage of Asian, Pacific Islander, and Native American women is less than zero (womansource HIV 5). On the whole they are also "younger and poorer than their male counterparts" (Girvan 3). Therefore women, already a minority, have another problem in relation to the AIDS crisis: many of them are also part of a cultural minority, a reality which must be kept in mind when addressing the unique perspectives of women living with HIV/AIDS. Sunny Rumsey, an AIDS activist and professional, and herself part of a cultural minority in America, states, "AIDS, on top of everything else, is breaking the back of the communities of people of color. Our women are in serious trouble (Rumsey 103). The minority issue, however, is not restricted merely to AIDS in America. In Tanzania, where by acceptable social standards men are still

encouraged to have numerous partners, the already marginalized status of women is only confirmed by their infection. Theresa Kaijage, a founding member of the Tanzanian AIDS Service Organization, expands on this idea by addressing the issue of gender minority in her country, as well as touching on some of the problems at the very foundation of the epidemic, which all countries, including the United States, are finding that they are facing:

All the gender issues we had never tackled came up at once. Initially we ignored them or thought they were irrelevant. We thought it was Eurocentric to tackle them in Africa. We thought our African culture was different and dealt with things in a different way. All the agendas that we had ignored: legal, educational and health problems, inequitable gender relations; suddenly we are dealing with these multiple issues, which people have not learned to analyze in a way that promotes equal sharing of both resources and power at all levels. In order to deal with AIDS, we have had to confront these (Women and AIDS 4).

Legislation is being taken to remedy the situation. It is, however, slow to come about, especially in the face of a pandemic as serious as is AIDS. In October of 1990, a class action suit was filed against the federal government on behalf of the many Americans - including women - who were being denied federal disability benefits due to the narrow definition of AIDS provided by the CDC. Consequently, through the work of numerous world and national

conferences on women and HIV, the CDC officially declared in 1991 that it would work to strengthen programs "to prevent HIV transmissions in women" (Girvan 7). Worldwide, individual countries are making positive steps to affirm and to protect women who are living with HIV/AIDS; there is still, however, much work to be done. Women living with AIDS, the large majority of whom are Hispanic and black, are continuously abandoned to an "increasingly Dickensian public health and welfare system"; as to the mass media, whose penchant is for bottom-line marketing, the response "to these AIDS realities remains: out of sight, out of mind" (Kemp 229). Sue Rosser sums up the situation as it exists today:

In the beginning, women were a focal point as care givers in the AIDS epidemic. Eventually, attention was given to women as vectors for transmission to men and children. Now is the time to shift the focus to the women themselves as human beings with the disease (Girvan 8).

The International Conference for Women in 1995 took place in Beijing, China, and from that conference came many positive statements and goals for the international community in supporting women who are currently living with AIDS or who are HIV positive. The dire need for the recognition of positive women's unique needs, as well as the especial support positive women deserve, has begun to be glimpsed, but, as can be evidenced by

statistics, is far from a reality. "Positively Women", an HIV positive woman's periodical, has developed a statement of needs addressing these needs as a complete entity. This document speaks to the problem of empowerment of women throughout the world, and provides clear-cut means by which to improve the situation of women living with the virus.

The Statement of Needs includes the need for both infected women and the general public to receive accurate and realistic information regarding the status of women with the virus. It recognizes the lack of research which has been done on women, as well as the lack of "decision-making power" in all policies and programs which affect women. The glaring inequalities in general funding as well as in emotional support groups is addressed, as is the right for women to make their "own choices" regarding reproductive rights.

The document is too lengthy to include here, but follows in its totality in *Appendix A* as a tribute to women living with the virus, and as an enlightening force by which to fight HIV/AIDS.

IV. The Gathering Darkness: A Need for Spirituality Among Persons With AIDS

In the early eighties, the gay population was the only community widely-known to be infected with the HIV virus; thus it was the members of that community who had to find support and nurture among their own ranks. The homosexual community was already a tenuous one - persons, often bitter, trying to find an individual sense of identity within a Western world which did not accept even a slight variance from the heterosexual norm. AIDS devastated these communities, and changed the lives of those initially involved inalterably. Many persons then turned to religious communities for support, only to find them inept - still struggling with issues which, in reality, had nothing to do with the fact that people were dying by the hundreds and needed, as the dying do, spiritual support.

John Bohne, a man at the "heart" of the epidemic because of his sexuality, pinpoints many of the issues persons with AIDS are dealing with:

We must measure our lives in weeks rather than years; at the same time we must deal with anger and hollowness as we ponder the love of our church and wonder about the love of our God. That was true in 1982 when we felt the 'gathering darkness'. It is even more true today. . . (Bohne 65).

Just as any person who is dying, those living with AIDS need an acknowledgement of the value of their own individual death, and this often comes in the form of a greater sense of spirituality. These persons frequently have "unfinished business" - the need to resolve broken relationships, fears of abandonment and death itself, the need for reconciliation of past events or with past people, or simply a feeling of spiritual abandonment (Dudley, et al 34). These needs are only heightened by the stigmatization which individuals living with the virus have already faced; for women this situation is doubly so and multiplied again by the fact that so many who contract the virus, including women, are young, and thus do not have a well-developed idea of spirituality; it is easy to understand why AIDS presents such a crisis of faith for those who are infected.

Anticipatory grief, the grieving that is done for yourself when you know you will die, is a matter of deep faith and spirituality. Knowing that there is an end to life, and a definite end to the individual life, is a sobering and deeply disturbing thought, and it changes everything (Fortunato 78). There is now an urgent reason to care about humanity and about life and to make "this moment, whatever moment it may be - so very important" (Fortunato 78). John Fortunato continues by asserting that it is the fullness, the essence of the moment that is important; everything that mortality holds

becomes very important and very valuable. "Living as if death were a myth robs life of its conclusion," thus AIDS is not a death-sentence, but rather a reason to begin to live (Fortunato 78,79).

Anticipatory grief, however, also includes more of the concrete aspects of life, such as making arrangements for the living after the HIV positive individual's death. In addition to giving up the role of care-taker for a partner, for women this also includes finding guardians for children, an undoubtedly traumatic occurrence. Decisions regarding medical treatment are too, part of a holistic spiritual understanding. The termination of certain treatments means, of course, death, and attempting to attach a weight to the quality of life as opposed to the length of life is very difficult to discern, especially for women in light of the presence of children (Anderson).

In addition to the aforementioned spiritual dilemmas, persons with AIDS are living for longer periods of time now than they did at the onset of the virus; this longer survival requires a different kind of spiritual awareness than does sudden and imminent death. As long term survivors, these individuals have had to feed and care for their personal sense of spirituality; and through taking time for themselves and finding strength within their minds and hearts, if not within their bodies, they have found a joy in life, and often even a purpose in the disease. They have become active in ministering

to others, and actively "committed to life" ("Characteristics of Long Term Survivors").

Conversely, a greater faith in God has often led patients to be stronger overall, and to live for longer periods as well. Father Daniel Berrigan, a well-known author and tireless worker for social justice in the world, published the book, Sorrow Built a Bridge, a reflection on his own experiences with AIDS, and particularly with the faith of those infected. He speaks to the fact that those infected need spiritual support and need to find affirmation through the religious community. Father Berrigan draws on a text from St. John of the Cross; 'In the evening we will be judged by love,' and continues in writing that "what draws us to the embrace of love is . . . the courage to believe, church and state notwithstanding, [that] the only judgement will be that of love" (Berrigan 11). With this knowledge, a new life and a new purpose can begin for HIV positive individuals. Father Berrigan beautifully and vividly writes of this turning point in a friend hospitalized with AIDS:

And then a sea change. He reached a new resolve, somewhere in the dark that lies behind the eyes. Words he had spoken, instructions issued in comparative ease and health - these were invalidated. He resolved to live. The images that govern dying were radically altered. Other images, of life, combat, patience, courage, took hold He would change course, at all cost. And if he sank, that too was part of the risk. Implicit in the bargain his champion's heart made with . . . Someone. I never promised you a Red Sea (Berrigan 114-115).

All that is essential in life does not really begin until it is noted and appreciated. For persons with AIDS, life, and thus contentment and peace and meaning cannot come until the spiritual aspect of the person is tended to. Those individuals infected with HIV, and especially those women who are infected, absolutely require attention to be given to the spiritual aspect of their health. The initial lack of response by religious communities therefore, has caused a crisis which has been addressed only recently.

V. AIDS and God's Word: Religious Communities Respond

Throughout the HIV/AIDS pandemic, one of the largest forces enforcing the stigma associated with the virus, has been that of the religious community. Initially AIDS, as has been previously discussed, was seen as a disease sent to punish those individuals who took part in immoral sexual acts - namely, homosexual persons. When the body of mainstream Christian churches first heard of this malady, the seemingly obvious opportunity for a lesson in morality based in Old Testament fear could not be avoided: AIDS became known as the "gay plague", if it was discussed at all. Initial reactions from religious organizations echoed phrases such as that from Bishop Falcao of Brasilia, who condemned the disease, as the "consequence of moral decadence", or the Cardinal of Rio de Janeiro, Eugenio Sales, who stated that AIDS is, "God's punishment" and a "revenge of nature" (Sontag 61). Churches - mostly bastions of traditional, heterosexual orientation - simply did not take part in affirming anything which was at variance with the presumed norm, and thus the moral norm (Stiles 534). William Edwin Swing explains the negative, although not surprising, response of most churches through a particularly vivid means:

Before the church could arouse itself to a Christ-like response, it stumbled into self-righteousness. It was as if Jesus found someone caught in a homosexual act and said to the gathered church crowds, "Whoever is without sin, cast the first stone." What followed was an avalanche of rocks that buried the afflicted one, the Holy One, and any venture into the subtleties of sexual morality (Swing 225).

There was, however, one church body in particular which from the onset of the virus has catered to the spiritual acceptance and counseling of AIDS sufferers in the nonprejudicial manner which persons infected have so needed. The Universal Fellowship of Metropolitan Community Churches, or the MCC, has been the "foremost religious group to respond to the AIDS crisis," mostly due to its known identity as a community which not only supports, but also welcomes persons who are gay, lesbian, or bisexual (Stiles 534). The MCC has worked tirelessly to provide pastors, chaplains, and spiritual hope and support to those infected. It has acted as a "bridge" in some communities - spanning the gap between the gay religious communities and the AIDS-related service organizations (Stiles 535). Many persons living with AIDS in the early eighties found spiritual guidance under the roof of the Metropolitan Community Church, but due to its nature as a mostly urban entity, many more were simply left to die, without any form of spiritual or religious support.

The lack of acknowledgement and support by mainstream religious communities reached its turning point when, in Houston, Texas in the fall of 1985 numerous misrepresentational and false facts were circulated by some candidates in the mayoral election as an effort to gain support by "exploiting people's fears about AIDS" (Shelp, et al 64). The situation was only aggravated when mayoral candidate Louis Welch, a recently retired president of the Chamber of Commerce, voiced his opinion regarding the AIDS epidemic; his solution was simple - "shoot the queers." Following this speech he attended a prayer breakfast hosted by pastors of his denomination, where he received a standing ovation for his views. As a result of this situation, many clergy in the Houston area saw that immediate action was needed, and formed the Clergy Consultation on AIDS. The Consultation is made up of members of many different faith traditions, and while all do not agree on many of the moral issues surrounding the AIDS crisis, all do agree, however, to provide a spiritual, emotional, educational, and dialogue-rich setting with which to minister both to those who are infected with the virus, and to persons within the area (Shelp, et al 65).

The Consultation represents one of the first organizations of its kind; now, however, other religious communities have followed the lead the Consultation set forth, and the earliest reactions by mainstream Protestant

and Catholic churches have given way to almost universal support for persons living with AIDS, if not for the lifestyle to which it is most commonly linked. Finally and thankfully, by 1985, the responses of other churches began to change. Once the initial shock was over, other more mainstream churches began to make some tentative positive responses. Although belated, this movement grew quickly and blossomed into books, devotionals, national conferences and public pronouncements, as well as a wealth of studies on sexuality education in conjunction with the doctrines of various churches.

It almost seems ludicrous that faiths would not, from the onset of the epidemic, view those infected, no matter their sexual identity, with the kind of love and concern with which Christ treated the outcasts of his day. Earl E. Shelp and Ronald H. Sunderland compiled a text in 1987 dealing with this very topic. They make a strong point in asserting that Jesus never saw illness as punishment, and more often spoke of it as a sign of disorder in God's creation which demanded response (Bohne 65). This model is easily and very correctly applied to the AIDS crisis both in its stated meaning, and in the implied understanding of those who have contracted the disease. Obviously, Jesus would have loved and cared for those persons living with AIDS, but he would also have acknowledged the fact that they contracted the disease as no

part of a punishment by an angry God.

When the change came, then, it came as a strong, although at first, not large, force. Many denominations began to form their own statements regarding the AIDS epidemic. It is selections from these, in the words of the various faiths, which follow. Bruce Garner, author of "Living on the Front Lines", a document which came out of the Second Conference of the National Episcopal AIDS Coalition, vividly addresses the same topic with a challenge to the members of his church, and to the entirety of the Christian community:

I challenge each of you to come to the front lines of the AIDS crisis. Don't come alone. Bring your faith in God with you. Bring your friends and family with you. Prepare yourselves. It isn't always pretty, it isn't always neat and tidy, but it is rewarding and it reflects the part of God that resides in each of us. You'll walk among the outcasts, the marginalized, those in need, the lepers - you'll walk with the same children of God that Jesus walked with (American Churches 2).

The 1989 representative for the Social Justice and Peacemaking Unit of the General Assembly Council of the U.S. Presbyterian Church echoes this perspective:

. . . The biblical message, God's message, is unconditional love, not selective caring and acceptance. Our mandate, as Christians, is clearly one of unconditional love. I believe that God calls each of us, in the midst of the AIDS crisis, to find our own means of expression. I invite and encourage each of you to find your own way to acknowledge and celebrate God's call to each of us (American Churches 1).

The Christian Church (Disciples of Christ) published a similar statement in their 1987 document, "Resolution Regarding Current Crisis in the United States Government's Response to the AIDS Crisis". They assert that God's love is for all people, not simply a selected few, and members of the church can be powerful "advocates for research, education, increased treatment services and disease prevention" through their power as witnesses to God's unbounding love (American Churches 1).

Many religious communities too, recognize the epidemic as a challenge to live the Gospel, as has already been seen in the Episcopal church's statement, and realize the opportunity to step in as primary educators, a role which had been (often gladly) handed over to the government in the form of the public school system. The Evangelical Lutheran Church in America states this opportunity for mission well:

Frank discussion of the facts involved is absolutely necessary, though many may feel it to be inappropriate in a church setting. In fact, there is no other agency or institution that should be as well qualified. The church should have something to say regarding sex education in the home, churches, and schools, the destructive dynamics of homophobia, and intimacy and relationships. . . (American Churches 2).

The Union of American Hebrew Congregations published AIDS: A Glossary of Jewish Values, and within this text stated, in a like manner, that Judaism must support "a variety of efforts to provide people with honest and realistic information on AIDS", and in so doing, also support not only those living with the virus, but also projects which further AIDS research and thus further quality of life (American Churches 2).

Although the attitudes which some church bodies profess regarding homosexuality are not universal throughout all church communities, the recognition of a Christ-like response of love and care for infected individuals is. The Sunday School Board of the Southern Baptist church, while not fully agreeing with acceptance of homosexuality, has nevertheless chosen to support infected individuals, as is evident in the following statement, written by a Southern Baptist doctor and published in a Southern Baptist text:

AIDS is not strictly a homosexual disease. . . . Homosexuals are a high-risk population, as are intravenous drug users. However, no one group of people is responsible for AIDS. We must reach out to all persons with love, compassion, and forgiveness, as Jesus Christ did. Before we can minister to AIDS patients, we must know the forgiveness and love of God that are available to all people, regardless of their past (American Churches 1).

A similar statement was put forth by "United as One", the Catholic Church's AIDS Ministry organization:

Whether women or men contract AIDS by accident or by chosen behavior is relevant to directions and decisions in health education and personal responsibility. But it is incidental to the acceptance, friendship, care, love, prayer, and strength we must all offer and be. If Jesus were to walk into the room of an AIDS patient who happened to be homosexual or a drug addict, he could not bullhorn words of condemnation or disapproval. He would say, "My friend, I love you. How can I show my love?" (American Churches 2).

Not all congregations, however, are ready for the AIDS epidemic, and while this is unfortunate, it is a reality which must be faced if persons with AIDS are to be appropriately given the support they so badly need. The Rev. Connie Hartquist of the Episcopal Diocese of California offered a solution to this dilemma in her concept of an "AIDS - friendly congregation". This model is one which requires thought and discernment among parishes, and

challenges each congregation to take literally Jesus' message of love for all persons (Doubleday 295).

Despite the initial conflict between support of persons with AIDS and mainstream religious discrimination, it is important to realize that there has been much accomplished by religious communities in support of persons living with the HIV virus.

The AIDS National Interfaith Network (ANIN), was created in 1987 to afford the religious community with a means by which to begin to be part of the solution, rather than simply continuing to aggravate the problem. ANIN works to coordinate educational and counseling services with many existing HIV support groups and organizations, and serves as a representative group of a variety of faiths within the United States in matters of legislative and policymaking importance. ANIN's core is made up of a "working group", which represents approximately fifteen different religious communities. ANIN has been both a driving and a revolutionary force in not only the AIDS movement, but also for ecumenism as a whole. Part of ANIN's mission statement reflects this spirit:

As people of faith, we believe that God's reassuring presence reaches out to all those who are alienated and oppressed. We serve God and humanity by striving to emulate divine compassion, to seek justice, and to provide service. This is our prophetic task (South 298).

In addition to organizational developments, it is important to realize that numerous faiths have made public statements regarding AIDS within their own faith tradition and as a fact which the entire human race must face. Many of these statements have been compiled and reflect a positive and energizing force in the face of so dehumanizing a disease.

The Atlanta Declaration, one of the most significant and most needed documents which has arisen from the AIDS crisis, has come from the religious community. It was formulated at the Carter Center at Emory University in Atlanta, Georgia, and was adopted on December 4, 1989 by members of a national religious leaders' consultation. The signatories include members of the African Methodist Episcopal Church, American Baptist Church, American Friends Service Committee, the Church of the Brethren, the Episcopal Church, the Evangelical Lutheran Church in America, the Jewish community, the Moravian Church, the National Spiritual Assembly of the Bahais of the United States, the Presbyterian Church, the Reformed Church in America, the Reorganized Church of the Latter Day Saints, the Roman Catholic Church, the Southern Baptist Convention, the United Church of Christ, the United Methodist Church, the Universal Fellowship of Metropolitan Community Churches, and various interfaith representatives, including the AIDS National Interfaith Network

(ANIN), as well as many secular individuals and organizations.

The Atlanta Declaration addresses a variety of topics in conjunction with the AIDS virus. Included is a recognition of the need for acceptance of spiritual diversity among individuals with AIDS, as well as the need for actions which speak only of hope for the future of the virus, such as a commitment to funding for educational and informational purposes and emotional support groups. The Declaration also specifically addresses the spiritual needs of those infected and the special needs of women, both especially pertinent to this discussion. Faith groups have pledged to work together to fight not only the disease itself, but also the hate and discrimination which are a part of the total HIV picture. The inequalities women with AIDS suffer are also brought to light, and a positive commitment is made to look upon the entirety of the situation with "vision" and "creativity" (Atlanta Declaration). The whole of the Atlanta Declaration is contained in *Appendix B*, at the end of this paper.

VI. Women Living With AIDS: The Journey for Spiritual Identity

Women living with AIDS face struggles immensely complex in nature. Not only do these women constitute a minority statistically, they also constitute a group which has almost no representation among the medical, research, or emotional counseling communities. These points are significant in that they represent the second-rate treatment HIV positive women must live with as a whole, but they are even more significant when viewed from a more personal level - the standpoint of individual women infected and trying to live a complete and fulfilling life with the virus. It is important to remember that living a life full of worth and value is innately connected with a sense of spirituality. To be a complete person and one enjoying a healthy lifestyle, an inner realization of faith or religion is necessary. This holistic concept of health, although in no way new, has only become popular within the last decade. Thanks to this ideal people are taking more time out for themselves in general and finding peace and comfort in God, whatever the individual conception of that being may be.

Concurrently, spirituality encompasses the wholeness of being, not simply Sunday church services or Bible studies. Spirituality includes the understanding of being in each individual, and affirmation of the whole

person - psychologically, socially, emotionally, intellectually, and physically. For women the physical aspect plays a large role, as sexuality has been a largely defining factor for women throughout history through both religious mores and social standards (Richter). When discussing HIV positive women, then, it is necessary to examine and reflect upon every aspect of these women's lives in order to understand the spiritual struggle they are faced with. In the end though, the fact remains that AIDS has no cure and will eventually lead to the death of the woman, and death is an inherently spiritual journey - often more so than is life.

Overall, women living with AIDS find very little in the way of support groups, accurate information, and up-to-date research, and these facts, compounded with the stigma which is already attached to the virus, often leaves HIV positive women distraught, frustrated, and especially lonely. They turn to their churches or faith organizations for support, and again often find that they are treated negatively and ostracized for the condition they neither wished to have, nor know how to live with. Many of these women soon become depressed; they have hit, as the poem written by JB Coles expressed, the "bottom rung" of the ladder. The options remaining are either to remain stagnant and powerless, or to try to find a form of identity, a sense of self despite the virus, and a way to begin the climb back into

life. Spirituality, whether in the form of organized religion or in a more personal sense of faith, plays an integral role in the lives of women making this ascent.

Woman's traditional role as care giver, a role accepted and expected by the majority of religious organizations, places women at the center of their families, responsible for the health, education, and welfare of their spouses and children (Boudin, et al 151). Women frequently find themselves as the last factor in this equation, caring for everyone else before caring for themselves. The AIDS virus challenges this role in a way that many women are not ready for. As they become infected and are diagnosed, they lose their ability to care for their family, and thus they lose a significant part of their identity. This loss of identity is, in fact, two-fold and encompasses both societal and religious standards and the personal beliefs of women in regards to themselves.

The debilitating effects of the AIDS virus do not allow for women to continue to care for their families, and especially for their children, in the way that they often feel they must to fulfill their role as productive females in contemporary society. Women with AIDS find that they need time out for themselves and need to draw inward, which directly conflicts with the notion of the female as care giver. The infected woman feels worthless either due to

her actual physical inability or to her knowledge of her impending physical inability.

Compounding this worthless feeling is heavy pressure from the religious and social communities that a woman who is infected will make a poor mother and care giver for her family, thus not fulfilling her duty to society as a woman. Women with AIDS are often pressured to not become pregnant, denying these women a right which is innately a part of being a whole woman. Being diagnosed with AIDS is a sure and awkward sign of sexual activity in a woman, a reality which popular culture and traditional Western religious belief is uncomfortable with, especially in young and unmarried or single females (Richter). Prostitutes have been scapegoated as transmitters of the disease, both to unsuspecting young men and to "upstanding" husbands who happened to be clients (Wiener 376). This fact succeeds in multiplying the already highly negative stigma associated with women who are sexually active.

Ironically, in actuality it is women who are often infected by husbands or lovers who were either unaware of their own HIV status, who refused to get tested in fear of what the results would be or who lied in order to engage in sexual activity, and thus inadvertently relegated the woman involved to mere "property" to use for gratification. The anger and rage women in this

situation feel is difficult to envision, but even more difficult to understand is the attitude of women who have transcended this pain and who are strong enough to forgive and to continue to love and to care for their partners, whether in reality or in memory. This position has been articulated eloquently by Marie Werner, a woman who was infected by her boyfriend of ten years who was also, unknown to her, a practicing bisexual. She has been able to forgive him, now dead, through reflection, and she remembers him as a truly "wonderful man":

So you have left me.
Clandestine, quietly, deliberately.
You hardly said a word.
Your apartment remained, the books.

The plants have dried out, you forgot to tell me
I should water them.

So you went away.
For always, forever.
Without pretending to buy cigarettes,
No indication where,
And I can't even write to you anymore.
There were still a few things to clarify:
What were you thinking of?

So, you went away, you have left me.
Since then I sit in a corner,
Not eating, not answering the telephone.

And you haven't left any explanations for the others.
They don't even ask - what could I say?
Tomorrow I shall plant your grave (Werner 61-62).

Her melancholy peacefulness and acceptance did not come easily, however, and she first had to search for a new identity as an "infected woman in a world of men" (Werner 60).

As has already been discussed, HIV positive women are the object of discrimination both within the world of AIDS and within society in general. They must survive what was first termed a "man's disease" and accomplish this with media and a medical community which are decidedly androcentric. To find a new identity within this world is the challenge which all HIV positive women must meet if they are to continue to live with the kind of inner contentment which Marie's poem displays, and which ultimately indicates a peace of spirit. Marie's contentment is strongly linked to her personal sense of worth, which is largely formed by her sense of spirituality as an individual. Thus without a personal sense of value, she could become lost in the maze of statistics.

This identity crisis is again heightened by the lack of positive female role models within religious communities. When females have been raped or infected by males, and then are repeatedly discriminated against by the

world which views AIDS as a man's disease, they are often hurt and unwilling to enter into a traditionally patriarchal organization for spiritual support (Gilbert). Female ministers and counselors can help a great deal, as can support organizations which form around particular denominations; however, the fact that God has been viewed as a male figure is hard to overcome (Richter).

In response to this tendency, God has become an abstract conception for most women living with AIDS. God, traditionally the "Father" and "Law-Giver", has been replaced by a dynamic and universal presence. For these women God begins to acquire traits such as nurturance and unquestioning acceptance. It is for this reason that for many women spirituality - a sense of self in connection with a higher being - is much more important than alignment with a particular religious institution.

Vicki-Lynn Earls, a woman living with the virus, experienced a great deal of rejection from her home Catholic church when she was first diagnosed. She became very angry and, in reflection, terms that point as the "lowest in my life" (Earls). She continues, however, to say that "God was there for me". She turned inwards and God made her realize the strong and special person that she is - as an independent woman and both as a whole female and as a holy female; God gave her a new direction in life: AIDS

Ministry. She now knows that she is more appreciative of life than she had ever been before, and she is busy with nationwide speaking engagements and planning retreats for other women like herself, looking for a new direction and a new meaning following their positive diagnosis, through a spiritual journey (Earls).

Nicole Nemeth, another woman living with HIV, relates a similar statement:

Live. Life goes on. I look at things so differently now. I have an appreciation for life. I have a real value for what is important. I realize that happiness and being healthy and enjoying your time are the best gifts in the world. I almost think maybe, in a way, this is a positive thing. I have a real great sense of what it's like to be alive. And I cherish it (womansource HIV 22).

Didi, another woman living with AIDS, confirms the importance of faith in herself through faith in God with her story. When she was first diagnosed, after her husband had died, she remembers:

I was cold. I was very cold I needed to understand my own feelings . . . a week later I needed my meditation (some say prayers) just to take time for myself; not to understand anything, or to question anything, only to find the warmth I had deep down inside but couldn't feel anymore (Didi).

Didi has continued to stay strongly connected with her image of an

androgenous God and often talks about "another side", a "truer" side which is developing within her as she becomes more and more connected to God through her battle with AIDS:

. . . my true self is developing, and of course that is my innerself - the one that is truly living; my first, pure thoughts behind my actions come from there, and I am glad that this unconscious is getting more conscious all the time (Didi).

She concludes by wondering if perhaps the differentiation of the two selves is her physical self slowly withdrawing, and her soul's rapid approach to the "crossing over" of death. At moments of lucidity, she can see the path. Didi expresses the feeling that her identity on the other side is beginning to take shape. She knows, however, that she will not be alone, as she has had many infected friends die before her, and as she has faith in the God who has guided her through this journey and who has made her stronger (Didi).

The importance of this strength cannot be denied and is well-recognized by Dambudzo, a young black woman from Zimbabwe, who has written a statement on how to live with AIDS. At the top of her list reads: "Become a believer . . . this will help you to find comfort" (Dambudzo 171).

Albert Camus once wrote the statement, "In the depth of winter I finally learned that within me there lay an invincible summer". HIV positive women have found their summer despite the winter of the virus.

Remarkably, these women have discovered a deeper sense of spirituality and thus of self through their struggle with AIDS. They, having nowhere else to turn, have turned both inward and thus to God, and only then have found the strength they needed to survive. Women living with AIDS continue to take the role of care giver naturally; however, they first must take care of themselves and then, in turn, widen the circle. Women have not stopped being care givers, they have continued to preach, speak, minister and delight in the opportunity life has given them to become fuller persons by helping others to become richer and more valuable persons.

"M", a young woman in Germany, acknowledges AIDS as her early winter, cutting her off from her hopes for a traditional life - a husband and children. From that point of desperation however, she moves on to find hope in her life, and in alternate routes to contentment:

My last period of life has begun, my old age, the evening of my life. And for all that, I am only 27 years old and have not yet lost my will to live. . . . What can one make out of one's life? Most people at [my] age are established, have children by now, family. But we, who can't have children - which perhaps is good - must look for other ways, must set other goals, must find other experiences and meanings (M 94, 100).

Finally, Leetia Geetah, an Inuit woman from Canada, writes a statement typifying the emotional spectrum of HIV positive women. She

addresses the anger and hurt at first being diagnosed, but her backlash quickly turns proactive, and her spiritual growth is evident. She concludes by declaring her wish to care for other persons who are HIV positive - a commitment which transcends AIDS the statistic and affirms the persons, especially women, who are continuing to turn the winter of AIDS into an invincible summer:

When I found out I was HIV positive, the only thing that went through my head was: 'Why me, Lord? Why are You putting me in this situation?' . . . I blamed God for it. I blamed him for everything. . . . Now I am coping and doing my best. At times I just wish that I could die in my sleep. But when I wake up in the morning, I am grateful to God that he takes care of me. I take it one day at a time. I just couldn't throw it away. I am praying to my God to support me and lead me so I can help my people to understand more. I am grateful now. . . . I'll be there for people who cannot accept what they have. I'll be there to teach them that they have supporters everywhere (Geetah 191, 192, 194).

Appendix A:

**International Community of Women Living With HIV/AIDS
Statement of Needs**

To improve the situation of women living with HIV/AIDS throughout the world we need:

1. Encouragement, support, and funding for the development of self-help groups, local and international networks of women living with HIV/AIDS.
2. The media not to stigmatize but to realistically portray us.
3. Equitable, accessible, and affordable treatments for HIV and research into how the virus affects women, covering: psychosocial and medical aspects, and complementary and allopathic treatments.
4. Funding for services and support for women living with HIV/AIDS, to alleviate their isolation and meet their basic needs. All funding directed to us needs to be evaluated and monitored to ensure that we get it.
5. The right to make our own choices about reproduction and to be respected and supported in those choices. This includes the right to have children and the right to not have children.
6. Recognition of the right of our children/orphans to be cared for and of the importance of our role as parents.
7. Education and training of health care providers and the community at large about women's risks and needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be readily available.
8. Recognition of the fundamental human rights of all women living with HIV/AIDS, with special consideration for women in prison, drug users, and sex workers.
9. Research into woman-to-woman transmission and recognition of, and support for, lesbians living with HIV/AIDS.
10. Decision-making power and consultation on all levels of policy and programs affecting us.
11. To provide economic support for women living with HIV/AIDS in developing nations to help them to be self-sufficient and independent.

(womansourceHIV 8)

*Appendix B:*The Atlanta Declaration

“We are Living with AIDS:
An Interfaith Call to Hope and Action”

We come together as members of different faiths. Our traditions teach us different ways to embrace God. We represent humanity's wide range of ways to be human. Across our diversity, however, AIDS magnifies the fact that we are also one. AIDS is not only an affliction of individuals or particular groups. AIDS is an affliction of the whole human family.

Our religious vision proclaims that living with HIV/AIDS is a condition in which we must all participate actively. It is a scandal that many people living with HIV/AIDS suffer and grieve in secret. We seek hope amidst the moral and biological tragedies of this epidemic in order to pass on hope for generations to come.

The tragedy of the Human Immunodeficiency Virus epidemic has confronted each of us personally, each of our religious institutions, as well as the whole society with the need for a new understanding of the interconnectedness between physical disease and social responsibility. It calls for creative action among all our institutions - medical, social, economic, political, educational, and religious - for the purpose of providing systematic, compassionate attention to the epidemic. The religious community in particular is faced with these extended responsibilities:

- A. To embody and proclaim hope, life, and healing in the midst of suffering;
- B. To assure that all whose lives are affected by the epidemic will have access to compassion, non-judgmental care, respect, support and assistance;
- C. To generate a prophetic vision of society in which the “general welfare” becomes the abiding obligation of public, private and voluntary sectors of society;
- D. To provide accurate and comprehensive information for the public regarding HIV transmission, related behavior patterns, and means of transmission;
- E. To transform public attitudes and policies so that adequate care and preventive measures will be available for all people in need.

Fulfilling these responsibilities will require of us new commitments as individuals, as religious bodies, and as a nation.

As individuals:

Because we are relatives, friends and neighbors of persons with HIV/AIDS, and are ourselves persons living with HIV/AIDS, we commit ourselves to personal ministries of care for those infected with and those affected by HIV;

Because we are members and leaders of religious institutions, we commit ourselves to the work of insuring that our institutions renew their calling to ministries of health and healing;

Because we are citizens of this nation, we commit ourselves to establishing public policies through which all citizens contribute to the care of all persons with AIDS and to the health and well-being of the nation as a whole.

As religious bodies:

Because the presence of HIV calls us to mutual cooperation, we commit ourselves to work within interfaith coalitions wherever and whenever feasible;

Because the needs in local communities are so great, we commit ourselves to promote and support local interfaith coalitions for education, provision of care, community service, public policy advocacy, and specialized training for religious professionals and laity in care and counseling;

Because religious professionals, faith communities, and the public need accurate and comprehensive education, we commit ourselves to provide accurate and complete information about the transmission and prevention of HIV/AIDS disease; and we commit ourselves to produce and promote culturally and linguistically appropriate HIV related educational materials - audio, video, and printed - in a context that promotes individual self-esteem, teaches the fundamental goodness of human sexuality, and supports the integrity of responsible and caring intimate relationships.

As citizens:

Because the President's Commission on the HIV Epidemic has issued a comprehensive, balanced, and informed report based upon the expertise of hundreds of America's best scientists, as well as the testimony of many other professionals and persons living with HIV/AIDS, we call for immediate implementation of its recommendations;

Because HIV is a threat to the life and health of all people in the nation, we call upon President Bush to demonstrate moral and political leadership in assuring adequate care for all who are afflicted and responsible federal action including the ends of:

- o protecting against HIV related discrimination of all forms;
- o expanding of drug-treatment programs to include all who choose them;
- o placing highest priority on HIV/AIDS education and care programs within the African-American, Hispanic, Asian/Pacific Islander and Native American communities;
- o for all HIV infected persons:
 - eliminating of mandatory segregation and isolation in prisons as well as provision of humane and professional medical care;
 - assuring decent, appropriate and affordable housing for the homeless;
 - continuation of AIDS service programs;
 - establishing comprehensive, affordable and accessible health care;
- o insuring expeditious approval by the Food and Drug Administration of HIV/AIDS treatments, expeditious experimental drug trials, easier access to promising HIV/AIDS treatments, and wider availability of new drugs to

- o persons with HIV/AIDS;
- o expanding the availability of residential health care facilities, hospices and affordable home care for persons with HIV/AIDS;
- o Encouraging the prudent use of voluntary HIV anti-body testing with the strictest of safeguards whether anonymous or confidential as used for medical evaluation, epidemiological or prevention modalities;
- o advocating for the continuation of comprehensive prevention and risk-reduction programs for drug users including the distribution of AIDS prevention information and materials including bleach for the sterilization of hypodermic needles;
- o allowing otherwise eligible foreign nationals, without regard to their HIV status, access to visitation and/or citizenship in the United States.

As a people dedicated to a future of hope:

Because barriers among us based on religion, race, class, gender and sexual orientation that continue to generate fear, persecution and violence are intensified by the HIV pandemic, we call upon all sectors of our society, particularly our faith communities, to adopt as highest priority the elimination of racism, classism, sexism, and homophobia;

Because America's businesses and industries must address the presence of AIDS, we call upon its leaders to endorse and implement the "Ten Principles for the Workplace", and we commit our institutions to adopting these principles;

Because the presence of HIV/AIDS creates special needs among different people, we call for all sectors of society to contribute to support for infected infants and children in need of foster care and adoption services ; to support HIV infected women who suffer discrimination from many sources; for families who need community care;

Because economic disparity and the poverty it engenders is a major contributing factor in the AIDS epidemic, and a barrier to the accessibility to prevention and treatment, we call upon all sectors of society to seek ways of eliminating poverty in a commitment to a future of hope and security.

Finally, we commit ourselves to call for accountability on the part of this nation's public officials and corporate leaders. It is a time for envisioning a new society, one committed to the health and welfare of all people, and united in anticipation for that time when we will know that to respond to today's crisis is our only hope for tomorrow.

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