The Impact of Spirituality on the Attitudes and Success of HIV Patients: Voices of the Infected

Author: Christopher McLaughlin

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The Impact of Spirituality on the Attitudes and Success of HIV Patients

Voices of the Infected

by

Christopher McLaughlin

Martin Cohen, Advisor
April 2008
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Voices of the Infected

Abstract

HIV is a complex, life-altering infection that often challenges patients to change their attitudes towards health and hope in order to survive. In developed nations, such as the United States, HIV is no longer a terminal illness, but a chronic condition with tremendous social consequences. Because religion and spirituality are so significant to the life attitudes of millions of Americans, I wanted to explore the role that they may have for those infected with HIV. Specifically, the study attempts to examine the connection between spirituality and patient health attitudes, as well as the role of spirituality in successfully fighting the virus. Through a series of open interviews, I collected quantitative data and narratives from several patients. While the sample was overwhelmingly religious, the participants noted that religion has been one of the most significant motivators in their struggles against HIV. While the limited sample size prevents statistical analysis, I am able to present the life stories of many patients infected with the virus. Their experiences provide insight into the powers of spirituality and faith when facing HIV.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>5</td>
</tr>
<tr>
<td>Introduction</td>
<td>6</td>
</tr>
<tr>
<td>Methods and Materials</td>
<td>15</td>
</tr>
<tr>
<td>Results</td>
<td>19</td>
</tr>
<tr>
<td>Discussion</td>
<td>24</td>
</tr>
<tr>
<td>Patient Narratives</td>
<td>27</td>
</tr>
<tr>
<td>Closing Remarks</td>
<td>96</td>
</tr>
<tr>
<td>Works Cited</td>
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Acknowledgements

I am deeply indebted to the many individuals who have helped turn a passing idea into a lively thesis. I am most grateful for the support of two brilliant men, Martin Cohen, my advisor and academic mentor, and Zenon Protopapas, my longtime mentor in the field of medicine. For years, Dr. Protopapas has assisted me in finding fulfilling projects that connect my personal talents and passions with my interest in medicine. Dr. Protopapas informed me of the Haelen Center and suggested that I contact the personnel at the clinic. Without his support, I would not have had such a strong desire to pursue a medical degree, and would not have had the wonderful opportunity that became this thesis. I owe the intellectual motivation behind my work to Professor Cohen. A gifted teacher and passionate scholar, his open spirit and humility have inspired me to seek out truth and goodness is an unforgiving world. Not only did he provide ideas for this work, he kindly invested his time so that I could realize my goals in writing. Learning under Professor Cohen has shaped my writing style, gentle approach, and my attitudes on life experiences. This thesis is the product of his assistance as my advisor and the perspective he has granted to me through his teaching.

I wish to extend my gratitude to the staff at the Haelen Center, particularly Sharon Weissman and Michael Virata. Drs. Weissman and Virata were thoroughly accommodating while I was working at the clinic. They fully supported my research goals and helped me to design a study and to acquire IRB approval. Additionally, they assisted in recruiting patients for my research and encouraged other staff members to do the same. While Dr. Virata introduced me to research opportunities at the clinic, Dr. Weissman guided me through the logistics of hospital research. Without the kind support of the dedicated caregivers at the Haelen Center, this project would be little more than a series of proposals and theories. I am honored to have shared a summer with such able professionals.

I cannot discuss my academic endeavors without crediting the financiers of my education and lifelong supporters of all of my work, my family. My parents have dedicated the last 22 years of their lives to raising their two children. They wish to provide their children with the opportunity to learn and grow in the most loving of environments. I hope to honor their sacrifices through my life and works.
Introduction

HIV is a pathogen with a reputation for destroying lives, destabilizing communities, and taxing societies. The threat of death is not the sole issue with HIV. In industrialized nations, advances in synthetic drugs have transformed a crippling illness into a chronic condition. Spared the horror of a premature death, patients still face social stigmatization, confusion, and isolation. The social ills of HIV can sap a patient’s will to live, and without the desire to persist, advanced treatments lose efficacy. A patient who feels rejected by family and community may choose to discontinue treatment, or otherwise neglect the health needs of her body. In times of such suffering or abandonment, faith and religion can provide the support necessary for survival. For this reason, healthcare and religion have long shared a bond. Likewise, the spirituality of HIV patients may be linked to their success in combating the virus. The goal of this study is to analyze that link and determine the significance of spirituality to those infected with HIV.

The global HIV/AIDS epidemic has challenged clinicians and public health officials for decades. A disease unlike any before it, HIV is as much of a social crisis as it is a medical one. Due to its modes of transmission, mechanisms of infection, and ambiguity of symptoms, HIV brings with it instability and stigmatization. When combating the human immunodeficiency virus (“HIV”), individuals and societies must treat both social and physical ills. Therefore, it is important to understand the biology behind AIDS in order to adequately analyze the lives of the infected.

AIDS, or acquired immune deficiency syndrome, is the eventual result of prolonged infection by HIV. Like all viruses, HIV is an obligate intracellular parasite. It depends on living cells for energy metabolism, energy synthesis, and nucleic acid
synthesis. Specifically, HIV is a retrovirus, a type of virus that has a protein envelope and uses RNA as genetic material. Retroviruses reproduce by forcing their cellular hosts to produce viral RNA. Infected cells act as factories, mass-producing viral RNA so that viruses can manufacture themselves within the cell. Infection begins when the protein envelope of the retrovirus binds to a receptor on the membrane of the host cell. The virus then penetrates the cell membrane and leaves its coat. Inside the cell, the retrovirus forces a process known as reverse transcriptase to convert viral RNA into viral DNA. The viral DNA then enters the cell nucleus and is integrated into the host’s chromosomal DNA. The host then synthesizes viral RNA and releases it from the cell nucleus into the cytoplasm. The viral RNA and mRNA then synthesize proteins and assemble new viruses through budding along the cell membrane. Immature viruses break from the productive host cell and mature, and soon thereafter invade additional healthy cells. Infected cells become productive host cells, and are not killed by the virus. The process repeats, and the retrovirus reproduces via the above mechanisms at an exponential rate.¹

HIV is a uniquely insidious retrovirus, and its unusual characteristics allow it to compromise the human immune system. The primary set of features unique to HIV includes the nature of the HIV receptor, additional genes, and infection of T_helper lymphocytes and macrophages. The envelope protein of HIV binds to special protein known as CD4 protein. This protein is predominately found on T_helper lymphocytes, and occasionally located on macrophages. Both T_helper lymphocytes and macrophages are essential components of the immune system, and HIV specifically targets these cells. Aside from the typical genes found in a retrovirus, HIV contains genes that specify for six additional proteins. These additional proteins allow HIV finer levels of control and a

¹ (Fan, Conner and Villarreal)
more versatile life cycle. For example, one of the additional genes can amplify viral gene expression in the infected cell, while another can control for the type of viral proteins manufactured within the cell. Like a normal retrovirus, when HIV infects a macrophage it uses the cell to produce viral particles but does not kill the host cell. However, when HIV infects $T_{\text{helper}}$ lymphocytes, it kills the cell as a result of the production of new viruses. HIV can also kill uninfected $T_{\text{helper}}$ lymphocytes, but scientists are uncertain of the mechanism responsible. In both white blood cells that it generally infects, HIV may become latent. Following a period of latency, HIV may reactive and begin producing new viruses in the host cell.\(^2\) Because HIV actively kills $T_{\text{helper}}$ lymphocytes, it can eventually cause immune system failure.

$T_{\text{helper}}$ lymphocytes are perhaps the keystone of the immune system. They act as the sentries of the body, alerting the immune system of invaders and activating various components of the immune system. $T_{\text{helper}}$ lymphocytes play a central role in the two direct immune responses: humoral immunity and cell-mediated immunity. In humoral immunity, B-lymphocytes produce antibodies that deactivate known pathogens. Humoral immunity allows the body to rapidly nullify repeated infections by the same pathogen. During the process of antibody production, $T_{\text{helper}}$ lymphocytes provide a signal to B-lymphocytes. Without the signal, antibodies are not produced. In cell-mediated immunity, the immune system actively targets and eliminates unwanted microbes. When T-lymphocytes bind to antigen, they become activated. In order to grow and divide, they require the growth factor interleukin-2 (IL-2). However, $T_{\text{killer}}$ lymphocytes, the cells that bind to infected cells and kill them, do not produce IL-2. Only $T_{\text{helper}}$ lymphocytes produce IL-2, so in order for $T_{\text{killer}}$ lymphocytes to divide and destroy infected cells,\[^2\] (Fan, Conner and Villarreal)
T\textsubscript{helper} lymphocytes must be nearby to secrete IL-2.\textsuperscript{3} Thus, without T\textsubscript{helper} lymphocytes, the immune system cannot produce antibodies and cannot kill infected host cells. HIV infection can therefore strip the body of its major means of adaptive immunity.

If untreated, HIV causes AIDS, which generally results in death. Without T\textsubscript{helper} cells to activate T\textsubscript{killer} cells, antibody production, and the other benefits of T\textsubscript{helper} lymphocytes, pathogens have free reign once inside the body. HIV infection progresses into AIDS at an average rate of 10-12 years. Following infection, the patient remains asymptomatic and does not present signs of infection. Shortly thereafter, T\textsubscript{helper} lymphocyte depletion begins, and initial symptoms, such as lymphoadenopathy syndrome appear. Soon the patient experiences early immune failure. As T\textsubscript{helper} counts continue to decrease, the immune system buckles. With a compromised immune system, the patient’s condition descends into what can be classified as AIDS.\textsuperscript{4} The basic principle behind AIDS is that it does not kill. Instead, AIDS allows assorted pathogens to infect the patient. With no immune system in place, illnesses such as omnipresent bacteria can be fatal, even with antibiotic treatment. HIV, due to its biological properties, such as rapid mutation, cannot be cured and no vaccine exists. The treatments available in Western nations are effective, but are costly and require special “cocktails” of assorted antiretroviral drugs.

Drugs known as antiretrovirals (“ARVs”) are effective against retroviruses like HIV. Because HIV mutates readily, it can develop resistance to drugs. The high rate of mutation of HIV makes it extremely difficult to design an effective vaccine, and to date, no such vaccine exists. In order to prevent drug-resistant HIV, and to maximize the

\textsuperscript{3} (Fan, Conner and Villarreal)
\textsuperscript{4} (Fan, Conner and Villarreal)
efficacy of ARVs, a variety of these medications are used simultaneously. By disabling HIV across various fronts, such as DNA replication and protease activity, the mutations may develop resistance to one type of drug, but not to those of differing mechanisms. Because it is unlikely that the virus will develop resistance to all drugs simultaneously, ARVs are more effective when combined into a treatment regimen. Such combination therapies are generally prescribed in groups of three (two nucleoside inhibitors of reverse transcriptase and one protease inhibitor or non-nucleoside inhibitor of reverse transcriptase), and are known as triple combination therapies, or HAART (highly active antiretroviral therapy). HAART can enable patients to transform the threat of AIDS into an infection more akin to a chronic illness. However, most ARVs are associated with a variety of unpleasant side effects. Because no cure or vaccine for HIV exists, patients must rely on costly ARVs. Estimated to cost over $3500 per year, ARVs are not available to many citizens of the developing world. Prevention is a far more cost-effective strategy than treatment, and may be the greatest hope in stemming the global AIDS epidemic.

Transmission of HIV can be prevented, and is typically associated with risky behavior. HIV cannot persist outside of bodily fluids and therefore can only be acquired through shared bodily fluids. Four tiers exist for infectivity of various bodily fluids, ranging from very high infectivity to no infectivity. Blood, semen, and vaginal/cervical secretions are considered to have very high infectivity. Thus, any activities that involve direct exchange of blood or sexual fluids may spread the virus. Unprotected sexual intercourse (anal intercourse has a greater rate of transmission than vaginal intercourse)

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5 (UNAIDS)  
6 (Fan, Conner and Villarreal)  
7 (Messer)
can spread the virus.\textsuperscript{8} Contaminated blood transfusions or syringes shared during intravenous drug abuse can cause infection. Because unprotected sexual activity across multiple partners and IV drug use are considered risky, those infected with HIV may be judged as immoral. Those infected with HIV may not wish to divulge their condition in order to avoid assumptions about their activities. Experts label breast milk as a fluid with high infectivity, and label saliva, tears, perspiration, urine, and feces as fluids with no to low infectivity.\textsuperscript{9} Populations that engage in unprotected sex or IV drug use more frequently are more vulnerable to the infection. For that reason, people in poor economic and social conditions may suffer an increased risk of infection.

Those without access to prevention education or adequate healthcare are disproportionately affected by HIV. Because blood has very high infectivity for HIV, IV drug users are at high risk for infection. Due to the expense of replacing needles used for injecting drugs, users typically share needles. These needles may retain trace amounts of blood after injection, which are then injected into the next user, passing on any contaminants. Men who have sex with men (MSM) are also at great risk. Because the rectum has a high concentration of shallow capillaries, the stressful motion of anal intercourse may tear blood vessels and cause anal bleeding. The blood may carry the virus, or the virus may be carried in semen. The exposed capillaries may contact semen during anal intercourse, allowing the virus present in the semen to easily enter the recipients system.\textsuperscript{10} IV drug users and MSM are often rejected or ignored by mainstream society. These forgotten populations may put an entire community at risk, as they can spread the virus to heterosexual partners.

\textsuperscript{8} (Fan, Conner and Villarreal)  
\textsuperscript{9} (Fan, Conner and Villarreal)  
\textsuperscript{10} (UNAIDS)
Recent reports of the numbers behind the AIDS epidemic show that HIV is a
global health crisis which continues to expand. Numbers from UNAIDS and the World
Health Organization in 2007 estimate between 30.6 and 31.6 HIV-positive individuals.
Of the infected, 30.8 million are estimated to be adults, 15.4 million are estimated to be
female, and 2.5 million are estimated to be children less than 15 years. In 2007, UNAIDS
estimated 2.5 million new HIV infections and 2.1 million deaths due to HIV.\(^\text{11}\) The
United States has a large HIV/AIDS population. While ARVs are more readily available
in the US than in particularly hard-hit regions such as Africa, HIV remains a top public
health concern. According to the CDC, by the end of 2003, there were an estimated 1.1
million infected with HIV/AIDS in the US. In 2006, 33 states reported 35,314 new cases
of HIV/AIDS. Of the patients diagnosed in 2006, 73% were men and 26% were women.
67% of the new male cases were the result of male-to-male sexual contact, while 80% of
the new female cases were the result of high-risk heterosexual contact. Men who have
sex with men (MSM) are not necessarily homosexual and may have committed
heterosexual partners. Of the newly infected in 2006, 49% were Black, 30% were White,
and 18% were Hispanic.\(^\text{12}\)

The biological properties of HIV/AIDS make it an especially humiliating disease.
Patients infected with HIV may appear asymptomatic, and therefore, anyone can carry
the virus. Because the primary means of transmission are associated with socially
“immoral” behavior (unprotected sex, MSM, IV drug use), patients may choose to
conceal positive test results from their communities. Additionally, the potentially fatal
complications of AIDS can cause public fear or paranoia around the infected. Patients

\(^{11}\) (UNAIDS)
\(^{12}\) (Centers for Disease Control and Prevention)
must face the physical health degradation that may result from HIV/AIDS, but doing so requires great effort. General illness, skin problems, digestive complications, and the side effects of ARVs can cause substantial suffering to the infected, even when HAART is used to reduce the progression of HIV. The social challenges of HIV are relatively unique for an infectious disease and therefore can exacerbate the suffering of the infected. To combat both the medical and social difficulties of HIV, patients must summon courage and energy. My primary interest in conceiving this study was to evaluate the role of spirituality in providing the support necessary to face HIV. I wish to explore the relationship between spirituality, religion, and HIV. The purpose of my work is to determine how patients may or may not use faith to confront the virus, and if faith helps them to successfully fight infection.

My study was inspired by research opportunities at the Haelen Center, an HIV/AIDS clinic in New Haven, Connecticut. Located within the Hospital of Saint Raphael, the clinic claims to provide “Social services, education, pastoral care, counseling and testing. Outpatients with HIV and AIDS can receive medical care and treatment from a team that includes physicians, physician associates, nurses, social workers, pastoral counselors, HIV counselors/educators and nutritionists”\(^{13}\). The clinic is a well-rounded facility with a devoted and talented staff. As a student of theology with an interest in medicine, I have a strong interest in HIV/AIDS and the suffering of the infected. Given the opportunity to work at an active HIV care center, I wanted to design a study that bridges theology and HIV. I eventually arrived at the idea of an interview-based exploration of the relationship between spirituality and the attitudes of those infected with HIV. With few expectations of what my research may uncover, I turned to

\(^{13}\) (Hospital of Saint Raphael)
designing a study that would allow me to balance quantitative and qualitative observations.
Methods and Materials

While designing the study, I discovered that the unusual focus would require an unorthodox approach. I wanted to maximize my interaction with the patients, so I decided that a private interview would be more fulfilling than a written survey. I also wanted to include enough structure so that I could perform some form of statistical analysis with the results. To do so, I required quantitative data, so I designed a series of simple questions to include in each interview. Outside of the oral survey, I wanted to encourage an open dialogue in which patients could discuss their unique experiences with HIV and faith. Because I could not secure external funding for my research, I would not be able to provide financial or material incentives for participation. I hoped that enough patients would find an open discussion on HIV and faith appealing, and would therefore volunteer.

In order to perform research involving human subjects and medical care, I needed approval of the hospital. Facilities in the United States that perform biomedical research using human subjects use a review process with an internal institutional review board (IRB). The IRB examines all research protocols in order to ensure ethical treatment of human subjects, and continues to monitor research until it is completed. In order to run my study at the Haelen Center, I submitted my proposal to the IRB at the Hospital of Saint Raphael. After a few revisions, my plans were approved. From late June until late August I interviewed 15 patients and collected quantitative data alongside narratives on their experiences with HIV and faith.

In the typical language of scientific writing, this is the summary of the methods and materials employed during the study:
Patients volunteered to interview with the principal investigator while visiting the Haelen Center for their health needs. The goal of the study was to interview at least forty subjects, but due to limitations in design and patient interest, only 15 participated. Prior to meeting, each patient was assigned a random subject number in the range of 0 to 1000. Interview time averaged to about 35 minutes, with some interviews lasting less than half an hour, and others reaching an hour in length. The interviews were conducted in private office, one-on-one, without audio or video recording. The patients did not disclose personal information beyond first name (which will not be recorded), and the discussion was be guided by several questions. The interviews began with an introduction on the background and intentions of the study, followed by questioning as to the patient’s personal history with HIV/AIDS and religious background. The patients had the opportunity to explain changes in religious practice or personal faith during different stages of HIV (from initial diagnosis, to acceptance, to coping, to present). The principle investigator produced questions based upon the direction of the interview and the openness of the patient. In order to measure the status of each patient, the interviewees were provided with a sheet to present to their primary provider. The questions were designed to measure the relative state of physical well-being for each patient, and avoid the collection of personal data or the examination of medical records by the investigator. The questions provided were as follows:

1. What do you believe the possibility to be for the subject to be alive five years from now? (Unlikely, 50%, 75%, 90%, >90%)

2. What do you believe the possibility to be for the subject to be alive ten years from now? (Unlikely, 50%, 75%, 90%, >90%)
3. Twenty years from now? (Unlikely, uncertain, highly likely)

4. If you have seen the patient multiple times within the last six months to two years, how would you describe the observed changes in physical health? (No change, strongly deteriorating, mildly deteriorating, mildly improving, strongly improving)

The completed form was delivered to the principal investigator directly from the provider.

The following key questions were used to guide the interview between the investigator and the patient, and to collect quantitative data:

1. Are you a member of any organized religion?
   a. If so, do you consider yourself active and a strong believer in the teachings of your faith?
   b. If not, do you follow a set of beliefs outside of an established religion?

2. Did you hold these beliefs before being diagnosed with HIV?
   a. If not, did you follow a different faith (established or personal)?

3. How long have you been HIV-positive?

4. Directly following diagnosis, do you recall if your faith or attitudes towards your faith changed?
   a. If faith was weakened, why? Did you feel forsaken or somehow cheated?
   b. If faith was strengthened, why? Did you feel the need to become more spiritual in order to cope? Did your perspective somehow change?
   c. If confused and/or lost, did you question your faith?
   d. If upset and/or bitter, did you blame your faith?
5. Within the first few weeks following diagnosis, did you place blame on any individual, group, or institution (including yourself)?

6. Did you need time to accept your condition as HIV-positive and start to look beyond your radical change in physical well-being?
   a. If so, from what sources did you draw support? Was your faith at all helpful in this process?
   b. If not, how were you able to confront it? From what sources did you draw strength? Did your faith play any role?

7. As of now, what role does your faith serve? If uncertain, you may wish to explain your attitudes regarding life/mortality, suffering, or fate.

Following the above protocol, I collected data and narratives from each patient and divided the information based on quantitative and qualitative value. I used the quantitative data to search for numerical trends and correlations between simple answers and patient health and attitude. With the qualitative data, I assembled a series of narratives, which I analyzed individually.
Results

Data was collected on 15 subjects. Of the 15 subjects, 12 labeled themselves as “religious” and 3 labeled themselves as “non-religious.” 14 of the 15 subjects belonged to a religious institution, and of the 14, 13 claimed to be Christian. The remaining subject was Muslim. 12 of the 12 “religious” patients claimed to be active in their religion, and 3 of the 3 “non-religious” patients claimed to not be active in any faith community. All 3 of the non-religious subjects identified as agnostic. 4 of the 15 subjects stated that their religious denomination changed following positive HIV test results. Of these 4, 3 converted to another sect of Christianity, and 1 converted to Islam. (Fig. 1)

14 of the 15 subjects reported time elapsed since diagnosis with HIV. The mean time was 11.64 years. 7 of the 15 subjects claimed that their faith and/or spirituality increased following diagnosis, while 1 claimed that his faith decreased. The remaining 7 subjects reported no change in faith and/or spirituality following diagnosis. 11 subjects claimed to have struggled with accepting HIV, and the remaining 4 denied struggling with the news. When questioned on sources of support in fighting the infection, 7 patients listed themselves, 6 patients listed their families, 9 patients listed faith, 1 listed his friends, and 1 listed community. (Fig. 2)
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Figure 1

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<tr>
<td>845</td>
<td>19</td>
<td>Increased</td>
<td>Self</td>
<td>Yes</td>
<td>Family, faith</td>
<td>Support</td>
</tr>
<tr>
<td>905</td>
<td>18</td>
<td>None</td>
<td>Self</td>
<td>Yes</td>
<td>Self</td>
<td>Negligible</td>
</tr>
</tbody>
</table>

Figure 2
In summary, 80% of the subjects identified as religious and actively religious, while 20% of the patients identified as not religious and not actively religious (Figs. 3 and 4). 87% of the subjects were of Christian background, 6% of Muslim background, and 7% of “other” (i.e. no religion) (Fig. 5). Time since HIV diagnosis was relatively balanced (Fig. 6), and religious outlook following diagnosis varied (Fig. 7).
Religious Affiliation of Subjects

- Christian: 87%
- Muslim: 6%
- Other: 7%

Time HIV-Positive

- 0-5 years: 29%
- 6-10 years: 21%
- 11-15 years: 14%
- 16-20 years: 29%
- > 20 years: 7%

Figure 5

Figure 6
Figure 7

Religious Outlook Following Diagnosis

- Role of religion: Negligible
- Role of religion: Minor
- Role of religion: Support
- Role of religion: Major
- No change in denomination following diagnosis
- Changed denomination following diagnosis
- No change in faith
- Faith decreased
- Faith increased

Number of Patients
Discussion

The results suggest that religion plays a role for many individuals infected with HIV. While the study is limited due to a small sample size, the majority of patients interviewed claimed that religion had an overwhelming influence on their lives. The purpose of the study was to determine the connection between spirituality and the lives of HIV patients. The hypothesized connection was that faith serves as a primary means of support and growth for the infected. The data seems to agree with the hypothesis because many of the subjects demonstrated active spiritual investment in their recovery from HIV/AIDS.

According to the data, 80% of the participants were religious and actively involved in their faith communities. Faith played an active role in the lives of these patients, 87% of whom identified as Christian. HIV seemed to have a positive impact on faith, as most patients noted an increase in faith or no change in faith following diagnosis. While 7 subjects claimed that their faith increased in response to HIV, only 1 claimed that his faith decreased in response to HIV. The remaining 7 subjects noted no immediate change, but some admitted that positive changes occurred at later dates. The most popular category for support among the patients was faith. The participants listed the most important sources of support in their struggles against HIV, and faith received the most citations, at 9, compared to 7 for themselves and 6 for their families. While a minority, 4 patients converted to a different religion shortly following diagnosis, as a result of their new attitudes towards life. Additionally, the patients discussed the intensity of spirituality and religion in their lives. An overwhelming majority claimed that religion played either a major or supportive role in their recovery.
Due to limitations in time and funding, the sample size was smaller than intended. Small sample sizes reduce the effectiveness of statistical analysis. Ineffective statistical analysis generally results in unreliable conclusions. Because I interviewed such a small number of patients, I may be unable to draw statistically-valid conclusions about the spirituality of HIV patients in the New Haven area. With a limited sample size, results cannot be extrapolated to the national HIV population to discuss overall trends in spirituality amongst the infected. If the study were extended over several years, across various clinics, investigators could assemble a much larger and statistically-relevant sample. The recruiting methods used in the experiment may have produced an additional flaw. Because the interviews were voluntary and offered no material incentives, only patients with strong interests in religion or open discussion participated. Therefore, most of the interviewees were of strong faith and were attracted to the study due to that faith. Any conclusions made about the general clinic population may be invalid, as the study had an inherent bias in its recruiting methods. If incentives such as money were available, a more diverse set of patients may have participated in the study.

Based on the above citations, the research sample appeared to associate religion with combating HIV. Furthermore, HIV appears to have a positive impact on spiritual development. While the data cannot be used to prove the hypothesis across everyone infected with HIV, the interviews provided unique insights. Most of the insights are of a qualitative nature, as they come from patient narratives and not the oral survey. Some of the insights from the narratives were present across various interviews. Patients often expressed strong desires for confidentiality. Many of these patients were fearful of public perception of their condition, and did not wish to be judged for HIV. They often claimed
to pursue every possible means in order to protect the secrecy of their health. Most of the
patients also reported that faith gave them hope and motivation. The message of hope
present in many religions can imbue the suffering with the spiritual energy to persist
through trauma. Such insights are discussed in great detail in a later section, which
presents patient narratives and analyzes the roles of faith in their fight against HIV.

Future quantitative studies may benefit from greater resources. With greater
resources, investigators could assemble a larger sample from multiple clinics in different
regions. With a larger sample and a more diverse set of participants, investigators could
introduce statistically-valid data to the study. Data suitable for statistical analysis would
enable investigators to apply the intentions of the study to much wider conclusions. I
hope that the ideas presented through my research will inspire future studies. Hopefully,
these future studies could expand on the framework of this study to bring greater
attention to the role of faith on those with HIV.
Voices: Narratives on Faith and HIV
When designing the study, I did not anticipate participation from local religious leaders or clergy. I was delighted to hear that a Protestant pastor wished to meet with me. I would love to tweak my research to focus on clergy with HIV, so that I could examine how it has affected their lives, in terms of their spirituality and their relationships with their faith communities. Many of the patients I interviewed were fearful that if knowledge of their infection spread, their churches would judge them harshly and possibly reject them. I was curious about how a pastor would deal with HIV; would he tell his parishioners, or would he attempt to conceal the truth? Hopefully, my interview with the local pastor would provide an example of the challenge that HIV poses to clergy.

**Interview:**

The subject was visibly pleased to have the opportunity to speak with me, and showed great enthusiasm and courtesy through the entire interview. A Pentecostal Christian since childhood, he claimed to have always placed great emphasis on his spiritual maturation. As a result, he decided to pursue a life as a preacher and has recently been promoted to the position of pastor within his community. While he has always valued his religion, he confessed that prior to his experience with HIV, his faith was declining. His encounter with the virus forced him to reevaluate the role of religion in his life and his greater purpose as a living being.

When diagnosed with HIV in 2002, the subject was not especially involved with his faith. Although he did not abandon the religion of his family, he stated that it was not a significant part of his life. At the time of his diagnosis, he was confused. He could not
accept the news and was overwhelmed by the shock of HIV. He credited those around
him for providing the support necessary to face HIV and to reevaluate his path in life. He
stated that he has always been close with his direct family, and they provided much-
needed support following his diagnosis. Additionally, he found that the attitudes of
medical workers at the clinic were conducive to his acceptance of the infection.
Specifically, he cited their confidence in his ability to live a healthy life with the virus as
helpful in his transition from shock to action. Even though he experienced difficulty in
moving forward, he did not blame anyone, nor did he question his faith.

The subject asserted that his church is his life. While his faith was declining prior
to HIV, he was still actively involved in his church as a minister. Following his diagnosis,
he dedicated his life to his church. He found purpose in his faith and decided to pursue a
position as pastor so that he may serve others and support those who might benefit from
his own experiences with suffering. In the spring before our interview, he was awarded
the position of pastor, much to his delight. He told me that it may have been fated for him
to have acquired the virus, as it forced him to examine his goals. The shock of infection
forced him to determine his absolute vocation, and he decided that service to his
community, along with spiritual growth, was his true calling.

Much of the subject’s desire to explore his spirituality came from his passion for
helping others. He claimed that he wishes to use his position as pastor to reach out to
others with HIV and help them to restore structure and meaning to their lives. To the
subject, structure and meaning can come from the spiritual fortitude inherent to faith.
Based on my discussions with other patients, I would agree; religion can provide critical
support to patients who may otherwise see the world as cruel and unjust. He reasoned that
he would be doing far worse against HIV without his family and his faith. Because he
does not want others to suffer as he has, he wants to counsel those with HIV or who
otherwise are in hard times, so that they may find hope in his words. Like many of the
participants in the study, he stated that he wishes to employ his own suffering in ways
that could prevent others from sharing in such pain. Perhaps suffering, including the
experiences of HIV, is the greatest catalyst behind altruism. It must be difficult for those
with HIV to look upon others with the virus and not feel great compassion or empathy.
Fortunately, men and women like this subject are willing to devote their lives to helping
others fight the infection.

In the latter half of our discussion, the patient shared the details of his beliefs and
his ideas on the power of religion. He stated that faith takes on a significant role in the
lives of the faithful, as it enables them to live fully while remaining aware of their
inevitable deaths. Because we all die, he reasoned, we must accept our end and attempt to
do the greatest good so that our lives will bring greater meaning to the living world. He
further explained, “We must enjoy life but base it on faith.” He seemed to advocate a
balance between living well and cultivating our spirits. While I do not see these goals as
opponents (thus, there is no need to “balance” goals that may coincide with one another),
I appreciate his realistic approach. He did not appear to preach stoicism, nor did he
condone hedonism. He also shared his interest in other religious groups. The subject told
me that he believes in harmony between faiths, and that by coexisting, different creeds
provide diversity of thought. He wisely concluded that by learning about others and their
approaches to spirituality, we may better understand ourselves.

Prognosis:
A man recently diagnosed with HIV, the subject has responded successfully to his HAART regimen. According to his primary care provider, his chances of surviving for both five and ten more years are greater than 90%. Like many of the other patients, his state 20 years in the future is uncertain, according to his provider. Fortunately, his provider reported that over the past six months, the subject has been “strongly improving” in his overall health. It seems that the pastor, a man of strong conviction and a warm smile, has a positive outlook to match his overwhelmingly positive attitude and his will to thrive for the sake of others.
Some interviews were awkward due to the unusual character of some of the patients or the shock I experienced from some of their shameless remarks. It was often difficult for me to accept the trust of the patients, considering that I had done nothing to earn it. This subject, a jovial, but deliberate woman, forced me to carefully consider sexual urges and the degree to which we are able to guide them. Her story does not seem to be atypical; rather, her success seems to share a strong link with her faith. She demonstrated a well-developed faith in her own abilities, as well as an established belief in a higher power.

**Interview:**

The patient’s religious history is similar to many others in the study. A devout Christian, she did not follow any faith teachings prior to her diagnosis. She was born a Baptist, but did not participate actively in the church. Although she did not elaborate on the details of her faith as a young woman, she claimed that she did not put much thought into Jesus or Christian practices. Now, however, she is a highly active Pentecostal Christian who attends services twice a week and participates in a Bible study program. She attributes her rapid shift in spirituality to menopause. I am unfamiliar with menopause having such a significant impact on spirituality, but the difficulty she experienced through menopause may have led her to question her motivations. Suffering appears to play a significant role in the spiritual direction of HIV patients.

At the time of the study, the subject had been HIV positive for about four years. She recalled that following her diagnosis, she was emotionally numb. Confused about the
gravity of the news, as well as the source of the infection, she explained that the diagnosis “didn’t make any sense.” She did not place blame on anyone, and refused to blame herself. She reasoned that many people may carry the virus and are ignorant of their situation, and therefore, we cannot blame them if we should become infected. She admitted that she did not know who infected her with HIV and if she passed it on to other partners. While I find her attitude of forgiveness to be inspiring, as far too often we use blame as a means of escaping responsibility, her attitude during the interview was somewhat alarming. HIV carries with it tremendous health risks and social stigmas, so simply dismissing it may put others at risk. In her defense, she claimed to be very careful with her body and made every effort to protect others, but to treat her past so lightly may prevent her from grappling with the long-term implications of her illness.

An independent woman, she stated that she experienced no strong reaction following diagnosis, and quickly acknowledged that HIV is a challenge that anyone may encounter. She needed no support in coping with her HIV-positive state, and was eager to work with physicians and the needs of her body to live fully with the virus. She claimed to have never abused drugs, and expressed deep respect for her physical being. I was somewhat shocked by her discussion on sexuality. According to her testimony, the subject no longer has sexual urges. She has not been sexually involved with anyone since 2000. I could understand a shift to asexuality, but she apparently has lost interest for all romantic pursuits. She claimed to have no desire for companionship from a man, and was absolutely certain that menopause was responsible for this shift. Around the time when her sexual and romantic drives diminished, she developed an interest in faith, and began to attend church. At nearly fifty years of age, the patient lost her desire for a mate and
simultaneously awoke to a spiritual call. She did not explain the order in which these changes occurred; her interest in religion may have superseded her romantic interests, or her self-imposed separation from the opposite sex may have motivated her to find another source of meaning in her life. Based on her discussion of menopause, I believe that the suffering she faced during that period of her life may have forced her to reconsider her motivations and desires. The result, then, was a deeply religious woman in love with her God and her own being.

When questioned on her approach to religion, the subject was markedly enthusiastic. Her cheerful and loving openness are the manifestation of her beliefs. She stated that we must live in a way that reflects on the examples of Jesus, and she believes that a warm and friendly attitude is an important component in doing so. Her faith appeared to affect her views on science and medicine, as she had faith in God, not drugs. Religion and medicine are not natural enemies, but to patients like this subject, God, not science, has enabled her to live healthily with HIV. She told me that she did not like placing faith in her HAART regimen, and did not like taking drugs, due to her belief that only God could truly help her. I was somewhat alarmed by this attitude, as I would not consider faith in the power of modern medicine an act of betrayal. Likewise, belief that drugs alone can heal the entire being may be a self-limiting attitude. It seems that balancing HAART and a positive attitude are the keys to success when fighting HIV. Regardless, I found her optimism touching. She proudly shared that God took her though all of her troubles and thanks to Him, she has endured. According to her, God had blessed her with a good life, and allowed her to “live with HIV.” She repeated this statement to
emphasize its significance; she was not “dying with HIV,” but rather, growing in communion with her understanding of her purpose.

Although she discussed her preference for natural remedies and homeopathic medicine, she did not oppose her anti-retroviral therapy and generally followed the recommended regimen of her healthcare provider. Natural remedies are generally more attractive to consumers, as it is easy to believe that substances extracted directly from nature are more pure than man-made chemicals. Natural substances may have fewer unknown side-effects or may alter the body less severely than artificial drugs. However, so-called “natural” products can be ineffective or dangerous, due to a lack of standards and testing protocols. Some natural remedies have been successful for generations, and are wonderful alternative treatments, due to centuries of community testing. However, HIV is a young disease, and it is unlikely that any natural treatments have been tested for long enough to be appropriate. HIV patients who place too much faith in alternative medicine may not properly follow HAART regimens. As a result, some patients may be shaving years off of their lives in favor of the panacea of natural treatment. If effective, HAART can transform HIV from a terminal illness into a chronic condition. Using natural remedies to treat symptoms of opportunistic infections, alongside HAART, is a more reasonable approach than foregoing synthetic medicines entirely.

Like most of my interviewees, the subject shared her thoughts on society and HIV. According to the patient, the public should be more sensitive about HIV. She was convinced that most people unfairly judge the infected and are poorly informed about the realities of the virus. Because many are ignorant regarding the modes of transmission, she noted that they believe they will become cursed with a life-ending disease simply by
associating with HIV-positive individuals. Her attitude on the public’s perception of HIV seems to be a fear which developed from her experiences with HIV and society.

Following our meeting, I was concerned that her fear of misunderstanding will isolate her.

**Prognosis:**

According to the staff at the clinic, the subject was in relatively good health and should manage HIV relatively well in the coming years. According to the primary provider survey, her outlook for survival for five years is roughly 90%. Likewise, her outlook for the next ten years is roughly 75%. As for her health far into the future, the provider was uncertain. Her provider labeled her condition as “mildly improving,” which seemed to match her own attitude and outlook. Thus, her physical progress seemed to align well with her testimony. Her optimism therefore matched the reality of her illness.
During the design phase of my research, the staff at the Haelen Center inquired about my Spanish speaking proficiency. Due to the growing Hispanic community in the New Haven area, a large portion of the patients at the clinic speak Spanish as a primary language, and do not possess adequate English-speaking skills to participate in a conversation-based study. Unfortunately, my Spanish skills have faded as a result of years of disuse. In order to interview Spanish-speaking patients I required a translator. Due to a lack of funds and urgency, my work was deemed low-priority by the hospital and I needed to secure translators independently. I was disappointed that I would not have access to a great number of patients, especially a series of Hispanic groups with their own cultures and attitudes towards HIV. Luckily, a Latin American-born patient visited the clinic with her companion and agreed to participate in the study. Her companion, fluent in both English and Spanish, agreed to translate our discussion.

**Interview:**

Thanks to the translator, the language barrier did not inhibit the discussion. However, I feared that the presence of a translator would impair the emotional openness of the patient. My fears were validated by the depth of the discussion. The patient was one of the most indifferent, distant, and timid of the entire sample. While her young age may have affected her ability to discuss weighty issues with a stranger, she seemed reluctant to speak through someone else. When I was able to communicate with the patient directly through my fragmented Spanish, she seemed more enthusiastic and responsive. When speaking through her translator, she appeared bored and disinterested.
Because of the deeply personal nature of the interview format, the presence of a third party may reduce the comfort of the participant and lead to less revealing or detailed answers. Because she was the only participant with whom a third party was present during the interview, I cannot draw any conclusions on that theory. Regardless, I believe that she would have been more willing to discuss her experiences with HIV if the conversation were a one-on-one affair or, at the very least, if she did not know her translator. She may have felt uncomfortable sharing sensitive information, such as her emotional experiences, with someone whom she did not trust, but would have to face on a weekly basis.

The patient did not initially self-identify as a theist or atheist, but instead claimed that she followed no established religion. When asked if she believed in God or a similar higher power, she paused and hesitated. Eventually, she responded that she believes in God, and “prays” daily. Her translator explained that the patient does not pray in any traditional way, but tends to contemplate issues of life and death during moments of silence or when idling. As a younger woman, the subject belonged to an Adventist church, but the teachings of the church did not resonate well with her. About a year before the interview, she left the church and has been following her own quasi-agnostic set of beliefs, as discussed above. This subject’s experiences with HIV were unique in my study; a foreign national with poor English-speaking skills, she became infected after relocating to the United States. Thus, she not only faced the social stigmatization of HIV, but a language disconnect with her newly assumed home.

During our discussion, the subject’s translator informed me that the subject immigrated to the United States in 1991. She did not explain why the subject relocated to
the US and with whom she traveled. After several years in the country, she was
diagnosed with HIV. She refused to explain the details behind her infection and her
response at the time of diagnosis. While she was diagnosed in 1999, she may have
acquired the virus before entering the country. However, she would have most likely
presented symptoms of HIV before 1999 if she was exposed to the virus before 1991, as
8 years is an unusually long delay before the appearance of the archetypal opportunistic
infections. I tried to get her to divulge additional details on her history with HIV, but she
calmly refused. Fortunately, she was slightly more willing to discuss her spirituality and
its connection to HIV.

Following the positive test result for HIV, the subject did not blame others, nor
did she question God. She claimed to have placed all of the blame on herself, and she did
not modify her attitude toward religion and spirituality. Furthermore, she stated that HIV
has not altered her spirit and was in no way responsible for her abandonment of the
Adventist faith. She repeated throughout our discussion that HIV had no effect on her
religion or spirituality, but I believe that the virus may affect her attitudes more strongly
in the future. She appeared to be in shock and under the despair of indifference, as if she
had not yet confronted the challenge of HIV. She confessed that she felt no different than
she did when she received the test results in 1999. She may have not adjusted to the
gravity of her condition and therefore her spiritual outlook may change as she grows and
confronts the truth. Still a young woman in good health, she may mature as she ages and
considers carefully how HIV will affect her life and how she can best cope with it. Due to
limitations in the experimental design, I may never have the opportunity to speak with
her again and to track changes in her spiritual outlook.
This subject was one of my more difficult and awkward interviews. The presence of a third party, combined with the subject’s apathy, made for a relatively unproductive discussion. While I failed to collect all of the desired data, the unusual circumstances of the subject provided for a meaningful interview. According to the staff at the Haelen Center, a growing number of HIV/AIDS cases reside within the local Hispanic population. I regret that I could only secure an interview with one patient from that group, as Hispanics are severely underrepresented in my study. Thankfully, I obtained the framework of a narrative on the experience of an immigrant with HIV. Should I continue research at the Haelen Center, I would like to study the role of spirituality for Hispanics infected with HIV, with special consideration for the Catholic Church and its attitudes towards the virus.

**Prognosis:**

The subject appeared to be the youngest participant in the study. I was not surprised to discover that her physical health was also superlative within the study. Her primary care provider marked her chances of surviving both five and ten years into the future as greater than 90%. She was also one of but a handful of patients who were reported as “highly likely” to be alive 20 years from the study. According to her provider, she had been in good health for several years, and the provider noticed no change in her overall physical health in the past six months. The provider also added a comment at the bottom of the survey, explaining that the patient was diagnosed and treated during pregnancy. Treatment was halted after the delivery, and the subject has been in good health since then. The subject may have acquired HIV from the sexual intercourse that led to the mentioned pregnancy. I wish that she had discussed her feelings on pregnancy.
with HIV, as, according to the testimonies of the other subjects, she was the only such woman in the study.
Some of the patients I interviewed did not experience success during their first attempts to combat HIV. Some were not receptive to treatment, while others refused to take action until their health deteriorated significantly. Many of these patients found hope in local churches, and were able to reduce the impact of HIV through determined spiritual strength. I was honored that several patients would share the most intimate details of their condition, even though they could not share any of said details with anyone outside the clinic. For some subjects, such as this one, the fear of being identified as HIV-positive governed much of their lives.

**Interview:**

While she proved to be interesting conversation and a genuinely spiritual woman, the subject was unwilling to share many details of her life and the events connected to her infection. She said that she was “on the streets” with HIV, and alluded to a difficult life in the inner city prior to contracting the virus. She may have been infected while engaging in risky behavior when her life lacked structure, or she could have contracted the virus from a healthcare facility. She did not report the date of her diagnosis, so I cannot conclude if she was exposed to HIV through a contaminated transfusion. The only information she provided was her reaction following diagnosis. She stated that she was angry and placed blame on a local hospital (not St. Raphael’s). Based on her lifestyle prior to diagnosis, chances favor infection as a result her own poor choices. She did not explain why she was upset with the hospital, so I cannot draw any substantive conclusions.
Although the subject may not have a clear past, she articulated her attitudes and approach to spirituality. For four years she has been a member of a local Baptist church. She decided to join following an epiphany about her state in life. She realized that she had no economic stability (she was effectively living on the street, without a home or employment) and was struggling in her fight against HIV. She wanted to redirect her life so that she may find meaning and purpose, so she looked towards Christianity. She claimed that her church helps her to release the anger she has accumulated over both HIV and her mistakes in life, and that it gives her the strength to forgive those who have wronged her. Many patients in the study were especially concerned with forgiveness. I believe that forgiveness is a freeing act; we are released from anger, resentment, and pride through the act of forgiveness. HIV patients may feel trapped by the intense bitterness that can accompany diagnosis. Because transmission of HIV is preventable, but carelessness and dishonesty may play a role in increasing risks, patients may feel a great deal of animosity towards those who may have infected them. Forgiveness may free said patients from the cycle of blame, and is a valuable step in living with HIV. Because many religions teach forgiveness, their messages may be especially useful to those with HIV who hope to liberate themselves from ill feelings.

The subject, like many others, wished to keep her condition hidden from everyone outside of the clinic. She believes that her church and family would judge her, and likely disown her, if they knew of her HIV-positive status. She has only shared the truth with one person outside of the clinic, her daughter, but she forced her to take an oath of secrecy. Remaining silent about her condition is constantly on her mind, or as she confessed, “HIV and keeping it a secret are always on the back of my mind.” She told me
that she would be perfectly content to hide the truth forever, and she sees no need to inform the world. Her fear of openness may be related to her reservations regarding the opposite sex. She stated that she is very distrusting of men (which suggests that she may have been infected through sexual contact), and she has remained single due to these suspicions. The subject’s approach is a bit extreme, as she makes every effort to avoid all interaction with available men and keeps to herself in social settings. Following our conversation, I worried that she may be limiting her recovery and spiritual growth by distancing herself from men and stereotyping them as abusive, manipulative creatures. I am uncertain as to why she did not find me threatening, as I am male. Perhaps she only finds males to be dangerous if a potential for sexual or romantic relations exists.

A devout Christian, the subject attributed her success to her church. Once a sickly woman with a poor outlook, she regained her health and continues to live well. She claimed that her convictions and the structure of her religion have helped her to survive and thrive. She shared her beliefs in fate and salvation, such as her experience with HIV as the manifestation of God’s plan. She said that she wishes to study the Bible so that she may be “saved.” Religion not only shapes her understanding on the world, but also serves as her greatest source of support. During the interview, she told me that she looks to God to help her and guide her during times of confusion, and that she wishes to follow the example of Christ. She acknowledged that she knows little about the world and has only recently developed a desire to learn. While not an intellectual, she appeared wise and warm during our discussion, and expressed a genuine hope to grow in communion with the world.
I was honored to provide many of the study participants the opportunity to discuss their feelings on HIV in an open, safe forum. This subject claimed that she cannot speak freely with others about her condition due to fears of stigmatization, and she was markedly pleased to be able to speak with me. I never expected to make others happy simply by interviewing them about their experiences with HIV, but subjects such as this were grateful to meet with me. Unfortunately, her self-criticism and isolationist tendencies will most likely prevent her from escaping much of her suffering in the near future.

**Prognosis:**

The patient’s primary care provider reported that the patient would remain healthy for many years. The provider marked her chances of surviving for five years as greater than 90%. Likewise, her provider marked her chances as greater than 90% for surviving the next ten years. The provider was uncertain about survival 20 years in the future. According to her primary provider, the patient has been mildly improving in her overall health during the past six months. The provider also opted to comment on the subject’s past, stating that, “[She] was coming from a ‘tough’ life before she came to the clinic.” The provider also noted that the subject did not respond well to initial treatments, but following rehabilitation, she has been an overwhelming success. The comment on “rehabilitation” suggests that the patient may have used IV drugs, and may have contracted the virus through that channel. Unless I conduct a follow-up interview, her means of exposure to HIV will remain uncertain.
Some patients seemed to be less affected by HIV than others. When designing the study, I assumed that most of the participants would have experienced significant life changes as a result of infection. I was not prepared for some of the interviews, as the patients appeared less impacted than others. One such case involved a patient who spoke as if HIV was insignificant to his life as a whole. If he removed the name of the virus from our discussion, I would not have guessed that he had acquired HIV and had been living with it for well over a decade. For some, HIV may not be a life-changing infection or a call to action.

**Interview:**

The patient introduced himself as a Christian who had fallen out of practice. He identified himself as a Methodist. According to the subject, he was raised as a Methodist and attended church services sparingly as a child. As an adolescent, he stopped attending church, but continued to self-identify as Methodist. In 1992, he was diagnosed with HIV. Unfortunately he did not provide many details during the interview, especially involving his means of acquiring the virus. I attempted to collect sufficient background information on each patient, so that I would be able to identify the different ways that the patients may have contracted HIV. Because I wanted to limit my role in the interview, I encouraged the patients to share this information, but did not repeat my request if they answered indirectly. However, he noted that his faith did not change following his diagnosis.
Like many of the participants in the study, he claimed to have not placed blame on anyone for HIV. A self-described rational man, he stated that he did not panic, nor did he consider himself condemned. Instead, he attempted to reason through the changes necessary to survive with the virus. He did not experience confusion of any form, and alleged that his thoughts were on adapting to the virus, not on suffering. He remained optimistic following news of the infection, and appeared optimistic during our interview. It seems that pessimism does not serve HIV patients well. While some of the interviewees were unable to immediately accept positive test results, eventually they persuaded themselves to remain positive in order to live fully with HIV. In future discussion with HIV patients, I would appreciate a less optimistic perspective. I am curious as to how a patient without a positive attitude lives with HIV, or if it is possible to “live” with HIV as a pessimist.

The subject shared with me his methods of coping with HIV that do not involve drawing energy from the spirit. He said that he “faces it as part of living,” which implies that he treats it realistically. A realistic approach to HIV in a developed nation in the 21st century probably involves accepting it as a chronic illness rather than a terminal condition. Thus, the patient could remain positive without deluding himself or discounting his likely future. When I questioned his goals, he provided a simple answer: to live as long as possible. He claimed to approach each day no differently than before he had acquired HIV. To him, a new day is a new opportunity for life, not a step closer to death. When I asked him about the source of his strength, he replied that he does not need others. He asserted that he draws energy from himself, and he never calls on God for support, nor does he expect God to assist him.
Throughout the interview, the patient boasted of his independence. He claimed that from news of the infection until the time of the interview, he has not needed support from others. He told me that he draws all his strength and energy from within himself and from his own desire to prosper. The subject shared his belief in the “individual approach” to coping with illness and hardship. If he expressed faith in anything, it was the human capacity for independence. He seemed to believe in the power of the individual and stated that we do not need gods to bring meaning to our lives. I am not certain as to how he can identify as a Christian when he seems to place little value in faith or God. Such beliefs are only Christian insomuch as they acknowledge a Christian God.

While not an especially spiritual or religious man, the subject elaborated on the religious intensity of his family. Raised by devout Methodist parents, the subject claimed that he was the family skeptic. He did not understand the need for worship and church services, as he considered it foolish to rely on God. He believed that it was best to rely on one’s own abilities, and that strength of will could conquer the greatest challenges of life. His brother, however, found greater value in religion and eventually became a presbyter. His brother devoted his life to his faith, and eventually ascended to a position of leadership within his church. I did not question the subject on his relationship with his sibling. During the interview, I was curious about HIV and his brother (Was he aware? Was he supportive?), and I may pose the question in a future interview, should I have the opportunity.

The subject appeared to be very mature and thoughtful. He denounced risky behaviors such as substance abuse, and advocated a healthy lifestyle. He stated that he has not consumed alcohol for decades, and that he considers drinking to be a foolish
practice. Additionally, he told me that as humans, we should hold out hope and pursue things which bring us happiness. While he enjoyed a career as a cook before HIV, he left the culinary arts for another field in order to protect those who may be consuming his food. Apparently, he appreciates selflessness and sacrifice, yet balances them against his desires and needs as a human.

**Prognosis:**

The patient did not appear to be in the best physical condition, but he seemed relatively healthy for a man infected with HIV for 15 years. His primary care provider reported that his chances of living for another five years are about 90%. As for being alive in ten years, his provider estimated a probability for 75%. Like most of the participants, his provider listed his outlook for 20 years in the future as “uncertain.” Based on the subject’s health over the past six months, his provider described his condition as “mildly deteriorating.” While not the most successful patient in the study, he appeared to be doing well with his strong convictions for self-sufficiency.
Due to the nature of the study, participation was limited. As a result, the majority of patients that I interviewed were Christians. Fortunately, I had the opportunity to speak with a member of another religion, Islam. The American public tends to judge Islam harshly, and appears to lack knowledge of Islamic teachings. Islam and HIV are both misunderstood and can be sources of stigmatization, although to different orders of magnitude. I hoped that an HIV-positive Muslim would provide a unique and exciting interview. As expected, the patient not only provided insight into a non-Christian religious response to HIV, but his strong faith and optimism further emphasized the connection between attitude and recovery.

**Interview:**

Some of the interviewees were unwilling to provide potentially humiliating details of their lives prior to infection with the virus. This subject, however, allowed me a clear narrative of his past. Diagnosed with HIV about 16 years ago, he confessed to upholding few, if any, morals, and told me that his life lacked purpose, direction, and hope. Yet, after the results of an HIV test, he found inspiration in the faith of others and devoted his life to prayer. By finding hope in the example of strangers, his life was transformed. The nature of the transformation is testament to the power of the human spirit.

The subject grew up in a household with Jewish and Christian morals and religious practices. As a young man he left the values of his family for self-described “adventure.” For many years, he engaged in criminal behavior and substance abuse. He calmly stated that he used a variety of hard drugs, including cocaine. He put himself at
risk for a variety of diseases, including HIV, through sexual promiscuity and IV drug use. His criminal activity escalated to heroin use and even a bank robbery (he interjected to point out that after coming clean much later in his life, he opened an account in the same bank that he robbed as a young man). If caught, he would have spent years in prison. If he continued his life in crime, he would have faced a variety of potential futures, including death. He described himself as a “sick kid” who did not consider others. However, a chance encounter with Muslims proved to be the catalyst in his metamorphosis away from immorality.

When on the run from a crime, the subject observed Muslims praying. Initially confused by their practices, he reasoned that the event forced him to question the direction of his life. Before being diagnosed with HIV, he was arrested and spent six years in prison. Although he did not specify whether the diagnosis came during or after his incarceration, he professed that HIV and his time in prison served as a “wake-up call to my future.” Initially hurt and confused by the infection, he decided to confront it and not dwell on blame and misery. Shortly following discovery of the virus in his body, the subject converted to Islam and started attending regular services at a local Mosque, a practice which he continues to this day. In the 8 years that he has been out of prison, he has remained clean and maintained a spotless criminal record.

I admire the strength of the patient in realizing his mistakes and working to add purpose to his life. Unfortunately, while many of those infected with HIV are drug users, lost in the cycle of crime and hopelessness, not all of them find the motivation to work for stability in their lives. Thus, the success of this subject provides hope for those who do not believe that they can escape their suffering. I believe that those who escape
hardship can be a resource to those who are trapped within their own struggles. I admire the subject not only because of his struggle, but because he uses his experiences to educate and inspire others, so that they might avoid the suffering which defined much of his life. He revealed that he invests much of his time in the education of others, so that they may avoid bad choices in life. Additionally, he articulated the role that charity has in his new life; giving to others so that they may make the right choices and find peace is a meaningful practice for him.

The subject’s discussion of choices is central to HIV/AIDS. Because HIV infection is strongly associated with risky behavior, the choices we make determine our chances of acquiring the virus. By working with his community to discuss the importance of good choices in life, the subject may have a profound impact on HIV awareness and prevention. Choosing to participate in risky sexual contact and intravenous drug abuse may forever change a life. A momentary lapse of judgment can lead to a lifetime of HIV/AIDS. The decision to fight HIV, however, is a choice which everyone has the power to make. The choice to fight itself may provide the courage to seek support, as was the case with this subject.

The patient insisted that his decision to become a Muslim saved his life. He claimed that he would not be in such great physical condition without Islam. Although he believed that he would have cleaned up his life without his new faith, it introduced him to a new perspective. By providing structure and purpose, religion gave him the desire and the tools necessary to live and thrive with HIV. The subject proclaimed that his newfound spirituality connected him with others and gifted him with a sense of community. He shared his belief in a living faith, or in other words, realizing his beliefs through action.
His faith seemed to be his guide, as he consulted it when considering each significant decision. Before Islam, he did not involve his conscience in his choices, but with Islam, he found the consistency of an established moral code.

Islam also granted the subject the quality of selflessness. As a young man, his selfishness enabled him to commit crimes with little remorse. Selflessness has helped him to find joy in helping others, which now occupies much of his effort. He proudly stated that he learned to put the “me” aside following his conversion. In fact, he now supports his wife as she suffers from a debilitating psychological condition. In less than twenty years, he has transformed his life completely, started a family, and confronted and nearly conquered HIV. He credits his strength of spirit and religion for his success.

His tone during the interview indicated great enthusiasm in the subjects of our conversation. He seemed to love discussing wisdom and stories of suffering and triumph over hardship. His appearance and posture were strong and radiated healthfulness; I would never have suspected HIV in such a robust man. He is a man with great love and compassion for others, who uses his unique experiences to reach those who may otherwise be isolated. I wish that his schedule allowed for a longer interview, but I would be most grateful if I have a chance to speak with him again.

**Prognosis:**

The patient appeared to be one of my healthiest subjects, and according to the report from his primary care provider, he had one of the strongest outlooks. The provider reported that the patient’s chances of surviving for 5 years and 10 years into the future are well over 90%. Additionally, the patient was one of the few participants in the study to be marked as “highly likely” to survive for at least twenty more years. While his changes in
the last six months were described as “no change,” his provider added, “[He] responds
very well to treatment.” The patient had one of the most positive attitudes and a great
deal of compassion relative to the other participants. While most of the subjects were
optimistic, his optimism and love for others were of a far greater magnitude. His
overwhelming positive physical outlook correlated strongly with his state of mind and
spiritual investment.
Subject: 300
Date: 8/08/07

I was surprised to interview so many individuals who were so far removed from the HIV-positive stereotype. Through my meetings with various HIV patients, my image of the typical HIV-positive individual transformed into a wider, more humanized portrait. I eventually accepted that anyone, with any set of traits or any attitude, could be infected. Data from public health organizations may provide us with risk groups and critically-infected populations, but experience has provided me with the knowledge that HIV can infect the most unlikely of subjects.

Interview:

The subject met me with a firm handshake and a steady gaze, as if we were going to talk business over lunch. A healthy, lively looking man, he introduced himself as a recently infected patient, whose HIV diagnosis was followed by cancer in only a few years time. This subject was raised in a Catholic family, and practiced as a child and young man. However, he no longer attends services, nor does he follow Church traditions, but he claimed to be very faithful. I am not certain as to how common such views are amongst Catholics in the new century, but they appear to be widespread. Catholics who do not attend mass or participate in the sacraments seem to label themselves as faithful followers of Christ through conscience and prayers alone. This may speak well of Catholic religious education, as ceremony is replaced by action, but tradition remains a central value in the spirit of the Church. Regardless, the subject shared that his spiritual practices were limited to a few staple prayers (Our Father, Hail Mary), and a strong belief in God. His optimistic attitude hinted at faith in some form of good in
the universe, but living with both cancer and HIV must be an unimaginable challenge to this belief.

The patient was infected in late 2003 through a blood transfusion at an overseas worksite. Although he did not provide details about the transfusion, nor the time between infection and diagnosis, he shared his initial reaction. He confessed that upon learning of his HIV-positive status, he was relieved. In his words, he, “needed to know” the truth about his health. Perhaps uncertainty can be a greater stressor than knowledge of a life-changing condition; we cannot face what we do not know, and ignorance is therefore far more frightening to some. The subject’s desire to know the complete truth (so that he may address it) may be related to his military background and pragmatic approach. The heavily regimented lifestyle of the military appears to favor knowledge over ignorance, as knowledge grants the freedom to adapt and search for a solution to a given problem.

Although relieved with the news of his health, the patient admitted that he was upset with, and continues to resent, the employer which sent him overseas and put him at risk. He claimed that his employer at the time, a company with international business, sent him to an area with poor healthcare and forced him to receive treatment at local facilities when he needed a blood transfusion. Unfortunately, the blood contained the virus and he became infected. His employer refused to provide compensation for the infection, even though they were indirectly responsible for his exposure to the virus. Thus, he must finance his HIV-related treatments through other sources and stated that he still suffers from a lack of closure associated with the incident. In fact, according to this subject, the lack of closure was directly responsible for a painful bout with depression. Depression is relatively common among HIV patients, as HIV is not simply a physical
struggle, but a series of challenges which range from social difficulties to family collapse. Many HIV/AIDS clinics, such as the Haelen Center, provide social workers for the social, economic, and mental complications of HIV infection, including depression. Hopefully, the subject’s faith and optimism blunted the additional suffering from his depression.

As with any significant life challenge, support following HIV diagnosis is critical to the success of the patient. Fortunately for this subject, he received a great deal of support, primarily through his family. During the interview, he stated that his support came from his religion, his mother, his sister, and his three close friends (ordered from most significant to least significant). Although he is not a practicing Catholic, I assumed that his idea of support from his religion is based on his beliefs and faith in his place in life. He did not elaborate on the specific support mechanisms from each of the mentioned sources, and I regret that I did not have time to provide greater details. He added that his ex-employer (not the one who sent him overseas, but his boss at a more recent job) was very supportive during his battles with HIV and cancer and the employer continues to support him emotionally. According to the patient, his employer wanted him to return to work, as the patient is a hard-working, skilled professional. This personality, combined with the subject’s low-risk lifestyle, contrasts strongly with popular images of those infected with the virus.

Throughout the interview, and for much time following it, I was astonished and inspired by the positive nature and healthfulness of the subject. He possessed a bright, glowing personality, radiating as much life and hope as anyone I have met. Throughout our discussion, he smiled, expressed his hopes, and carried warmth in words and body.
Physically, he was in excellent condition and seemed to have absolutely no health problems. Even during the more sensitive sections of the interview, he remained pleasant and positive, and continued to come across as a driven man who refused to give up on his life and career. The role of religion in his attitude and recovery, while not entirely clear, was to encourage the patient to believe in a good greater than the suffering that he faced.

Interviews such as this have heightened my interest in the spirituality of the average American Catholic. While the subject did not attend weekly mass, nor did he partake in most of the sacraments, he considered himself to be both spiritual and religious. I sense that this attitude is widespread among American Catholics. Perhaps the ability to believe in certain things, in conscience as opposed to through doctrine alone, is a trait of the American faithful. Regardless, this subject demonstrated that personal spirituality and established religion can imbue people with great strength.

**Prognosis:**

According to his primary provider, the subject is very healthy and will most likely continue to remain healthy for many years. Specifically, the provider noted that his chances for survival for the next five years were well above 90%, and his chances for survival in the next ten years were about 90%. As with many patients, the provider was uncertain as to his health status in twenty years. The provider also noted that due to the subject’s recent rectal cancer diagnosis, his physical condition over the last six months has been deteriorating mildly. The physical status of the patient seems to align well with his testimony, as he appeared to be in relatively good health and spoke highly of his success in combating HIV.
Devout followers of a given creed often report spiritual experiences that have forever changed their perspectives. While I believe that for some, HIV itself may be a spiritual event which calls for new life attitudes, I imagine that many HIV patients have had especially significant experiences which have motivated them to combat the infection until death. One of the more emotional patients I met had such an experience, and it encouraged him to remain faithful and to never lose hope in his future.

**Interview:**

The subject was one of the most passionate individuals that I interviewed. Not only did he declare great faith in his religion, but he professed a great love for his spirit. He appeared to love his life and believed that his spirituality played a major role in his ability to love and thrive with HIV. Unlike many of the subjects, his faith did not change as a result of HIV. Instead, he claimed that HIV reinforced his belief that strength of spirit can overcome all obstacles. His emotionally-charged and loving perspective on life was inspiring and infectious.

Raised in a religious family, the patient stated that he has never rejected his lifelong faith. A strong Baptist, he claimed to have always practiced at a local church, but did not limit his spiritual growth to church services. He proclaimed that God has always been on his mind, and that presence determines his every action. He read the Bible frequently as a young man and continues to read passages. He said that the scriptures provide solace and wisdom that have helped guide his thoughts and actions. When not attending church or involved in faith-based activities, he claimed to be praying.
“passively.” His passive prayers seemed to be a sort of meditation, during which he imagines a dialogue with God and thanks Him for his health and wishes for the strength to continue living. The patient appeared to have a mature spiritual outlook that is more than a passing comfort or a sanctuary to conjure in times of suffering.

When he was first diagnosed with HIV in the late 90s, the patient was gravely ill from an opportunistic infection. He claimed that he could have died that day, but instead experienced a spiritual event and was spared. He arrived at the hospital with a fever of 105°F, and as he lay in his hospital bed, he accepted that he may not survive the night. As he drifted in and out of consciousness, he contended that his spirit departed from his body and he observed himself in bed, suffering and near death. He returned to consciousness and managed to survive for weeks, but his physical strength was sapped by the virus and he could not walk without the assistance of a cane. While still crippled by his illness, the daughter of his minister told him that she would pray for his recovery. Shortly thereafter, she took his cane and he found himself able to walk unassisted, and remained fully mobile up to our meeting. He seemed to see his recovery as aided by the power of faith. He appeared persuaded that his out-of-body experience and the prayers of a young girl have blessed him with his present health. Thus, mercy may be an important principle of his faith.

The story of how he became infected is equally as profound as his experiences in fighting HIV. Growing up, the subject lived with his father, who at the time was fighting an addiction to controlled substances. He stated that his father was a loving man but could not grapple with his addiction and often lost control while under the influence of heroin. The father was so deluded by his abuse of drugs that he attempted to get his son
to join him. One day, he summoned his child and stuck him with a heroin needle, to the horror of the boy. The patient did not share what happened to him after that offense. Due to the nature of heroin, a physical addiction may develop after a single injection. The syringe that his father used on him may have been tainted by HIV-positive blood. Another possibility is that the patient developed an addiction to heroin and started to abuse it alongside his father, and acquired the virus from an outside source. Regardless, his father was responsible for his suffering. I cannot imagine how crushing it would be for my parents to expose me to something as terrible as heroin, let alone HIV. I am not certain if I would be able to forgive my own father for such an offense, as he would be condemning his own son to addiction and possibly death. I believe that it is the role of the parent to make every effort so that his child can avoid undue suffering. I believe it to be a violation of the duties of parenthood to intentionally destroy the future of a child. While the mind-warping powers of heroin may have confused the intentions of the subject’s father, such behavior is inexcusable. Considering my stance on the issue, I was shocked to hear that the patient forgave his father for the infection. Some people may use forgiveness as a means of avoiding confrontation and escaping the past. However, the patient seemed fully aware of the pain inflicted by his father, and chose to embrace a suffering man. I admire such courage, and I cannot deny a connection between the subject’s love and his spirituality.

The patient has employed a variety of mechanisms that enable him to live fully and openly with the virus. Like many of the other subjects, he keeps himself occupied with his job, so that he does not become inactive or dwell on the infection. On the subject of remaining active, he said, “I believe in keeping on going with life, no matter what.”
Depression is a common co-morbid condition for HIV and remaining active may help to offset the effects of depression; perhaps doing so may prevent it entirely. He also claimed that by helping others, he was able to remove HIV from his active thoughts and could instead focus on his health. Furthermore, he expressed gratitude for the support of his family and friends. Unlike many of the study participants, he claimed to be open with nearly everyone in his life, and instead of rejecting him on the basis of HIV, they embraced him. While he may simply have more understanding relatives, I believe that some of the other patients would be able to find support from their loved ones if they could look past the fear of rejection. He also credited his faith and tenacity for his success. He refused to submit to the virus, and even when faced with a high fever and strong chances of death, he retained the will to live.

Throughout the interview, the patient exuded passion in his words and his body. At certain points of the interview he became tearful, a reaction I only noticed in a handful of patients. He shared his love for all people and all faiths, with the advice that by embracing others, we open ourselves to love and growth. When I questioned him on how he would advise others with HIV, he smiled and recommended that they “Go deep into their souls and find the energy that empowered them before […] and tap into it.” He was optimistic through our entire discussion. On the topic of living fully, he stated that he has no choice but to continue until he is fated to die. I was grateful for such openness and emotional expression. I do not know if I would have the courage to share such thoughts with a stranger, but he appeared to enjoy the opportunity to spread his message of hope. For such an insidious disease, HIV does not appear to weaken the strong of heart.

**Prognosis:**
Like many of the other subjects, I expected this patient to be in good health. He did not appear ill, and certainly not in any obvious state of decay. Sadly, his outlook is poor. His primary care provider reported his chances of survival for five years as 50%, a startlingly low value. Likewise, his provider believed his chances to be alive at ten years in the future as unfavorable (the provider selected “unlikely” on the survey). His provider also selected “unlikely” as his chances for surviving 20 years. His health has apparently been deteriorating rapidly. According to his provider, the subject’s overall health was “strongly deteriorating” during the six months prior to the interview. Perhaps this patient was especially emotional because he was aware that his time was limited. While many of the patients could casually be positive because they have favorable chances for surviving decades into the future, his optimism indicated true hope in a time of desperation. I wish him well as he faces an uncertain future with HIV.
There seems to be a growing number of people who identify as spiritual, but not religious. While I am not certain as to what forms of spirituality can exist outside of the foundation and structure of an organized religion, I believe that spirituality can be rooted in religious experiences. While a spiritual person may claim to be non-religious, her life experience with religion can provide the basic ideas to support a lively spiritual presence. Due to the limited number of participants in the study, I was only able to interview one such patient. The patient turned out to be one of my most intellectual subjects.

**Interview:**

When I met the subject, he immediately introduced himself as a man with great depth of spirit, but one who does not subscribe to any given religion. I asked him to elaborate on his beliefs and the role of spirituality in his life, and he provided a clear framework. He grew up in a religious household. His family frequently attended church services, and his parents believed in well-defined morals. However, as he matured he lost interest in established religion and eventually severed all connections to it. His present beliefs were shaped by his family and his experiences outside of faith. While they resemble Judeo-Christian values, they are not connected to any rites of worship or communities of faith.

The subject described his beliefs as “an optimistic vision of good in the universe.” He believes in a higher power, be it a deity, a universal will, or something more abstract. He also believes that said higher power is a loving being and favors creation and order over chaos. He claimed that he acknowledges its existence daily and is grateful for the
stability it provides to all creation. His “acknowledgments” appear to be somewhere between meditation and prayer, as he actively thinks of a higher power and gives thanks for the beauty of life. Such a framework appears to be strongly influenced by his Judeo-Christian background.

While the patient appeared to be deeply spiritual and has subscribed to the idea of a higher power, he also expressed belief in the power of the individual. He believes in strength of will and the ability of the individual to overcome hardship through determination. He stated that we do not need a god in order to prosper, and that we must believe in ourselves if we wish to progress in our corporeal world. He attributes his success in fighting HIV as the result of his strong will to live fully and to his ability to draw support from his spirituality.

Diagnosed in the mid 90’s, the subject was not shocked or bitter upon discovering his condition. He claimed that he did not blame anyone other than himself and his poor choices. He expected a positive diagnosis at some point, and was therefore prepared for the news. He was quick to accept the diagnosis, and told me that those who do not accept such weighty news only hurt themselves by falling into a cycle of denial. He said that his partner was very supportive following his diagnosis, and continues to support him through his battle with HIV. While he appeared to have a great deal of willpower and a strong desire to thrive, I believe that the support of his partner saved him from the isolation and paranoia that many of the study participants claimed to have experienced. He also stated that by occupying himself, he did not dwell on the negative gravity of HIV. He remained productive as a means of removing his mind from thoughts of loss or hopelessness.
The subject offered a unique testimony on his experiences with intolerant religious groups. He alleged that several local religious institutions had refused to meet with him because he was HIV-positive. Additionally, these groups refused to provide any form of pastoral care. Even though several religious institutions had mistreated him, he refused to dismiss the whole of religion as intolerant or superficial. He stated that some people need the structure of a church in order to flourish spiritually, and that ritual can provide an important foundation for spiritual growth. He declared that ritual is not useful to him and that he believes it to be counterproductive in many cases, as it often replaces ethical practice and selfless action. He affirmed his belief in doing the good as the primary means of moral living. To the subject, ritual serves little purpose if it is not accompanied by ethical behavior and charity. He was careful not to dismiss the value of ritual in his criticisms of its shortcomings. Many people appear to use ritual as a means of escaping responsibility. Attending mass or meditating daily may serve as substitutes for love and conscience in the outside world. The HIV patients I interviewed seemed aware of this practice and overwhelmingly favored the active approach to faith and love. Many of the patients were dissatisfied with belief alone, and were instead concerned with action. The reality of HIV and the obstacles patients must face may encourage them to confront ills in their lives. Thus, HIV may increase the spiritual investment of the infected by illuminating the presence of confusion and suffering.

Although the subject claimed to not follow any creed, he stated that religion is important and can bring purpose to many lives. He described religious teaching as a “good guideline to live by” for the faithful. He stressed the importance of personal responsibility in any school of worship, as religion cannot encourage poor decisions, but
must help us to carefully consider consequences. On accountability, he said, “Keep love on your mind all the time and do the right thing by taking responsibility.” His message to those suffering with HIV was to remain open and find hope and guidance in spirituality. As a young man, many of his friends died from AIDS, and he considers himself fortunate to be alive (“I was spared”). His attitude seemed to align with his feeling of being spared in order to serve a greater purpose.

The subject proved to be pleasant conversation and had a profound interest in spirituality. He displayed a desire to discuss the role of attitude in fighting HIV, and he claimed that positive attitude and healthy choices were important to his own success and would likely help others with the virus. His moral considerations seemed to be linked closely with his active intellect. He appeared to be very thoughtful and carefully considered his beliefs in both spiritual and intellectual contexts. I thank him for his time and an interview with a patient who not only was unique in his views on spirituality, but who was engaging and accommodating of my inquiries.

**Prognosis:**

In the primary care provider survey, the patient was evaluated with a chance of greater than 90% for good health in the next five years. Likewise, the provider found his chances to survive over the next ten years to be about 90%. As for twenty years in the future, his provider was uncertain as to how he would progress. According to the provider, the subject’s health has been deteriorating mildly over the past six months. His provider noted that his kidney problems make his future especially uncertain. Chronic kidney disease has progressed from a stable to a more crippling state, as the patient requires dialysis and may require a transplant in the near future. Regardless, the patient
has survived well with HIV and appeared healthy and full of vigor. His positive, yet realistic, attitude matches his physical status.
When imagining my research program, I hoped to encounter the Prodigal Sons of HIV; faithful children, who distanced themselves from religion and order as adolescents, engaged in risky behavior, contracted the virus, and then returned to their beliefs with genuine humility. I was fortunate enough to meet with such people during my study, and I discovered the profound resonance between gospel narratives of mercy and redemption and many of the patients at the clinic. I am grateful to be able to share such a story.

**Interview:**

The subject was very vocal in her religious views and her fear of social stigma. Born a Baptist and raised with Baptist values, she attended weekly services as a child and held strong beliefs in accordance with Christian doctrine. However, as she matured, she rebelled against all institution and authority, including her Sunday worship. The subject confessed that at the age of 17, she left the values of her family and her religion behind, and started to engage in risky behavior. She did not provide details as to the sorts of risky behaviors she explored, but I suspect that her sexual choices may have put her at risk for infection. She may have experimented with IV drugs, but she never mentioned them during our interview.

While the patient admitted to abandoning her faith, it seems that she never truly lost it. Diagnosed with HIV about 19 years ago, she blamed herself for taking risks and making poor decisions. She found that she needed a great deal of support in order to adjust to the painful news. She found support through her family, who took her in and cared for her when she felt most alone and hopeless. Struggling with her place in life, the
subject finally found meaning when she returned to her church four years ago. Although fellow parishioners were not aware of her infection, they welcomed back their lost daughter and she was able to reclaim her place within the community. Her story draws obvious parallels to the oft-sighted parable of the Prodigal Son. A daughter leaves her family of faith and loses herself in chaos, only to return to love and redemption. I question what role HIV played in her story; would she have sought forgiveness and returned to her family if she had not encountered the virus? Would she have needed the stability of her religion if she were not HIV-positive, which inspired her to return to Sunday worship? Based on her words, I believe that she would have returned eventually, but HIV granted her the urgency of spirit that compelled her to act.

Through much of the interview, the subject shared in her love of God and Jesus. She told me that she always loved Jesus, even when she left her church and sinned according to her conscience. Similarly, she shared in her belief that God knows her as a whole being, and that she places all of her trust in God. She was a visibly faithful Christian and seemed to follow the teachings of her church without question. She claimed to believe in fate, miracles, and the spiritual conduit between Jesus and His followers. Her faith was important to her development before HIV, and will likely continue to shape her life as a woman with HIV.

The patient referenced Jesus frequently, and expressed a strong desire to share with me her hope for humanity. When we discussed the future of our species and the goodness of being, she stated that faith alone will save us. She thinks that by believing in Jesus and following His teachings, Man can make the world a far better place than it is today. Although I did not introduce the topics of religious freedom and tolerance, I
believe that she sees Christianity (or specifically, her version of it) as the ultimate religion. While she may respect the rights of others to worship as they please, during our discussion, her tone suggested that her faith was superior to all others and it alone could bring the greatest good to the world. Thus, I am not certain if she is a devout, humble Christian with a heart open to different ways of loving, or if she is a zealot with a warm smile. It is a far greater challenge to believe in something while still upholding the views of others and not reducing them to lower modes of being. For a woman lost, who returned to family, stability, and health, all while struggling against HIV, I believe that she has the capacity to open her mind. As a Catholic and a skeptic, I find it convenient to dismiss visibly devout evangelicals as sheep who could never truly respect outsiders. Our pluralist society tends to give in to this temptation, and may label women like this patient zealots or fools. I cannot speak ill of her attitude in good conscience, as she has conquered suffering that many of us will never have the misfortune of experiencing.

While I admire her strength, shortly after the interview, I worried about how vulnerable she would become without her faith. She said that her identity was tied closely to her beliefs, frankly stating that, “There is no me without Him.” Jesus appears to be the major, and perhaps sole, motivator in her life. She did not respond to my attempts to discuss her spirituality in a more intellectual context, which suggests that she has not logically considered her beliefs. She did not say if she has questioned the reasons behind her faith. Perhaps we stress intellectualism as master in realms where it is but a tool; spirituality may not depend on thought, but rather feeling and conviction. Regardless, her faith may have prevented her from fully addressing the social reality of HIV.
The patient shared with me her fears about the virus. While she claimed that physical hardship and a potentially truncated lifespan did not cause her unrest, the possibility that others may discover her condition was a source of great anxiety. Outside of her direct family, she had not disclosed her HIV-positive status to anyone. She fears harsh judgment should anyone acquire knowledge of her infection. She was convinced that the public is ignorant about HIV and has never trusted others with her illness. Of course, such statements led me to a question that came to define my research at the clinic: why share such sensitive information with a complete stranger?

I had some difficulty in following the patient through much of her story, as she seemed to contradict herself regarding her attitude at different points of her life. For example, she declared that she had always loved Jesus, yet she admitted to abandoning her faith in its entirety as a teenager. Unfortunately, due to time constraints, I was unable to obtain clarification. Should I return to the clinic for follow-up interviews or extended study, this subject will be one of my top priorities for more involved discussions.

**Prognosis:**

While many of my interviewees were in good health, this subject had one of the best outlooks. According to her primary care provider, the subject is likely to remain in good health for at least ten years, as her provider estimated that the patient has chances over 90% to survive five and ten years beyond the interview. However, it is difficult to forecast twenty years into the future, so the provider chose to list the subject’s outlook for the distant future as, “uncertain.” Apparently, she has been improving in healthfulness in the last six months, as her provider labeled her progress as “strongly improving.” The patient was markedly hopeful during the interview, and her physical condition correlates
strongly to her attitude. I am certain that her faith has provided her with the motivation to
live well and combat HIV, and is at least partially responsible for her success against the
virus.
HIV, unlike most infections, has a social component. The social stigma that accompanies the virus can amplify the suffering of the infected, perhaps to a greater extent than the physical effects. Those with HIV may be abandoned by their families, rejected by their communities, and deserted by their churches. To combat only HIV can be a tremendously painful and isolating experience. However, some may have to fight HIV alongside outside emotional trauma. One of the patients I interviewed was forced to confront HIV and rape. Rape, a heinous act of sexual aggression, can forever taint the peace of its victims. To cope with memories of rape alongside the battle of HIV requires tremendous courage, and I was fortunate enough to speak with a woman whose very presence overflowed with such courage.

**Interview:**

Before discussing her past with HIV, I questioned the patient on her religious background. She explained that she grew up in the South, and recently moved to Connecticut in search of a new life. Raised in a Baptist household, she attended services as a Baptist for most of her life. Following her arrival to New England, she joined a local non-denominational church. She converted roughly two years before the interview, and has remained with the church. She stated that she was happy with her new faith and that it has been an important aid in the process of healing the emotional and spiritual wounds of HIV and rape.

In 1994, the patient was diagnosed with HIV. Unlike most of the other participants in the study, she did not become infected through poor judgment or risky
behavior. She shared with me the sensitive truth behind her infection: rape. As a young woman, a male intruder in her home raped her and transmitted the virus to her via unprotected intercourse. Upon hearing her story, I was appalled by the horror of such a cruel act, and simultaneously shocked by her willingness to share such information. I was further surprised by the individual she blamed for her exposure to the virus; she criticized herself for allowing the rapist into her home, but did not directly criticize him for violating her. I am aware that victims of domestic violence often blame themselves for the abuse they endure. However, I was upset that she could blame herself for the rape, a crime for which she held absolutely no responsibility. I suspect that by placing blame on herself, she may be avoiding the gravity of the crime. The absence of anger or resentment suggests that she has not confronted the entirety of her feelings surrounding the rape. Additionally, she claimed that she has been able to recover from the trauma of rape and HIV without external support.

When questioned on how she coped with the combined anguish of HIV and rape, the subject replied that she consulted only herself. Following the rape, she attempted to find support from her mother. However, her mother refused to listen to her when she mentioned “rape.” Unable to share her experiences with a parent, the subject decided to not seek additional support outside of her own being. She continues to face the challenges of HIV alone, and she has not informed anyone outside of the clinic about her condition. She stated that her primary motivator in remaining silent is fear, because she believes that others would judge her for being a woman with HIV. I find it unfortunate that for so many of the participants, fear discouraged them from seeking support or being open with
others. Fortunately, this subject found solace through her growing spirituality and new church.

Since relocating to Connecticut, the patient claimed that her spirituality has matured tremendously. She described the change as, “I was once sitting at a table but not eating, but now I eat daily and want more.” Her words represent a common biblical metaphor, in which the faithful dine at the table of Christ. To “dine at the table” is to take in the loving message of the Gospels as a form of spiritual sustenance. Thus, it seems that the subject fed her spirit with faith. She elaborated that following her struggle with the rape and HIV, she wanted to move to a new region. Upon securing employment in Connecticut, she moved north and started a new life alone. While running errands in her new hometown, she met the pastor of a local non-denominational Christian church. She introduced herself to him as a newcomer, and they shared a pleasant conversation on life and religion. She asserted that she found him so charismatic that she visited his church. Enamored with the faith community at his church, she soon joined and has remained a faithful member of his ministry. She stated that she considers herself blessed to have found the church and through her new beliefs she has finally found meaning and peace.

The subject credited the wisdom of the Bible as a major contributor to her healing process. At her new church in Connecticut, she joined a Bible study group and immersed herself in the Word of God. She recommended that all Christians consult the Bible in hard times and study it with others, as it is an irreplaceable tome of wisdom. A very loving and faithful survivor of rape and HIV, her voice indicated great enthusiasm to be sharing her story and her faith.
I am deeply grateful for the subject’s testimony. Facing such a painful past must have been unimaginably difficult, but to share it with a stranger is a sign of great courage. Although I met her at the clinic, due to time constraints, I interviewed her via telephone. Thus, I did not have the opportunity to observe her gestures and physical responses during our conversation. Regardless, she proved to be a fascinating subject and an inspiring woman. I never imagined that conducting research on HIV would allow me to meet with such wonderful people. Patients such as her will remain in my thoughts for many years.

Prognosis:

Due to the date of the interview, the patient’s primary care provider did not complete a post-interview physical health outlook survey. However, I had the opportunity to discuss the patient with clinic staff before our telephone conversation. According to several healthcare workers at the Haelen Center, the patient was in superb health and would likely continue to thrive with HIV.
Very few of the study participants were interested in discussions on theology, and even fewer seemed biblically literate. My first interviewee was the only patient who discussed passages from the Bible and their significance to her life. Many of the patients claimed to read the Bible and identified it as an important component of their faith. However, with the exception of the first subject, they did not discuss the relevance of biblical texts to their experiences with HIV. Fortunately, this subject proved to be a wonderful woman with whom to begin my study, as I appreciated her emotional openness and theological discourse.

**Interview:**

The patient had a strong religious background; raised as a Pentecostal Christian, she has remained a practicing member of a local church through the entirety of her life. She claimed to attend services frequently, from traditional Sunday services to weekly biblical studies groups. She stated that as a child, her parents told her that religion and spirituality would always provide comfort and motivation. The subject admired the devotion of her parents and followed them in their faith as she matured. Thus, from infancy until middle age, religion has defined her character. When she contracted HIV, her church and her community did not hesitate to support their sister.

Recently diagnosed with the virus, the subject did not acquire it through risky behavior. In 2006, she received positive test results for HIV, and immediately blamed her ex-husband. During their marriage, she suspected him of infidelity and drug use. As a married couple, they had unprotected sex, but she trusted in his ability to make intelligent
choices and not share needles or have unprotected sex with others. Unfortunately, he violated that trust and transmitted HIV to his wife. The patient did not mention if he was aware of HIV prior to infecting her. I suspect that he may have been aware that he was putting himself at risk, but was probably not tested for HIV while he was married to the patient. However, his ignorance does not free him from responsibility, as he knowingly engaged in risky behavior. Because her husband had transmitted the virus to her, she was upset at the time of her diagnosis. She expressed gratitude to her church, family, and community for their support during that difficult time. She claimed that many members of her church visited her and offered their services and love, should she ever need them. However, she contended that she never questioned God during the time of confusion following the diagnosis. Her spiritual energy and her faith in the good of God helped her to imagine a healthy future.

As part of her perceived spiritual mission, the subject started working at her church. She claimed to have been “called to serve” as the realization of her faith. Thus, she became a minister at her church and now provides for the spiritual needs of those in her community. When questioned on fate, she replied that all that has transpired in her life was part of “God’s plan.” She claimed that her acquisition of the virus and her decision to work as a minister were both fated events in her life. Like many of the other subjects, she expressed great concern for the welfare and spirituality of others. If I pursue studies in theology or public health I hope to someday write in great depth on the selflessness of HIV patients. A cynic might argue that the act of helping others serves as a distraction from the gravity and suffering of HIV. However, I believe that the suffering
and confusion experienced by HIV patients inspires them to save others from all pain. Perhaps HIV intensifies the empathic capacities of the infected.

I was delighted by the patient’s willingness to discuss scripture. A longtime student of the Bible, she said that it provided her with irreplaceable wisdom. Her favorite book is the Book of Revelation, and she claimed to be a fan of apocalyptic literature. Perhaps an interesting future study might examine the biblical preferences of HIV patients and/or the terminally ill. I am curious as to the popularity of apocalyptic texts such as the Book of Revelation and Daniel amongst said groups. In our discussion of the Bible, the subject also mentioned her affinity for Job (book and character). She said that she sees her suffering self in the character of Job, and believes that God would not directly subject a loyal servant to misery or pain. Job is somewhat of an enigma in the Hebrew Bible that presents a timeless narrative on suffering and faith, without a clear setting. Perhaps HIV is a parallel to the book; it is unlike other diseases and it can affect anyone, anywhere.

During the interview, I could not help but to take note of the subject’s mature spirituality. She had a clear energy about her being, which I found calming, yet moving. She claimed that her conscious life is devoted to spiritual growth, and that rarely do other thoughts occupy her mind. As she stated, her personal philosophy is to live with God, or “walk with Christ along every step.” She was open to discussion of other religions and told me that her relationship with God evolved as she learned about the faith of others.

The patient was a wonderful candidate for my first interview. Truly in love with all creation, she called the world “awesome.” She claimed to see God’s love in all things, and therefore justified loving them. Through much of the interview, she was either
smiling or in tears. She did not hide her emotions, nor did she appear to present an incomplete portrait of her life. I left the interview with shattered expectations, hoping that every interview would be as electric as the first. I was also honored by the honesty and courage of the subject for sharing such sensitive details with a stranger. Those feelings of gratitude and honor would continue until the final patient.

**Prognosis:**

Diagnosed recently, the patient responded well to treatment. According to her primary care provider, the patient’s chances of being alive in five years were estimated to be greater than 90%. The probability of her survival for ten years, according to her provider, was estimated at 90%. As for 20 years in the future, the provider was uncertain about the patient’s outlook. However, based on the last six months of treatment, the provider observed the patient’s physical health as strongly improving. Thus, the hopeful attitude of the subject correlated well with the realistic chances of her recovery and success in fighting HIV.
Although many of the patients who participated in the study reported that religion was significant in their battle against HIV, only one patient declared that a spiritual intervention had saved his life. In our pluralist society, we generally define miracles as unlikely, beneficent events. From a more Christian perspective, a miracle could be defined as a rare intervention by God for the purpose of preserving life and love. One of the participants claimed to have experienced a miracle of sorts that saved his life and forever changed his spirituality. A deeply religious and charismatic man, the patient seemed delighted to speak with me.

**Interview:**

The patient introduced himself as a “Born Again” Christian. Born Again Christianity is a rapidly growing non-denominational sect. Many of the self-identified Born Again Christians I have met during my life report spiritual events that compelled them to convert. This subject experienced such an event, and converted from the Catholic tradition to the rising Born Again Movement. During the interview, when I used the term “religion” to discuss the patient’s spiritual foundation, he corrected me. He preferred the term “relationship with God,” as he sees “religion” as a relationship with an institution. While I disagree with that analysis, I can understand his weariness with institution and tradition, as he was raised Catholic and became disillusioned with the Church. At the time of the interview, he stated that outside of his full-time job, he works as a children’s minister at a local church. He appeared to hold his position with great passion and concern for his faith community, and claimed to attend services several times a week. In
2003, he attended a Bible college so that he could grow in understanding of his faith and the Christian scriptures. A loving and humble man, HIV has not only shaped his desire to follow Christ, but has completely altered his spiritual being.

As a young man, the patient felt out of place in the Catholic Church. According to Church doctrine, his homosexual urges were sinful, and he could not openly speak of them or address them in a constructive way. Thus in the 1980s, he secretly engaged in sexual activity with other men, unaware of HIV and the risks of unprotected sex with relative strangers. By the time HIV prevention campaigns arrived, he had already contracted the virus. In 1985, he was diagnosed with HIV. Because he concealed homosexual desires, he married at a young age and attempted to live a traditional heterosexual life. His wife, unaware of his sexual preferences, was shocked by the HIV diagnosis. Although he eventually parted with this wife (his first), he was inspired by the warmth of her Born Again faith. As a Catholic, he found little compassion in his community. Shortly following diagnosis, his parish priest denied him Eucharist, likely due to fear of the virus. Overwhelmed by feeling of hopelessness and abandonment, the patient slowly succumbed to HIV and his health steadily declined.

As the subject’s health deteriorated, he accepted that death may be imminent. In 1995, he was hospitalized for an asthma attack. His condition was so dire that he was placed on a respirator for 7 days, and physicians were not certain if he would survive. Doctors at the hospital informed his wife that he was dying and suggested that she prepare for the worst. The hospital, a regional healthcare facility not experienced with the treatment of HIV patients, lacked the resources to adequately treat him. Unwilling to accept his fate, the subject claimed that he screamed out with his remaining strength,
begging for someone to save him. His panic attack taxed his body so heavily that he lost consciousness. He recalled that upon waking, a minister was at his bedside. The minister was sitting beside him, smiling, and praying for Jesus to come and save him from suffering. In less than an hour’s time, the subject recovered completely from his respiratory ailment and could breathe unassisted. Convinced that he was spared through the love of God, he “accepted into a relationship with Jesus.” To the subject, this small miracle was testament to the love and compassion of Christ, and he knew that he had no choice but to follow in the love that saved him.

Despite hopes for acceptance into his newfound faith, the subject discovered that those who teach compassion and openness may cower from the stigma of HIV. The first church he joined as a Born Again Christian was wary of the infection. He served in the leadership of the church and found that the other leaders were uncomfortable with HIV. As a result, he felt unwanted and out of place at his first church, and decided it best to seek worship elsewhere. Unfortunately, he encountered similar attitudes at his second church. While the leadership at his second church seemed more accommodating of him as a man with HIV, their concerns for him were limited to words. He alleged that when he contracted pneumonia, the leadership and parish of his second church abandoned him. Members from the church refused to see him in the hospital during his fight against a potentially fatal bout with pneumonia. Upon recovering, he decided to move on once again, hopeful that he would find a faith community that acts on their words of compassion for the ill. He reported that his new church has been very supportive and that he is deeply grateful for their commitment to his struggle with HIV. He stated that he was
pleased with his position as children’s minister, and that he hopes to continue serving at his church.

The subject was especially spiritual in both his outlook and presence throughout the interview. Visibly passionate about his faith and service to God, he was engaging in conversation and was thrilled to provide his story for the study. He is the quintessential example of a patient who transformed his life completely following a near-death spiritual encounter. At the time of the interview, he said that he has no doubts about his continued good health. He claimed that the virus was undetectable in recent tests, and that Hepatitis B was also undetectable in his system. He told me that he wishes to continue spreading the hope which saved him during the moment of his greatest suffering.

**Prognosis:**

The patient claimed to be in fantastic health, and according to his primary care provider, his medical future is overwhelmingly positive. When asked of the subject’s chances of surviving for another five years, his provider selected the option for over 90%. Likewise, his provider marked the chances of the patient living an additional ten years as greater than 90%. As the patient was middle-aged, the provider was not certain as to his health 20 years in the future and therefore marked it as “uncertain.” As for changes to the patient’s health over the past six months, the provider described his condition as mildly improving. The provider added comments, noting that the subject prefers a multidisciplinary approach to health. His provider explained that he likes to balance traditional medicine with non-traditional medicine, including faith-based healing and natural treatments. Thus, he has been highly involved in decision making with his provider. The clinicians at the Haelen Center expressed a preference for patients who
were well-informed about healthcare and the importance of HAART, so this subject must be well-liked by the staff; I was certainly impressed by his devotion to healthfulness and spirituality.
Not all of the patients I met with were receptive to my style of interviewing. Some were less willing to divulge the more intimate details of their struggles with HIV. These subjects were generally less emotional during the interviews and tended to speak quickly, without elaboration. I can imagine how difficult it can be to share the details of such a struggle with another, especially a complete stranger. The variety of responses I received led me to question the motivations behind sharing personal details with a stranger, as opposed to taking a more conservative approach.

**Interview:**

Compared to most of my other subjects, this patient was visibly less emotional and far less interested in our conversation. He may have been interested in my study, but he seemed to hold little interest in a meaningful discussion. Instead, he would answer my questions quickly and in a concise manner, and would then pause as if expecting a new question. I did not attempt to force fluid, bidirectional dialogue, and he did not appear to have much interest in me doing so. Thankfully, his answers were still useful and revealing, and I was satisfied with his willingness to participate.

The subject shared that he was raised as a Baptist, but has not committed to any particular sect of Christianity during his life. For many years he has jumped from institution to institution, but he did not explain the lack of consistency. However, he claimed to be a practicing Christian and attended services at least once a month, usually participating on a biweekly basis. Thus, his religious background appears to be somewhat volatile, but he has remained faithful and places value on attending services.
This subject has been HIV-positive for a longer period than most of my interviewees. Diagnosed nearly twenty years ago, the memories of his initial reaction may be less vivid than those diagnosed within the last decade. He claimed that he suffered from depression shortly after discovering his condition. In order to deal with the pain of his depression, he looked to his faith. He stated that his faith not only helped him to confront the reality of HIV in a constructive way, but he also found support in God, which enabled him to eventually defeat the depression. Depression which accompanies HIV is an unfortunate co-morbid condition, one which may be prevented. The social stigma and feelings of hopelessness that may follow diagnosis may develop into a cycle of depressive thoughts. Perhaps it is close support, from family, friends, and faith, which helps patients to stand against the gravity of sorrow and to look forward. This subject is fortunate to have found support in his beliefs in order to cultivate a more positive outlook.

The patient seemed to hold core Christian values, and claimed that his family and religion were interrelated. While he admitted that his family was his main source of support, he repeated that his beliefs helped him to function independently. He shared that he believes in the goodness of God and creation, and that he employs those beliefs to make the best of his situation. He stated that those beliefs help him to get by each day, and without them, he would not have survived for nearly two decades with the virus. He also told me that he approaches each day as a unique, separate window of life during which he can face obstacles as they appear and grow as a person. When I questioned him on the quality of his life, his answer matched his spiritual outlook; he simply responded with, “I’ve had a good life.” I wonder how difficult it must be to have struggled with HIV
for nearly twenty years, yet still be able to summarize it with such a positive tone. Perhaps this hopeful attitude is responsible for the subject’s relative success against the virus. If I had the resources to design and run a clinical trial of the benefits of HAART on HIV patients with and without optimism and faith in their recovery, I would be most curious of the results. I estimate that patients with greater faith experience far greater success with HAART than those who simply take the drugs and lack the will to survive and flourish.

While the subject had an overwhelmingly positive attitude, his tone and speech contained little enthusiasm. Through the entirety of the discussion, the subject used very few words and seemed to give as few details as possible to sufficiently respond to my inquiries. He spoke quickly with a dry, almost unattached tone. I could not determine if he was tense, disinterested, or did not trust me with sensitive information. He seemed rather indifferent to the study, but I wonder how open he is with those who know of his condition. He claimed that he had told many people outside of the clinic about his HIV-positive status, but he was not as open with me as patients who had not shared news of their illness with anyone outside of the hospital. Perhaps people who have been unable to share the stories of their struggles with HIV will more readily elaborate on their lives, due to a desire to open up within a safe environment. This subject, however, was open with others about the virus, so he may have lacked a feeling of urgency or opportunity to impart such secrets to me.

While the subject appeared to have established religious views, he did not possess an outwardly obvious spirituality. He displayed no strong convictions and no interest in discussing the reasons behind his faith. He may be a deeply spiritual person, but for some
reason, he presented himself as someone with powerful beliefs but little passion. I also noticed that physically, he had more obvious signs of HIV infection, including skin lesions and gum damage. Most of my interviewees were not as visibly ill, which may have influenced his attitudes towards the public, and me.

**Prognosis:**

As with many of the patients I interviewed, this subject was doing well with the virus. According to his primary care provider, he is likely to live another five years (an estimated chance of over 90%) at the very least. His chances for good health extend beyond ten years, as his provider believed he has a 90% chance of surviving to that point. As for twenty years in the future, his provider was not certain of his chances. Furthermore, based on the past six months, his provider described his general condition as mildly deteriorating. While he appeared relatively healthy, his skin disorders and other opportunistic infections made it seem like he was in poor health. However, his neutral attitude masked a physical outlook that is overwhelmingly positive.
Subject: 905

Date: 7/18/07

For the sake of comparison, I wanted to interview patients who did not consider themselves spiritual or religious. Scientific research traditionally calls for an unmodified control group against which to compare results of the experimental groups. While this study is by no means traditional, I wanted to have patients of varying degrees of spirituality, in order to examine the roles spirituality may play in the attitudes and progress of the patients. While I did not have the opportunity to interview an atheist, a few of my subjects were agnostic or otherwise uncertain as to the existence of a higher power. One such subject did not believe in a Christian god, and seemed to have little interest in religion in general.

Interview:

Through our entire discussion, the subject displayed little interest in spirituality. He must have had a desire to participate in the study, as I was unable to provide a financial or medical incentive. Perhaps he was interested in spirituality but was unable to articulate his interests. Regardless, I appreciate that someone without an active religious conviction volunteered for the study. His words are a meaningful contrast to those of the more visibly faithful patients.

Raised in a Catholic household, the subject no longer practices the faith of his family. He has not attended Church services or otherwise participated in the sacraments for years. He casually stated that that God and Jesus have no place in his life. I am not certain if those words imply a complete lack of belief; he may have some idea of a higher power, but he did not express that idea during our conversation. However, he did
reference the idea of fate. He affirmed his belief in a pre-determined purpose, which all humans are granted through fate. Fate, according to the patient, is a place in life and a set of chance events which transpire in a destined order so that our lives may have meaning. When asked if HIV was part of his destiny, the subject did not answer directly. Instead, he responded that he had acquired HIV through his poor judgment earlier in life, and that fate may not supplant free will in every choice or crossroads we face.

The subject was diagnosed with HIV approximately 18 years before the interview. Unlike many of the participants in the study, he recalled his reaction with great detail. He claimed that he was young and strong, and was horrified of anything that could threaten his youth and vitality. Following diagnosis, he feared that the virus could be a death sentence, and news of the virus shattered his sense of invulnerability. He did not provide details as to how he might have acquired the virus, and I did not press the issue. Based on his mention of “poor choices,” it seems that he was conscious of how he may have put himself at risk, so I assume that he partook in unprotected sexual activity or IV drug use. He confessed that he blamed himself and his foolishness, but did not blame others for their poor judgment that may have increased his chances of contracting HIV. He wished to conceal the news from everyone, including his family. He feared that should anyone discover the truth, he would face expulsion from his family and social circles. He also attempted to minimize anxiety, as he did not wish to, “kill myself with worry.” Thus, he decided to face HIV alone, and to feel no shame. I questioned his notion of “shame,” as concealing something such as HIV seems to indicate a great deal of shame and a fear of humiliation. He responded that should others discover that a member of his family had contracted HIV, the shame it would bring to his loved ones would increase his own
suffering. He was determined to draw all of the strength necessary to fight the infection from his own being. Despite this desire, he found peace in living for someone other than himself: his mother.

For several years, the subject served his ill mother. He said that because he believed that his own death was imminent, he should spend his remaining days caring for the woman who gave him life. However, by caring for his mother he removed himself from thoughts of his own fated death. He started to take better care of himself in order to best serve his mother. Thus, by living outside of his own suffering, he found reason to maintain his health. Many of the patients I interviewed found that selflessness inspired them to watch their health more carefully in order to best provide for others. This subject noted that when he was infected with chickenpox, which can be fatal to those with a compromised immune system, he was certain that he would die. However, he survived, and he decided to fortify his resolve and to maintain his body as to live his life as healthily as possible.

While attitude played an important role in the success of the subject, he also credited the power of HAART. During our discussion, he listed three key elements for success in combating HIV: medication, physical maintenance, and positive attitude. By taking his anti-retroviral drugs, eating and living well, and remaining optimistic, he has been able to survive for nearly two decades. His means of fighting HIV, while lacking an explicitly spiritual component, focus on the balance between medicine and personal practice. The desire to survive is critical to success because it motivates those with the virus to practice good diet and physical maintenance. Likewise, that desire encourages them to follow their prescribed HAART regimens. Taking the antiretroviral medications
alone may not have a full impact, as an indifferent patient may not follow dosages
properly or may not attempt to assist the immune system by living well. All of these
components seem to synergize in order to maximize the effectiveness of the medications.
Faith may play a role in improving attitude, as was evident for some of the other subjects.

The patient not only lacked faith in a given religious creed, but did not appear to
be spiritual. His attitudes were grounded firmly in rational thought. Strangely, while a
rational person, he did not seem intellectual. His approach to life was earthly and
grounded in practicality. He justified chance and uncertainty in life through his own
interpretation of fate. When I asked him to comment on his ethics, he stated that his
morals are based on the best possible outcome, not the act itself. He appears to value
consequential ethics over deontology, and did not seem to possess a sense of duty to do
the right thing. While not morally ambivalent, he said that he did not disagree with
relativism. He did not dismiss the religious views of others, but stated that he simply
could not share in their beliefs. His testimony proved to be a good contrast to some of the
heavily religious subjects. Without his participation, my study would have lacked
sufficient representation of non-religious individuals.

**Prognosis:**

The subject’s primary care provider believed that he has a 90% chance to survive
for the next five years. Likewise, the provider believed that the patient has a 90% chance
to be alive in ten years. As with most of the subjects, the provider was uncertain as to
health status of the patient 20 years in the future. Over the last six months, according to
his provider, the subject has been “mildly improving” in his overall health. While not
necessarily spiritual, the subject had a positive attitude during the interview, and his attitude correlates well with his physical outlook.
Closing Remarks

I never intended for summer research to enrich my character. Through my work with various patients at the Haelen Center, I found inspiration and humility. Over the few short months at the clinic, I met many individuals who had confronted illness and social isolation. Through suffering they found the courage to face a debilitating illness and the stigmatization that surrounds it. With little reason to hope, they looked to faith to draw the energy needed to succeed against HIV. My struggles seem trivial compared to the gravity of their suffering, yet they were generally optimistic. Determined to live with HIV, and not die with it, they continue to fight a virus that cannot be defeated. Perhaps we see life through a foolish paradigm; curing a disease may not be the ultimate manifestation of healing. Caring for the soul and the body may bring far greater value to our lives, an approach that those with HIV appear to truly understand.
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