



Depression and HIV: Context and Care

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Introduction

Depression has been associated with human immunodeficiency virus (HIV) infection from the very beginning of the epidemic. To some, depression must still seem the only possible response to an illness that can devastate psychological and social—as well as physical—integrity. Who would not be depressed by the loss of bodily control and by being marked by a disease of almost mythic proportions? Yet the responses of individuals to the enormous challenges of living with HIV are disparate: while some people collapse in resignation and despair or become eerily indifferent, others seem to come alive, manifesting an inner strength and resolve. Nor are these states fixed: HIV infection initiates a long and complicated emotional process during which there are often moments of despair, of denial, but also of strength, even heroism. This unfolding process necessarily includes moments of sadness and

personal loss. But when does such a depressive response become significant enough to warrant mental health intervention?

One cannot work with people with HIV and be insensitive to the inevitability of profound loss. But this sensitivity cannot blind providers to the possibility of intervention. This monograph provides practical guidelines to the process of diagnosing and treating depression in people with HIV, without diminishing the complexity of these challenges.

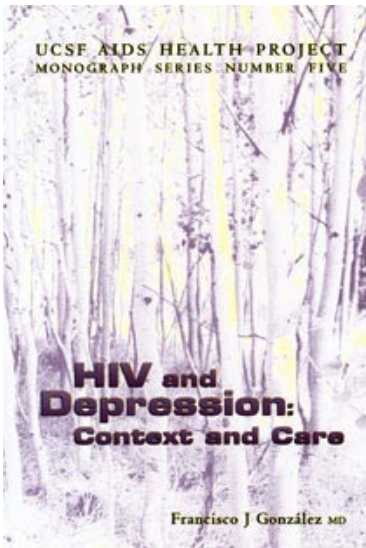
The Historical Context of HIV

To understand depression in the context of HIV, it is useful to understand HIV in the context of its history. In the early 1980s, the first years of the epidemic in the

United States, science could offer very little in the way of treatment or even social support. At the outset, the disease did not have a name, its agent and the mode of transmission were unknown, and it was invariably fatal. In urban epicenters, gay and bisexual men fell seriously ill, were diagnosed, and died, often within a year after presenting for medical care. Some were diagnosed with AIDS only after watching their closest friends sicken and die. Many in the so-called high-risk groups (primarily gay and bisexual men and injection drug users) felt a sense of inevitability, guilt, fear, and hopelessness, and ultimately a state of sustained bereavement fed by the repeated trauma of loss. Such accumulated loss could easily result in depression, demoralization, and numbness. It was not uncommon to find “burn out” among informal and professional caregivers, as wave upon wave of casualties exhausted psychological reserves. Hopelessness, exacerbated by a lack of information, characterized that confusing and anxiety-ridden time.

The U.S. Food and Drug Administration (FDA) approved the HIV antibody test in 1985, it was not until the late 1980s that it approved zidovudine (ZDV; AZT), the first HIV antiviral treatment. Up to that point, treatment for opportunistic conditions offered little more than a temporary postponement of illness. By 1990, early hopes about the promise of ZDV met with disappointment.

By the mid-1980s, reports began to indicate elevated levels of psychopathology, particularly clinical depression, among people with HIV disease. Suicide rates among people with AIDS were alarmingly high: in one New York City study, 66 times higher than the general population; in a California study, 21 times higher. These early reports may have established an expectation among caregivers that depression was correlated with HIV disease, but closer examination shows that



these early studies were often conducted on individuals with advanced illness and at a time when there was little hope. These historical artifacts may continue to color perceptions about the relationship between HIV and depression. While studies have become more sophisticated, the published data on the prevalence of clinical depression and the nature of its relationship to HIV is inconclusive and widely divergent: depression prevalence rates range from 0 percent to 80 percent in HIV-positive populations.

Fortunately, the social and clinical background of the HIV epidemic has changed dramatically since the 1980s. Providers now diagnose HIV infection much closer to the time of seroconversion rather than late in the course of HIV disease, allowing both clients and clinicians to adjust to the illness over time and plan for the eventualities of disease progression. Researchers have slowly developed new and improved treatment options, resulting in greater control both of opportunistic conditions and HIV infection itself. With the advent of multidrug antiviral treatment in the mid-1990s, the psychological landscape of the epidemic changed radically: these new regimens introduced the possibility of managing illness and sustaining quality of life, rather than simply surviving HIV disease. Moribund fatalism has been transformed into nervous hope. In fact, when triple combination treatments were first introduced, some rashly declared the end of the epidemic, a prediction that has lamentably not come to pass. But advances in the late 1990s did end the epidemic as it had been known to that point: the future has brightened, although it remains fraught with anxiety and new burdens.

Over the past two decades, HIV-related services have also become more sophisticated and more readily available. AIDS service organizations have developed specialized programs based on the specific needs of the subpopulations most affected by the epidemic: self-identified gay and bisexual men; men who engage in homosexual activity but do not identify as gay; women; transgendered people; people of color; sex workers; injection drug users; and homeless people. (Of course, these subpopulations overlap within themselves.) In a truly unprecedented project of coordination, medical services have been more closely linked with social outreach and mental health programs. Activists who challenged the medi-

cal and pharmacological establishments in the 1980s forced dramatic changes in the structure and delivery of services, the development of medication and access to clinical trials, and the setting of state and national policy. If the early 1980s were a time of shock and despair, the late 1980s and early 1990s were a time of response and action, arguably leading to improved mental health conditions. While the statistics are not beyond methodological reproach, by 1992 a national assessment of people with AIDS reported a significant decline in the rate of suicide among men from 10.5 times higher than men in the general population in 1987 to 6.0 times higher in 1989.

Making the Darkness Visible

Suicide rates are at best the grossest markers of depression. While these rates have declined, depression nonetheless remains a common problem in HIV-related practice, probably ranging between 15 percent and 20 percent among people with HIV. Even when it is not life-threatening, severe depression causes a significant loss of function and a marked diminishment in quality of life. Close relationships become extremely difficult, straining social networks. Productive work is significantly impaired or made impossible by the mind's sluggishness and its reluctance to focus or attend. Individuals suffering from depression often describe it as a bleak prison, a deadening and painful heaviness that entraps by infiltrating every moment and aspect of their lives. A person's very relationship to the sense of self becomes distorted, so that rather than feeling compassion or pity for one's predicament, a person suffering from clinical depression often feels a pervasive attitude of self-castigation and disgust. To make matters worse, the usual avenues an individual might use to help him or herself feel better—contact with others, pleasurable distractions, nurturing indulgence—become closed off by isolation, a lack of motivation, and an absence of pleasure. The experience of depression is indeed a deeply painful one, a “darkness visible,” as writer William Styron has called it.

Beyond these damaging psychological effects, depression can also influence physical well-being. Whether there is a direct link between HIV disease progression and clinical levels of depression remains unclear. For example, while controlling for immune status and markers of

HIV disease progression, one study found that depression, but not other accompanying health conditions, led to a higher risk of progression to an AIDS diagnosis. The reasons why depression might contribute to progression are many and unproven.

It is conceivable, however, that depressed individuals might be less likely to seek medical attention or to follow self-care recommendations. Self-care is a critical component of maintaining health in HIV disease, and depression typically erodes the nurturing relationship to oneself. A Pittsburgh Veterans Administration Medical Center study significantly correlated high rates of adherence to HIV medication regimens (defined as taking 80 percent or more of prescribed medications) with lower levels of depression, better adaptive coping, and diminished psychological disturbance. In a general medical study (not specific to HIV), researchers found that depressed patients were three times as likely as non-depressed patients to be nonadherent to medical treatment recommendations.

Yet, despite the high rates of depression and its clinical significance, many providers and clients fail to recognize depression when it occurs. In a survey of 475 HIV-infected men without AIDS, for example, researchers found that clinical depression was seriously undertreated: of the 176 men (37 percent of the entire sample) who demonstrated significant symptoms of depression, only 40 percent had seen a mental health clinician in the previous year, and only about 6 percent were taking antidepressant medications. Why, in an age when depression is the subject of talk shows and national bestsellers, should this be the case?

The answer may have to do with the complex and confusing relationship between depression and HIV disease, in part a result of the epidemic's history of uncertainty and despair and the distorting shadow it casts on current clinical situations. Consider the following questions. Isn't it normal for someone who has a life-threatening illness to feel depressed? Rather than calling attention to depressive feelings, isn't it better to put them aside and get on with living? Aren't complaints of fatigue and decreased motivation more properly attributable to the malaise and other physical symptoms of HIV disease rather than to a "mental condition"?

There are also other, perhaps more academic or scientific, questions that confuse this issue. Does HIV progression predispose

an individual to depressive disorders? Conversely, does depression promote immune system malfunction and illness progression? What is the relationship between the stress and trauma of HIV-related events such as initial diagnosis or the development of symptoms and other life traumas? Does depression significantly contribute to high-risk sexual activity? Do different groups at risk for HIV have different rates or kinds of depression?

Finally, for medical providers caring for HIV-positive patients, there are a host of other concerns. How do I recognize clinical depression and differentiate it from other symptoms of HIV disease? What can I do to help an individual who is depressed? What are the best ways to treat depression in HIV-positive clients? When should I refer a client to a mental health provider for treatment of depression?

Monograph Overview: Clarifying Confusion

The purpose of this monograph is to clarify the confusion that often surrounds the assessment and treatment of depressive symptoms in the context of HIV disease—without becoming formulaic or oversimplistic. Specifically, the monograph seeks to focus on depression within a human context, a context that does not sacrifice social and cultural understanding for reductionist medicalization. To accomplish this, the monograph defines the assessment and treatment of depression in terms of the contexts in which they occur: the context of normal sadness versus clinical depression; the context of cultural factors that play out in the therapeutic relationship; and the context of the care venues in which depression may arise.

Depression is a protean, multifaceted phenomenon resulting from complex and often interacting causes. Indeed, the generic rubric of "depression" actually includes several different formal psychiatric diagnoses as well as a range of normal responses. Because of this complexity, this monograph strives to focus on clinical realities, recognizing that individual clients present with complaints, not with neat diagnostic categories. These complaints are often characterized by a confusing amalgam of fuzzy symptoms and unrelated signs. The monograph conceptualizes depression as a spectrum with a broad range, its endpoints located in everyday transient sadness at one end and suicidal crisis at the other. Providers must locate a client's condi-

tion along this spectrum by analyzing clinical phenomena—the client’s symptoms and his or her interactions with the clinical context—a process that allows a more complete understanding of depression than one that routinely medicalizes depressive symptoms. There are times when depressive feelings are both natural and necessary and need to be given room to resolve themselves, and other times when they are malignant and eroding, and should be aggressively rooted out.

Depression manifests in various ways ranging from the client’s subjective narrative of “what’s wrong” to more objective physical dysfunctions such as changes in appetite or in the quickness of routine movements. In whatever way a client expresses depressive symptoms, however, it is always in the context of a relationship with a provider. Both individuals in this pairing—the client and the provider—are embedded in an intersection of rich cultural matrices: the culture of an institution or clinic or discipline; an ethnic, religious, racial, or immigrant culture; a culture of sexuality and gender; or a culture of drugs or the street. A principle thesis of the monograph is that cultural factors play an essential role in the particular manifestations of depression and so should constitute a determining force for providers in assessment and treatment planning.

Finally, psychiatric disorders and psychological symptoms do not occur in a vacuum, any more so than do viral load levels or CD4+ cell counts. If anything, it has long been apparent that issues as disparate as housing, social support, financial resources, and psychological resiliency are as critical to the successful outcome of a medical treatment plan as are state-of-the-art antiviral treatments and good nutrition. These days, HIV disease management is often carried out by a team of providers who attend to these various needs. Recognition and treatment of clinical depression constitutes a critical intervention in this spectrum of care. As such, this monograph is aimed at a wide variety of HIV providers, including mental health practitioners, HIV primary care clinicians, and social service providers.

The monograph designates specific psychiatric diagnoses of depression following standard nomenclature as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV), for example, major depressive disorder, dysthymia,

and so forth. By grouping detailed symptom clusters, DSM-IV diagnoses offer clinicians efficient ways to think and communicate about complicated information. These diagnoses are indispensable tools for assessment, treatment, and research. When referring to depressive symptoms that are severe enough to warrant diagnosis along the lines of DSM-IV criteria, the monograph uses the generic term “clinical depression.” As outlined above, not all depressive symptomatology attains the level of clinical depression.

The monograph is divided into four chapters. Chapter One presents the concept of depression as a spectrum of symptoms that range from normal to those constituting a clinical disorder. This chapter reinforces the biopsychosocial model of understanding psychiatric disturbance and applies it in the context of HIV. It also examines general methodological difficulties involved in determining the prevalence of HIV-related clinical depression. Chapter Two outlines important variables in the assessment of depression, including sociocultural, psychological, and medical confounds that complicate an understanding of HIV-related depression. It returns to the prevalence literature on clinical depression to examine studies pertaining to various subpopulations affected by the epidemic—gay men, injection drug users, people of color, and women. This chapter emphasizes the critical importance of understanding the context of depressive phenomena. Chapter Three defines an approach for the assessment of depression, including a review of the DSM criteria for a major depressive episode and the differential diagnosis of clinical depressions. Chapter Four presents treatment interventions and strategies, including the use of antidepressant medications and a review of important psychotherapeutic approaches. Each chapter draws from the scientific literature as appropriate and provides illustrative clinical case material and vignettes.

Over time, the HIV epidemic has unquestionably inflicted a trauma concentrated in particular communities. It is natural and healthy to express distress in the face of such devastation, but providers and their clients are by no means helpless in the face of depression. This monograph seeks to provide some direction for those struggling against the tide of loss imposed by HIV. ■