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Confronting Death: Co-infection with HIV/AIDS and Hepatitis C

Ian Parker

Providence College, iparke08@providence.edu

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CONFRONTING DEATH:
CO-INFECTION WITH HIV/AIDS AND HEPATITIS C

A research project based upon independent investigation,
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degree of Bachelor of Arts in Social Work.

Ian Parker
Providence College
Providence, RI

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ABSTRACT

This paper discusses a qualitative study completed by the researcher revealing the need for assistance for people living with a co-infection of HIV/AIDS and hepatitis C. It is the role of a social worker to assist this at-risk population. Services must be made available to those co-infected, including courses on end of life coping skills, substance abuse, stigma, and depression and anxiety. Included in this article is a study that documents qualitative data from clients at a Drop-in Center in Providence, Rhode Island for people living with HIV/AIDS. The data proved inconclusive with regards to co-infection and death and dying, but demonstrates that death and dying still play a large role in persons diagnosed with HIV. Within the excerpts, the following 5 themes were identified: initial shock and references to dying, drug use as a method for coping with death, perseverance after initial diagnosis, hepatitis C adding additional worry and stress to HIV diagnosis, and the inability to cope with death and dying. Implications suggest that further data be collected on this topic and that death and dying needs to be addressed by social workers in a therapeutic setting when working with this population.

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Preface

The following paper explains the biological and psychological affects for co-infection of hepatitis C and HIV/AIDS. Through highly active antiretroviral therapy, HIV has shifted closer to a chronic illness rather than a fatal one. However, those who are co-infected with HIV/AIDS and hepatitis C have a higher mortality rate. Research advancements, magnitude, mental health care, and stigma are discussed in relation to the disease. This paper includes an investigation of the coping mechanisms those who are co-infected use in regards to the possibility of death. Findings are presented through qualitative data collected from a Drop-in Center offering services to HIV/AIDS clients in Providence, Rhode Island. Finally, the qualitative data is discussed, followed by conclusions, and implications for social work practice.

Introduction

Advancements in the treatment of the human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) have led this disease to be thought of more as a chronic illness, rather than a fatal disease (Matic, Zalarus, & Donoghoe, 2006). Acquired immunodeficiency syndrome (AIDS) is defined as a “specific group of diseases or conditions which are indicative of severe immunosuppression related to infection with the human immunodeficiency virus” (HIV) (CDC, 2001 as quoted in Moremen, 2003, p.397). In layman’s terms, a person carrying the virus has his or her immune system weakened to the point where even a harmless illness, such as a cold, can turn into pneumonia and eventually, death. AIDS is now being treated with highly active antiretroviral therapy (HAART), which has proven to be very effective in keeping the virus in check (Soriano, et. al., 2004, p. 1). Highly active antiretroviral therapy (HAART)

has led to a marked decline in many opportunistic illnesses (Sulkowski & Thomas, 2003, p. 1).

However, many people with HIV are co-infected with the hepatitis C virus (HCV) (Soriano, et. al., 2004, p. 1). This co-infection is the result of similar routes of transmission, including injection drug use, and hemophilia (Bica, et. al., 2000, p. 2) Co-infection leads to a variety of medical complications that do not arise with HIV alone (Sulkowski & Thomas, 2003, p. 197). Persons co-infected with HIV/AIDS and HCV have higher mortality and morbidity rates than those with HIV/AIDS alone or HCV alone (Sulkowski & Thomas, 2003, p. 197).

HCV is an infectious disease of the liver that can worsen at any given time, even if the disease is being treated (CDC, "Basic Facts," 2007). Studies suggest that HIV may alter chronic hepatitis C (CHC) and accelerate the course of CHC "from chronic active hepatitis to cirrhosis, end-stage liver disease, and death" (Bica, et. al., 2000, p. 2).

Co-infection of HIV/HCV creates a new sub-category of each disease. Many people who are co-infected are facing the same ultimatums that AIDS patients faced concerning their health in the 1980s. Persons with co-infection must now face a life of treatment, uncertainty and side effects (Weitz, 1989, p. 270). Persons that are co-infected desperately need treatment, prevention, addiction counseling, therapy, and in many cases, grief counseling when dealing with the strong possibility of death. While more information is needed concerning the medical management of co-infected persons, more attention should be paid to this special population (Sulkowski & Thomas, 2003, p. 204). Not only are co-infected persons living in a culture that stigmatizes HIV/AIDS and HCV, they are also living with the strong possibility of death everyday, which is especially

difficult in a culture of death-denial (Becker, 1973, p. 11). This is a problem that social workers need to address.

HIV/AIDS is a worldwide epidemic (CDC, "Basic Facts," 2007) and HCV is the most common blood-borne disease in the U.S. with at least 3.8 million people infected (Swan, 2006, p. 5). "Liver disease caused by chronic hepatitis C virus (CHC) infection is now a leading cause of morbidity and mortality among HIV-infected patients in the developed world" (Soriano, 2004, p. 1). In the United States, 150,000 to 300,000 persons are co-infected with HIV and HCV (Sulkowski & Thomas, 2003, p. 197) representing 15% to 30% of all HIV infected persons in the U.S. and 5% to 10% of persons infected with HCV (Soriano, 2004, p. 1). The primary means of transmitting both HIV and HCV is through needlestick exposures, homosexual sex, heterosexual sex, and from mother to fetus (Soriano, 2004, p. 1). Therefore, minorities, intravenous drug users (IVDUs) or at-risk populations are most affected.

For instance, HIV/AIDS in America is a major cause of concern in African American populations because African Americans are diagnosed at almost twice the rate of white Americans (CDC, "Basic Facts," 2007). High-risk sexual contact with men is the chief manner in which HIV has been passed on in African American males (CDC, "Basic Facts," 2007). High-risk heterosexual contact was the chief means of HIV infection among African American females (CDC, 2007). Since HCV is passed on through IVDU, and HCV is a liver disease, IVDUs and alcoholics are at great risk for severe health problems associated with HCV (Kraus, Schäfer, Csef, Scheurlen, & Faller, 2000, p. 378). Care needs to be given to treat addictions and substance abuse in order for treatment to be effective (Swan, 2006, p. 13).

Specialized mental health services are needed to deal with the co-infection crisis occurring right now. People diagnosed with HIV/AIDS and HCV need a social network with other people living with the virus so that the feelings of alienation and depression that coincide with the disease can be discussed and shared (Kraus, 2000, p. 380). The stigma associated with HIV/AIDS (Fife & Wright, 2000, p. 50) and HCV is paramount because many people associate these diseases with death (Kraus, 2000, p. 377). Finally, services need to be given to co-infected persons at the end of their lives, so they can learn how to cope with death. This includes learning healthy coping skills to dealing with the uncertainty of their condition. Social workers should not wish to find themselves in the predicament of one social researcher: “when interviewing an AIDS patient, one cannot offer hope for a cure to the individual, but merely that his or her data may at some time help others” (Jarlais, 1986, p. 34). Yet this is the predicament with co-infection today. Social workers must help this specific, at-risk population deal with their own mortality, and confront this problem of co-infection.

HIV/AIDS and Hepatitis C Co-infection

The problem of co-infection is an increasing one. Since more and more people are living with HIV/AIDS rather than dying from it, HIV/AIDS is seen more as a chronic illness than a death sentence (Matic, Zalarus, & Donoghoe, 2006); however, persons that are co-infected have more complications due to their infections of HIV/AIDS and HCV as well as a general state of uneasiness for HCV can worsen at anytime (Swan, 2006, p. 6). This state of limbo, facing everyday with the unknown and death is rare in society, but co-infected persons deal with their illnesses and their mortality everyday.

Co-infected Persons

Co-infection of HIV/AIDS and HCV is a common problem among sexually active persons who have sex with an infected person, notably gay men and women who prostitute themselves, and intravenous drug users (IVDU) (Swan, 2006, p. 5). Other sources of infection include improperly sterilized kidney dialysis equipment (perinatally) (Swan, 2006, p. 5). Some people that contract HCV can clear the virus from their body, unlike HIV, spontaneously (Swan, 2006, p. 5). However, 55 to 85 percent of people infected with HCV develop CHC or chronic hepatitis C (Swan, 2006, p. 5). As co-infected people age, their chances of the disease worsening becomes greater. Approximately 20 percent of people with CHC will develop liver cirrhosis over a 20-50 year period (Swan, 2006, p. 6). Those persons with HIV/AIDS and HCV advance more rapidly to cirrhosis of the liver and the progression of liver disease is increased in persons that are co-infected (Swan, 2006, p. 6). Consuming alcoholic beverages serves as a main factor in liver disease progression (Swan, 2006, p. 6). Throughout the United States, liver disease due to CHC is the leading cause of liver transplantation (Swan, 2006, p. 6). Eight thousand to 12,000 deaths annually are caused because of complications due to CHC (Swan, 2006, p. 6). In short, "HIV-positive individuals with HCV infection progressed faster to AIDS and death than those who were HCV negative" (Soriano, 2004, p. 2).

Among people living with HIV/AIDS (PLWHA), co-infected persons represent between 15 to 30 percent of this total (Swan, 2006, p. 8). Of those persons that acquired HIV through IVDU, the percentage of co-infection is 50 to 90 percent, more than three times higher (Swan, 2006, p. 8). PLWHA are more apt to develop end-stage liver disease because HIV causes HCV to advance more rapidly (Swan, 2006, p. 8). In the best of situations, HCV can be controlled with end-stage liver disease being prevented in many

patients (Swan, 2006, p. 8). Co-infection is especially prevalent among the IVDU population and hemophiliacs (persons who have difficulty clotting) (Bica, 2001, p. 2).

Federal health guidelines recommend testing HIV positive individuals for HCV antibodies (Swan, 2006, p. 9). However, in order to confirm, or rule out chronic Hepatitis C, an HCV viral load test must be conducted (Swan, 2006, p. 9). In PLWHA, 15 to 45 percent of individuals clear HCV spontaneously; however, spontaneous clearance is less likely to occur in co-infected persons, notably those with higher CD4 counts (Swan, 2006, p. 9). CD4 counts are counts that indicate how strong a person's immune system is. If a person who is HIV positive has a CD4 count of less than 200, that person is then diagnosed with full-blown AIDS.

If a person tests positive for HCV, the next step is HCV RNA (viral load) testing (Swan, 2006, p. 10). If this test is positive, the person infected has chronic HCV, if negative, the patient will be retested in 6 months (Swan, 2006, p. 10). If an HCV test for antibodies is negative, there will be no more tests unless symptoms develop, however, in PLWHA with a CD4 count of less than 200/mL an RNA HCV test should be considered (Swan, 2006, p. 10). Co-infection is a surprisingly common issue and is often found among IV drug users, hemophiliacs, women who prostitute, and gay men. Often persons infected with HCV or HIV are required or suggested to be tested for both viruses.

Treatment

Once a person is diagnosed with HIV/AIDS or HCV there are common treatments for both diseases. Highly active antiretroviral therapy (HAART) is a technique used in PLWHA (Soriano, 2004, p. 1). HAART has caused the progression of HIV to slow in a person's body and has increased mortality rates among PLWHA (Bica, 2001, p. 1). In

fact, the politically correct manner to refer to PLWHA was previously PWAs, or people with AIDS, however, since science has advanced and people have been learning how to live with HIV/AIDS, the term PWAs has been replaced.

Patients with HCV are often given interferon treatments (Soriano, 2004, p. 2). They are often instructed to abstain from alcoholic drinks as this can accelerate the progression of liver disease (Sulkowski & Thomas, 2003, p. 200). In fact, co-infected persons are also suggested to abstain from alcohol, but this can be very difficult since this particular population has a high rate of drug and alcohol abuse and addiction (Sulkowski & Thomas, 2003, p. 200). It is extremely difficult to treat co-infected persons while they are actively using drugs and many physicians delay Interferon treatment, especially since Interferon can interact negatively with severe neuropsychiatric disorders, exacerbating such conditions (Soriano, 2004, p. 2).

Treating PLWHA is becoming easier, and treatment for HCV has proven to be very effective. However, when a person is co-infected and they have a mental illness or drug and/or alcohol addiction, the process of treatment becomes extremely difficult. There is a fine balance physicians work with between treating the HIV/AIDS virus and treating HCV. For instance, if a co-infected patient has a high CD4 count (ideally above 350), a doctor may cease the use of HAART because it can increase the progression of liver disease and liver toxicity in order to treat HCV (Soriano, 2004, p. 2). During treatment, Soriano and coworkers suggest, "A multidisciplinary team, including experts in addiction medicine, psychologists/psychiatrists and infectologists should take care of these patients" (2004, p. 2). As of 2003, there were not approved therapies by the U.S. Food and Drug Administration for the treatment of co-infected persons (Sulkowski &

Thomas, 2003, p. 201). Co-infected persons are able to have HCV cleared from their body; however, HCV infections can return and persons with low CD4 counts and whom use drugs and/or alcohol make treatment difficult (Sulkowski & Thomas, 2003, p. 201). Co-infection complicates the process of ridding the body of HCV while external influences, such as alcohol, can prove detrimental to a persons health.

Stigma

Just as treatments and medicine has changed in the past 20 years or so, so has AIDS related stigma. Physicians in New York and California in 1981 were seeing a rising number of rare diseases, such as Kaposi Sarcoma and other opportunistic infections (Fauci, 2003, p. 839). Over the course of many years, AIDS became coupled with homosexuality and immorality (Fife & Wright, 2000, p. 52). HIV/AIDS is associated with a “blame-the-victim” ideology through physical imperfections, character flaws, and a negatively viewed life style-homosexuality (Fife & Wright, 2000, p. 52). Much of this stigma continues to exist today, as HIV/AIDS is still widespread among gay communities. PLWHA sometimes condemn themselves, inferring that their illness is due to their immoral behavior (Fife & Wright, 2001, p. 53). However, because of African relief and the outpouring of support from governments and celebrities alike, AIDS has become less stigmatized and seen of more in light with other diseases such as cancer, where we can make a stand to fight a disease.

Coping with an Illness and Death and Dying

Another aspect of HIV/AIDS stigma is death. This is a main area of concern with death tolls in Africa exceeding one million people and thousands dying annually in the U.S. (“On the Socioeconomic Impact of the HIV/AIDS Epidemic,” 2001, p. 620). In 35

highly infected African countries, life expectancy has been estimated as low as 48.3 years through 1995-2000, approximately 6.5 years less than with the absence of AIDS a number that is expected to keep decreasing (“On the Socioeconomic Impact,” 2001, p. 620). With such high death tolls, it is natural that people will stigmatize HIV/AIDS as a death sentence, even though people are living with the virus longer. People in America have an aversion to death, incurable diseases, fatal diseases, homosexuals, prostitutes, hypodermic needle drug users, and the poor (Moremen, 2003, p. 397). Many persons who do interact with PLWHA or cancer are reminded of their own vulnerability and mortality and, ultimately, the lack of control one has over their fate (Fife & Wright, 2001, p. 52). Americans project their own fear of death onto people living with HIV/AIDS-the death virus (Moremen, 2003, p. 402). People associate increasing debilitation and eventual death with both HIV/AIDS and cancer (Fife & Wright, 2001, p. 52). However, a person’s cancer can go into remission, or a person can be seen as courageously battling cancer, whereas a person who is HIV positive or has AIDS will always have the virus no matter how valiantly they fight (Fife & Wright, 2001, p. 53). This social dynamic speaks loud volumes. It essentially separates the “living”-those without the virus, and the “dead”-those with the virus (Moremen, 2003, p. 402).

Patients with chronic hepatitis C (CHC) are forced to develop various coping mechanisms and styles to deal with their illness. Since CHC is the most frequent cause of liver disease and liver cancer in developed countries, this can certainly cause uneasiness and uncertainty, much like that of AIDS (Kraus, 2000, p. 377). “Similar to human immunodeficiency virus (HIV) infection, [CHC] patients often estimate their infectious disease as fatal and stigmatic” (Kraus, 2000, p. 377). The idea of death is evident

everyday for persons with CHC as their quality of everyday life is reduced even with the absence of severe symptoms (Kraus, 2000, p. 378). That having been said, coping style and emotional state have pivotal roles in people with a chronic disease (Kraus, 2000, p. 378). Many persons with CHC require a liver transplant and this has been shown to increase depression and cause a person with CHC to perceive themselves as having a lower quality of life (Kraus, 2000, p. 378). CHC patients who needed a liver transplant were likely to die before they are able to receive a liver (Kraus, 2000, p. 378).

In Kraus and company's study on CHC, the researchers found that depression and anxiety did not differ significantly between IVDU and non-IVDU (2000, p. 380). However, CHC patients who were greater than 50 years old were significantly more depressed than younger patients (Kraus, 2000, p. 380). In those patients that had recently been diagnosed with HCV, depression and anxiety were significantly lower than in patients who had known about their infection for more than five years (Kraus, 2000, p. 380). In the sample of Kraus' study, problem-solving behavior, distraction and self-revalorization were the top three methods of coping in decreasing order (2000, p. 380). Patients dealing with cirrhosis of the liver had a higher mean score for religiousness and search for meaning than those individuals with hepatitis or fibrosis (Kraus, 2000, p. 380). This may show that as a potentially deadly illness progresses, some people look to religion for comfort and coping with death. Indeed, religiousness and a search for meaning in life were positively correlated with age (Kraus, 2000, p. 380). Kraus and colleagues suggest that as CHC progresses and the unseen risk of complications rises, assessments should be done on individuals to analyze psychosocial variables and those

patients who display signs of emotional disorders or inappropriate coping styles should be referred to a specialist (2000, p. 383).

In both HCV and HIV/AIDS patients, there is a notion of living on borrowed time and living with a degree of uncertainty. Weitz studied this uncertainty in PLWHA. She categorized coping skills for dealing with the uncertainty of AIDS into two basic categories, vigilance and avoidance (Weitz, 1989, p. 270). Vigilant PLWHA seek out knowledge of the disease to understand how the disease works, why they feel the way they feel and use this knowledge to expect what is to come in the future (Weitz, 1989, p. 270). Avoidant PLWHA protect themselves against the very knowledge that vigilant PLWHA seek out (Weitz, 1989, p. 270). This includes denying initial symptoms of HIV/AIDS to other ailments and avoiding contact with a physician (Weitz, 1989, p. 270). Weitz explains that although these two different mechanisms for dealing with uncertainty appear oppositional, “they are linked in fact by a common goal: the construction of normative frameworks that enable individuals to explain their situations to themselves” (Weitz, 1989, p. 271). Therefore, even if a framework is unreasonable, this acts to reduce the stress and anxiety of the unknown, for them PLWHA can have some degree of control over their lives (Weitz, 1989, p. 271).

Because Weitz’s study was conducted in the 1980s, before more effective treatments were developed, many persons who were gay knew that they partook in activities such as homosexual sex that could contract AIDS. Therefore, before a person was even diagnosed, they had to wonder whether they would develop this new deadly disease (Weitz, 1989, p. 271). Once symptoms common to AIDS began to develop, a person must then decide how to respond to the illness that has befallen them. PLWHA

have erratic changes in their health from day to day (Weitz, 1989, p. 271). This causes daily uncertainty of how a person will feel. A PLWHA will also experience further uncertainty in their lives as they grow older and ask questions such as, will I be able to live with dignity and this illness, or will this disease eventually kill me, and if this disease is going to kill me, will I be able to die with dignity (Weitz, 1989, p. 271)?

Many gay and bisexual men have to concern themselves with HIV/AIDS because of the nature of transmission through homosexual sex. Weitz found that coping with this uncertainty of contraction caused gay and bisexual men to find some control in their life (Weitz, 1989, p. 272). Such men found control by justifying their behaviors as more responsible than other gay men who “choose their partners unwisely and are promiscuous (Weitz, 1989, p. 272). Further denial of the vulnerability of their lifestyles took the form of thinking that HIV/AIDS does not occur in the place where they were, just other places (Weitz, 1989, p. 272). However, once the possibility of contracting the virus became more imminent subjects in Weitz’s study would vacillate between denying that they would have HIV/AIDS and find it intellectually impossible to avoid the possibility of already having the virus (Weitz, 1989, p. 272). As a result many people in the study, and still today, avoid getting tested for HIV/AIDS because in doing so they can feel more in control if they refused to get tested (Weitz, 1989, p. 273).

However, even if a person is not tested they may have been infected with AIDS and remained asymptomatic, showing no signs of any AIDS related symptoms (Weitz, 1989, p. 273). Once symptoms of AIDS do appear, subjects from this study blamed other factors for the way they felt, such as the Arizona heat or the side effects of drug use and/or other medications (Weitz, 1989, p. 273). Once again, this allowed subjects to feel

in control of their lives, even if temporary. One subject explains, “I didn’t want to find out I had AIDS. Even though I kind of figured I did, I didn’t want to know. I wanted to live a normal life for as long as I could” (Weitz, 1989, p. 273). Eventually, the symptoms and the disease become so severe that a person must seek medical treatment (Weitz, 1989, p. 273).

At the time when this study was completed, 1989, many of the subjects reported that, even though they showed obvious symptoms of AIDS, a physician would not perform an AIDS test, denying that the virus could afflict his or her patients (Weitz, 1989, p. 274). This too, caused patients to defer treatment and end up in a state of limbo where they could not function as a normal person, but could also not say that they were sick (Weitz, 1989, p. 274). Patients showing AIDS related symptoms then either went from doctor to doctor and finally were tested or diagnosed themselves and urged their doctors for a test (Weitz, 1989, p. 274). This state of limbo is similar to what co-infected persons feel today. They do not know exactly what is happening to their body because people can live healthy lives with HIV/AIDS, but they also have other symptoms associated with HCV or CHC. Additionally at any time, either of these diseases could take a turn for the worse. Weitz writes that because persons with the virus (back in the 1980s) could become ill rapidly, any time a person with the virus makes long-term or short-term plans they risk facing disappointment (Weitz, 1989, p. 275). Co-infected persons must then face the uncertainty that persons with AIDS in the 1980s faced. Co-infected persons are made to confront their mortality on a daily basis. In Weitz’s study some subjects just avoided the thought of death altogether and denied the possibility of death and refuse to plan for their death (Weitz, 1989, p. 277). Co-infected persons face

this struggle with death now as they cope with their co-infection through various mechanisms.

Services Needed for the Co-infected Population

Those who are co-infected need support to help deal with the uncertainty of their illness, the progression of HCV to CHC to liver disease or cirrhosis. Networks of support and others stricken with co-infection would no doubt help the problem of isolation. Self-care must be stressed to prevent the unnecessary progression of these diseases due to the denial of sickness and death. When death is inevitable, sooner rather than later, some subjects in Weitz's study could cope in a healthy way, saying,

Those who accepted that death was inevitable now focused on living for the present-doing whatever they could do to give pleasure to themselves and their loved ones. By doing so they could feel that they controlled their present circumstances at least partially, even if they could not control their futures. (Weitz, 1989, p. 278)

Therefore, co-infected persons must work with social workers, in groups and individually, to find healthy means of coming to terms with their illness, the uncertainty, and death.

Increasing Our Understanding of Modern Co-infection

Co-infection is a problem that, although concerning, does not require immediate concern. Therapies for HIV/AIDS have become much more effective with highly active antiretroviral treatment (HAART) (Sulkowski & Thomas, 2003, p. 1). Using this treatment, PLWHA can live long, healthy lives (Sulkowski & Thomas, 2003, p. 1). Similarly, interferon treatments have proven to be effective in ridding the body of HCV (Swan, 2006, p. 5). HCV can even spontaneously be cleared from the body (Swan, 2006, p. 5). As medical research continues to progress, treatment for both of these illnesses will

advance. This means that the problem of co-infection will be a decreasing one as time passes. Additionally, stigmatization has decreased in recent years due to publicity supporting HIV/AIDS in Africa and through events such as HIV/AIDS awareness week on college campuses. Furthermore, co-infected persons must face death in their life just as everyone must. All people must cope with death somehow and as the co-infection population grows older because of medical advancements there will be little need for death and dying services.

Treatment Advancements and Prevention

As treatments have changed with the introduction of highly active antiretroviral treatment (HAART) for patients with HIV/AIDS, so have the lives of PLWHA. HAART has decreased mortality and morbidity rates of HIV/AIDS (CDC, "Essential Components of SAFE," 2007). HIV/AIDS is no longer a death sentence. Recent publicity has urged young men and women to be tested for the virus. Commercials featuring actor Jamie Lee Foxx and professional basketball players from the NBA highlight this cause of prevention. If preventative measures continue, and if treatment continues to advance, there will continue to be less and less need for death and dying services among the HIV/AIDS community. Studies that were conducted in the 1980s all featured stories of primarily gay men dying of AIDS. This is not the picture of AIDS today. New studies suggest that PLWHA may have a normal life expectancy (CDC, "Essential Components of SAFE," 2007). Of the leading causes of death for Americans, HIV/AIDS is no longer in the in the top 15 leading causes of death (CDC, "Essential Components of SAFE," 2007).

Prevention programs have also begun to reach out to the HIV community itself beyond condoms and abstinence. HAART may reduce the infectiousness of the virus (CDC, "Essential Components of SAFE," 2007). This means that if PLWHA take care of themselves, they can lower their viral load to a very small amount. This has been shown to decrease the risk of heterosexual transmission 2.5 fold for every 10-fold decrease in plasma (CDC, "Essential Components of SAFE," 2007). HAART reduces genital fluid and plasma viral load; with persons who have a lesser plasma viral load showing signs of undetectable HIV RNA in genital fluid (CDC, "Essential Components of SAFE," 2007). "By lowering viral load, ART can potentially reduce the duration as well as the degree of infectiousness and therefore reduce HIV transmission at the population level, provided that partner change, condom use, and sexual practices remain unchanged" (CDC, "Essential Components of SAFE," 2007). Perhaps more obvious, prevention begins with a decrease in promiscuous and unprotected sex, having high-risk persons be tested, and fighting IV drug use. The Centers for Disease Control and Prevention are actively campaigning for increased prevention among such high-risk populations using their new program called the Serostatus Approach to Fighting the Epidemic (SAFE) (CDC, "Essential Components of SAFE," 2007).

In addition to advancements in the treatment of HIV/AIDS, there is also effective treatment for hepatitis C (HCV). The use of interferon alone or in combination with ribavirin is 50 percent effective in persons with genotype one and 80 percent effective in persons with genotypes two or three (CDC, "Fact Sheet," 2006). In fact, the epidemiological trend from the 1980s to 2004 was characterized by a decline in HCV infections (CDC, "Fact Sheet," 2006). The number of persons infected reduced from an

average of 240,000 in the 1980s to an average of 26,000 in 2004 (CDC, "Fact Sheet," 2006). This data demonstrates that HCV infection can be very treatable in most cases and that less and less people are being infected with HCV. Prevention is also at the forefront in the fight against HCV. Persons who are at high risk of HCV infection should be tested by their doctors to ensure that if a person has HCV antibodies, that person can be diagnosed for HCV as soon as possible. In this manner, the best care can be administered. This is more of a health policy concern rather than a concern of social work. As caring for co-infected persons advances and prevention programs evolve, the need for social work intervention will decline with fewer cases of co-infection and longer life expectancies.

Stigmatization

In public conversation, HIV/AIDS is still a stigmatized illness. HCV is also associated with stigma. However, in recent years, there have been campaigns to reduce the stigma associated with HIV/AIDS. Celebrities such as Brad Pitt, Bono, Angelina Jolie, Julia Roberts, and many more are actively involved in raising funds and working with Africans with AIDS. This campaign against global AIDS has caused people to view the virus as more of a global issue rather than a gay issue as it was stigmatized in the 1980s. With the large amount of publicity gained through television, internet, and radio campaigns from various organizations, more of the public is being educated about HIV/AIDS. Through reducing the stigma associated with HIV/AIDS, campaigns allow persons to be tested with fewer stigmas. Educating the public allows for less infection and reducing the stigma allows for more prevention and quicker treatment for newly

infected persons. Education can also change the views of the public from viewing HIV/AIDS as a chronic illness instead of a death sentence.

Since co-infection is a relatively unknown problem, stigmatization is less prominent since fewer people know about it. Additionally, co-infected persons do not have to disclose to everyone. Co-infected persons only have to disclose their conditions in cases where medical information is required. Medical information is always protected under Federal health privacy laws, which give patients the right to determine who knows their health information (U.S. Department of Health & Human Services, 2007). In this manner, persons who are co-infected have fewer stigmas since the problem of co-infection is relatively rare and they only disclose to persons whom they choose. As education and publicity prosper, the stigmatization will decrease, allowing young men and women to feel more comfortable being tested and receiving treatment.

Dealing with Death and Dying

It is an obvious fact that every person alive must at some point die. Across the country and the globe, every culture and society has different means of coping with death and dying. If co-infected persons need counseling on death and dying, then all people need counseling on death and dying. In many ways, we are counseled throughout our lives on death and dying. A person may experience the death of a grandparent, a parent, a friend, or relative. There are already services in place for terminally ill patients. Such services include hospice care, where terminally ill patients are made comfortable in the weeks or months up to their death. Additionally, if we provide death and dying counseling to co-infected patients, services must also be made available to cancer

patients, leukemia patients, dialysis patients and others. Those diseases are also very serious and cause their sufferers to confront their own mortality.

Currently in society, religious institutions fulfill this role. Churches, Temples, Mosques, sanctuaries, and other holy places act to prepare those on earth for death. Religious institutions also ceremoniously grieve for those who have died and conduct rituals that can ease the burden of the sufferer, knowing that they will be well taken care of after they have died. Religious institutions also provide death counseling and many religions provide a liturgy of death rites to be read to someone who is very ill and may die.

Co-infection is a very serious disease and causes death in many of those afflicted. However, many times HCV is worsened by alcoholic consumption (CDC, "Fact Sheet," 2006). Those who are actively and knowingly consuming alcohol are bringing themselves closer to death and this can be of no fault except the person infected. If someone is slowly killing himself or herself, that is an individual choice, and that person is purposely decreasing their health instead of coping with their illness. If a person needs services, there are services currently in place in society to offer comfort and counseling to the terminally ill.

Co-infected Persons and Services

It cannot be said that every co-infected person needs death and dying services. Many co-infected persons are growing older and only time will be able to tell as to how old they are when they die and what exactly they have died from. Many co-infected persons are healthy and are in little need of the services previously described. Not all co-infected persons are IV drug users and can maintain a high level of self-care. Just as with

HIV/AIDS and HCV, co-infected people can have a steady job and be productive members of society who are surrounded by loved ones and family who need little assistance with death and dying. Finally, if co-infected persons are in need of counseling, there are already institutions in place for such persons, such as hospice care and other ministries for those facing their mortality.

Hypothesis

Persons living with HIV/AIDS and hepatitis C represent a large portion of persons living HIV/AIDS. Research indicates that many persons afflicted with co-infection may face a shorter life span than those who are affected with HIV/AIDS or HCV alone. This shortened life span may cause co-infected persons to be confronted with their death greater than persons who are not co-infected.

The research above suggests that there is a relationship between co-infection and death. There are various mechanisms in which people cope with their illness and death and dying. Many questions arise, from the basic to the complicated, such as, do people who are co-infected struggle with dying more so than anyone else? Is alcohol use and other self-care missteps a sign that a person has given up on life? Do co-infected persons feel comfortable talking about death with a social worker or a doctor? How do physicians give a patient their diagnosis of co-infection, do they deny the issue of death, or do they discuss such issues with a patient? Finally, what can social workers do to aid co-infected persons confront their death and live fulfilling lives?

Methodology

Author's Note

This study was originally meant to include a questionnaire with a needs assessment and questions concerning death and dying (See Appendix A for sample questionnaire). The researcher found that this approach proved taxing emotionally on the subject taking the questionnaire. Only one subject filled out the questionnaire and this process required the researcher to aid the subject through the questionnaire and proved too laborious and emotional for the researcher and the subject. The researcher believes that the questionnaire has value, but the questionnaire must be filled out with adequate time and a professional capable of handling emotional situations with subjects.

Sample

The sample is made up of Rhode Island residents, who mostly live in the city of Providence, RI. The subjects were solicited in downtown Providence at a Drop-in Center for persons living with HIV/AIDS. There were nine different subjects, all adults ranging in approximate age from forty to sixty years old. Two subjects were black, six were white and one subject was of mixed decent. Both co-infected and non-co-infected clients were sampled. Names were changed in the data to protect confidentiality.

Data Gathering

The data was collected between September 2007 and February 2008. The data involves short excerpts of conversations the researcher has had over the course of this period with clients at the Drop-in Center in which the exchange of death and/or dying has arisen. This data was then written down from memory, without the aid of voice recording equipment. The quotations contain inaccuracies since they were written down from memory, though the overall message is presented effectively. Some information about

subjects is unknown and some subjects may have been diagnosed as co-infected and were not forthcoming with such information.

Data Analysis

The data was analyzed by the researcher for common themes and experiences at the Drop-in Center, as well as themes within the data gathered.

Findings: Interview Data

Carl

This subject is a 55 year old gay black male (He referred to his age as “nickels”). He is diagnosed with HIV and hepatitis C. He also has a host of other medical problems, has had cancer in the past, and currently has diabetes. He receives medical treatment through the local VA. His primary source of income is SSDI and could be classified as poor. He has a history of alcohol abuse. He has had HIV/HCV (hepatitis C) for 25 years and believes he became infected via IV drug use.

“This is one thing (points to the word HIV on a piece of paper), but this is another altogether (points to the word AIDS). When people say you have ‘full-blown AIDS’ that’s when they really get thrown. You write here the words death *and* dying. You know, cause death happens to everyone. I could get hit by a bus, who the hell knows? But dying is different. People want to be able to die with dignity. I want people I love around me when I am *dying*. (At this point, the subject becomes emotional and his eyes begin to tear up.) Even if I am in a hospital bed, I want people to be around my bed.

“The thing is, is that people do all sorts of things to kill themselves. Me, because of the hep C, I keep drinking, even though I know its bad for my liver. Other people use Mary Jane or Maridol, or whatever kind of drug they want. See these people here, (points out to the other clients in the Drop-in Center) they know that they have to die, they just don’t know how it’s going to happen. People here really need to think and talk about this stuff, because nobody really deals with it. I don’t want to get in other people’s business, but we got a client here that’s barely 100 pounds, smoking crack, killing himself.”

<p>Bob</p> <p>This subject is approximately 50 years old, heterosexual, white male. He admits a history of alcohol abuse and currently lives with his daughter. He receives SSDI and can be classified as poor. He reports that he became infected with HIV through heterosexual sex. Although this subject showed no signs of an intent to hurt himself, as the researcher is writing this he had reportedly been admitted to a hospital with the intent to commit suicide. He was an active member of the HIV/AIDS men's group that the researcher facilitated.</p>	<p>“For a long time I didn't know that I had HIV. I found out while I was in prison. (This subject's story of how he got into prison is a bit long-winded, the client reports that he had been in the wrong place at the wrong time and served a short sentence.) They do a bunch of blood tests while you are in there. Basically, I had no idea, absolutely no clue. Then this guy comes with my test and says, 'you know you have HIV right?' I don't really remember what happened after that. All I could think about was that I was going to die. I just stood there in shock. I asked and made sure the test was right. Can you believe that? That's how I found out that I have HIV. I'm trying to be good now, I'm not drinking anymore and I'm remaining abstinent. I don't want to pass this on to anyone else. It's hard, but it's something I just have to do.”</p>
<p>J.D.</p> <p>This subject is approximately 50 years old and is a white, gay male of Brazilian decent. He receives SSDI and is homeless, sleeping under a bridge most nights, even through December, January and February. He receives medical treatment through the local VA. He is diagnosed with HIV, HCV, and HBV (hepatitis B virus).</p>	<p>“Not only am I HIV, I also got the hep B and C to deal with. Being homeless and all, my doctor wants me to get some housing before he can begin to treat the hep. He said that my HIV is good right now, and he wants to focus on the hep B and C.”</p>
<p>Susan</p> <p>This subject is a female approximately 50 years old. She is white, heterosexual and looks much older than age. This is because she nearly died before they tested her for HIV. Her cognition is slightly less than average, perhaps from AIDS related dementia, or a preexisting cognitive</p>	<p>“I'm here everyday by the grace of God. He (God) takes care of me. My brother is a minister and he takes care of me too. I am not afraid to die because I know that I will be taken to the Lord. Dying just means that I get to see my father and mother again. I really miss my parents. But I know they're with the Lord now and that I will see them again one day.”</p>

disorder. She became infected through heterosexual sex.

Ann

This subject is a white approximately 50-year-old female client. She is a lesbian and became infected with HIV through IV drug use. She is also co-infected with HCV. She is addicted to cocaine and recently has been hospitalized for severe pneumonia, likely related to her noncompliance with her HIV medical regimen. She currently receives SSI. She has shown signs in the past to the researcher of suicidal ideation. The first excerpt is from that conversation.

“The thing is, my doctor wants me to go to [a residential treatment program], [so he can] change my meds. But I don’t see any reason for it. I mean I’ve been on my meds now for years, and now they want to change them now. I just don’t get it. I mean, I just don’t get it. I’ve been on the same meds for years now. I guess I am getting sicker though. I don’t even know what my CD4 count is, probably less than fifty and my viral load must be in the millions. I’m thinking about just going out in a blaze of glory. I mean, I think I might just go out with a bang.”

“I heard Magic (Johnson) beat the disease. I mean, they’ve got to find a cure soon, man. I don’t know how much longer folks can deal with this disease. I mean you wonder where it came from.... Why did God put this thing on the earth? There’s people dying all over the world because of this, especially in Africa. I just don’t understand why.”

David

David is approximately 50 years old. He is a black, heterosexual male who is a recovering addict. He contracted HIV through IV drug use.

“You know, when I was in [a residential treatment program specifically for people living with HIV] I was struggling to stop feeling sorry for myself. I used drugs as a means for self-medicating. But the program director said something to me that really opened my eyes. She said, ‘so the fuck what? There’s people everywhere that got problems, people with cancer, leukemia.... You think you’re the only one that has to deal with shit?’ After that point, my eyes were really opened. I could no longer justify my drug use with my positive status. It helped me to learn how to live with the virus instead of killing myself with drugs.”

<p>Robert</p> <p>Robert is a white gay male who is approximately 50 years old. For approximately 10 to 15 years, he has been diagnosed as HIV positive and has hepatic C. He is an advocate for all people living with HIV/AIDS. He, unlike many of the other subjects in this study, is not poor. He could be classified as middle class.</p>	<p>“When I first heard I had the virus, I thought I was a dead man. For many years I just thought I was going to die. It took me a long time to realize that I could <i>live</i> with the virus. I could have a normal, healthy life just like anyone else. Now, whenever I talk to others who have recently been diagnosed, I try to let them know that this is just a thing that they have, but that it doesn’t have to control your life.”</p>
<p>Pam</p> <p>Pam is a white female who is approximately 40 years old. She is heterosexual, and reports that she is constantly solicited for sex by men. She is addicted to street drugs and says that she contracted HIV through heterosexual sex.</p>	<p>“Somebody gave this thing to me (HIV), he didn’t tell me anything. Now I have to live with this thing my <i>whole fucking life</i>. I’m never not going to have this thing. It’s (the HIV) there everyday of my life.... How am I supposed to have any sort of a real relationship now? Just because of that one time, now I have this thing forever.”</p>
<p>Henry</p> <p>This subject is a male, in his 40s who has light brown skin from a South American heritage. He is gay and became infected approximately 20 years ago, when he was in his late teens. This particular client can be classified as poor and is slightly higher functioning than many of the other clients that come into the Drop-in Center. He reports drug use in his teenage years as a young man, but reports that he has not used street drugs in many years.</p>	<p>“I am glad that I got HIV. It gave me a purpose, it organized my life. Before, I was just this wild kid, going to sex parties shooting up, shooting other people up (IV drug use). I had no direction; I had no idea what I wanted to do with my life. All of my friends were getting HIV around me, so I figured that I was going to get it, or already had it. I think it changed my life for the better. I didn’t know if I wanted to get married or have a kid and start a family or what. The HIV made me realize what I was doing with my life and how precious life really is.”</p>

Themes

<p>Initial shock and references to dying</p> <p>This theme centered around comments</p>	<p>2 excerpts</p>
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<p>such as “When I first heard I had the virus, I thought I was a dead man” that refer to the experience of finding out that one has HIV.</p>	
<p>Drug use as a method for coping with death and dying</p> <p>This theme concerned self-destructive drug use as a means to self-medicate instead of coping with thoughts and feelings about death and dying.</p>	4 excerpts
<p>Perseverance after initial diagnosis</p> <p>These comments included instances in which a subject found that living with HIV is possible and demonstrated effective coping mechanisms in relations to their HIV diagnosis.</p>	5 excerpts
<p>Hepatitis C adding additional worry and stress to HIV diagnosis</p> <p>This theme was found in subjects who felt that they had an additional “strike” against them with an additionally diagnosis outside of HIV.</p>	2 excerpts
<p>Inability to cope with death and dying</p> <p>These comments demonstrated subjects’ ineffective coping means as well as a continuing struggle to cope with death and dying.</p>	3 excerpts

Discussion

During the time the researcher has been with the non-profit agency that runs the Drop-in Center (approximately 5 months) there have been three suicide attempts that mostly involve the use of drugs and/or alcohol to overdose levels. Outside of these attempts, many clients, as one subject noted, seem to be killing themselves slowly. One

client who is addicted to crack cocaine continues to lose weight and weighs approximately 100 pounds. As Robert pointed out, he thought he was “a dead man” when he found out that he was diagnosed. It is easy to infer that if someone is an addict, they will use their HIV status as a validation for their continued use. This was the case with David, who is in early recovery. Clearly, he felt pity upon himself, and it was not until a recovery worker showed him no pity that he began to truthfully look at himself.

As research studies around HIV/AIDS have previously noted, many clients have appeared not to be so much afraid of death, as afraid of a long, painful, and debilitating death, as is the case with Carl. Carl became emotional while talking about circumstances of someone succumbing to the disease in a hospital. This reveals that, although PLWHA may fear death itself to a certain extent, they fear the process of dying much more than death.

The original purpose of this study hypothesized that the co-infected population, those living with HIV/AIDS and hepatitis C (HCV), was somehow more affected by the idea of death and dying than those persons not co-infected. To a degree, this may be true. As Carl alluded to, if someone has HCV and drinks excessively on a regular basis, the combination of alcohol and HCV can wreak havoc on a person’s liver and prove lethal over the course of time. However, HCV is a slow-working virus that affects persons twenty to thirty years after the original diagnosis with more severity. HCV is also considered by many to be a death sentence similar to HIV/AIDS. Therefore, this study seems to suggest that there is no concrete difference between someone who is co-infected and someone who is not. Subjects have often seemed to conceptualize multiple diseases differently after being initially diagnosed with HIV. This suggests that one ailment, in

this case, HIV/AIDS, that has a long-standing stigma of death associated with it, causes a person to confront notions of death and dying. Co-infection with HCV can serve to add some additional stress, but is not as concerning after a person has been diagnosed as HIV positive.

Additionally, the most common theme in the excerpts was perseverance despite having HIV/AIDS. Many clients noted that they can only take life “one day at a time” similar to the therapeutic practices employed in AA and NA. The perseverance aspect of living with HIV/AIDS seems to originate from the new medicines that have developed for PLWHA. One client, David, stated that now he only takes one HIV medication every morning, while previously he had taken multiple HIV medications throughout the day. Perseverance among PLWHA seems to indicate that as the virus has developed into a chronic illness, PLWHA must cope and find mechanisms for dealing with life with the virus, rather than dealing with death.

There are co-infected groups that provide therapy and mutual support. It is the opinion of the researcher that these groups have important value and should be continued. Because the Drop-in Center was open to all people who have HIV/AIDS there were both co-infected persons and non-co-infected persons, leaving the common thread of HIV/AIDS between the subjects. This may have served for subjects to consider themselves people living with HIV/AIDS instead of persons who are co-infected with HIV/AIDS and HCV.

Limitations

This study is limited in several ways. The sample size is small, containing only nine pieces of dialogue from different individuals. Most of the subjects the researcher

interacted with are from the ages 40-60. Additionally, most of the subjects were poor, which undoubtedly contributed to increased feelings of direness. The data was recalled from the researcher after conversations had taken place, without voice recording equipment, and contains inaccuracies, though the overall message is presented effectively. This study does have value, but it would be difficult to generalize to an entire population from this single study. The researcher would estimate that among the poor, similar experiences could be found, but that as subjects' economic well-being increases, feelings surrounding death and dying may be altered.

Conclusion

This study set out to analyze the differences surrounding death and dying between persons living with HIV/AIDS (PLWHA) and persons co-infected with HIV/AIDS and hepatitis C. The researcher hypothesized that co-infected persons would feel that death and dying played a more pronounced role in their lives than PLWHA. The findings were largely inconclusive. Death and dying seemed to play a role in PLWHA and co-infected persons equally, without any evidence of the co-infected population having a sense of death and dying more so than PLWHA. The original methodology of this study, including a questionnaire, would provide for more solid evidence of any differences between the two populations analyzed.

Implications for Future Practice

This study indicates that death and dying is an important process that clients need to become acquainted with through therapy. The questionnaire originally drawn up for this study served to allow subjects to analyze the manner in which they conceptualize and cope with the end of their lives. The questionnaire seemed to have therapeutic value if

utilized effectively in a one-on-one session with adequate time for clients to explore their thoughts and emotions. The process of confronting one's feelings towards death and dying are intertwined with drug use, abuse and dependence. This study implies that a worker will likely have to help a client work through substance abuse as well as thoughts concerning the end of one's life in order to be more effective.

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APPENDIX A

Needs Assessment

Sex: _____

Age: _____

Approximate length of HIV/AIDS infection: _____

Approximate length of co-infection with hepatitis C (if co-infected): _____

Means of infection: _____

For the following statements, please mark an X anywhere on the line.**Assessment of basic needs:**

I feel that my housing needs are adequately met.

----- ----- ----- ----- ----- ----- ----- -----
Strongly Somewhat Neutral Somewhat Strongly disagree disagree agree agree

I feel that I have enough food to eat.

----- ----- ----- ----- ----- ----- ----- -----
Strongly Somewhat Neutral Somewhat Strongly disagree disagree agree agree

My heating needs are met.

----- ----- ----- ----- ----- ----- ----- -----
Strongly Somewhat Neutral Somewhat Strongly disagree disagree agree agree

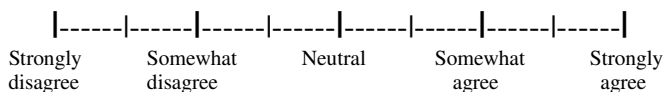
I have use of a telephone to make regular calls.

----- ----- ----- ----- ----- ----- ----- -----
Strongly Somewhat Neutral Somewhat Strongly disagree disagree agree agree

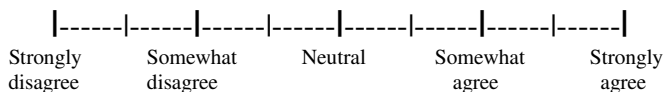
I have adequate electricity.

----- ----- ----- ----- ----- ----- ----- -----
Strongly Somewhat Neutral Somewhat Strongly disagree disagree agree agree

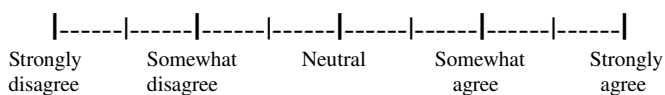
My clothing needs are met.



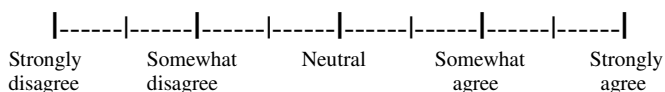
My child care needs are met.



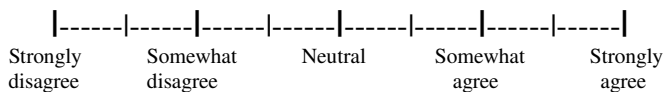
I have a primary care physician.



I have access to adequate transportation.

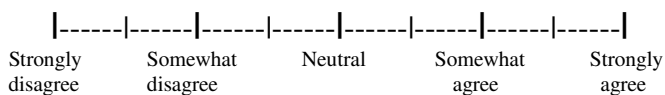


I feel that I am advocated for effectively.

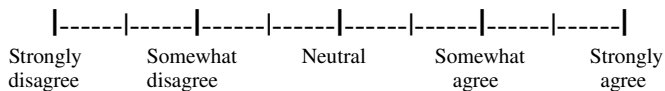


Assessment of Medical Needs:

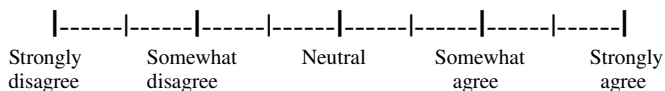
I feel that my medical needs are effectively advocated for.



The communication between myself and my physician is very good.



I need assistance in paying for health care costs.



Assessment of Psychosocial/Death and Dying Needs:

I feel I have adequate individual emotional/spiritual support.

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

I have adequate group support. (i.e. services from agencies distributed in a group setting)

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

I have talked about death and dying with my mental health provider.

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

I have talked about death and dying with my social service provider.

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

I have talked about death and dying with my medical provider.

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

I know where I can go to get help to deal with thoughts, feeling, and emotions concerning death and dying.

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

For Co-infected Participants Only:

I would attend a group for co-infected persons if offered.

|-----|-----|-----|-----|-----|-----|-----|-----|
 Strongly Somewhat Neutral Somewhat Strongly
 disagree disagree agree agree

I receive help coping with my co-infection from the agencies I utilize.

|-----|-----|-----|-----|-----|-----|-----|-----|

Strongly Somewhat Neutral Somewhat Strongly
disagree disagree agree agree

I receive help coping with my co-infection from medical providers. (i.e. doctors, nurses, etc.)

|-----|-----|-----|-----|-----|-----|-----|-----|

Strongly Somewhat Neutral Somewhat Strongly
disagree disagree agree agree

I feel that I struggle more with the idea of death and dying because of my co-infection than others diagnosed with HIV/AIDS.

|-----|-----|-----|-----|-----|-----|-----|-----|

Strongly Somewhat Neutral Somewhat Strongly
disagree disagree agree agree

Please use the space below to answer the following question:

How does death and dying play a role in your life?