

Pepperdine University  
Graduate School of Education and Psychology

PSYCHOLOGY AND PEOPLE LIVING WITH HIV/AIDS:  
A CRITICAL REVIEW OF THE LITERATURE

A dissertation submitted in partial satisfaction  
of the requirements for the degree of  
Doctor of Psychology

by

David Fischer

October, 2012

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under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

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Clinical Experience:

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Mental Health Therapist 2011-2012  
Supervisor: Jack Jensen, Ph.D.

Pre-Doctoral Psychology Intern, (APPIC member) 2010 – 2011  
Supervisor: Taige Bybee, Ph.D.

Provide psychological services to university students, including:

- Intake assessment, DSM-IV multi-axial diagnosis
- Individual psychotherapy
- Couples therapy
- Group therapy
- Crisis intervention
- ADHD and learning disability assessment
- Collaboration with psychiatric services
- Supervision of psychology practicum students

Implement clinical information systems

- OQ Analyst (Clinical outcomes measurement and tracking software)
- Titanium Schedule (College counseling center management software)

*AIDS Services Foundation Orange County* Irvine, California  
Pre-Doctoral Practicum Therapist, 2009 – 2010  
Supervisor: Maggie Decker, Ph.D.

Provide psychological services to lower socioeconomic status HIV+ adults, including:

- Intake assessment, DSM-IV multi-axial diagnosis
- Individual psychotherapy
- Collaboration with psychiatric services

*Bienvenidos Children Center* Montebello, California  
Pre-Doctoral Practicum Therapist, 2008 – 2009  
Supervisor: Bruce Rush, Ph.D.

Provide psychological services to lower socioeconomic status children and adolescents, including:

- Intake assessment, DSM-IV multi-axial diagnosis
- Individual psychotherapy
- Collaboration with psychiatric services
- Collaboration with parents, (50% Spanish-speaking clients)

*Union Rescue Mission, Pepperdine University Counseling Center* Los Angeles, California  
Pre-Doctoral Practicum Therapist, 2007 – 2008  
Supervisor: Aaron Aviera, Ph.D.

Provide psychological services to lower socioeconomic status adult residents in recovery from substance abuse and homelessness, including:

- Intake assessment, DSM-IV multi-axial diagnosis
- Individual psychotherapy, (50% with Spanish-only-speaking clients)
- Collaboration with psychiatric services

*Telecare Recovery Center* Gresham, Oregon  
Recovery Specialist, 2006 – 2007  
Art Therapy Intern, 2005 – 2006

Provide art therapy, psychotherapy to adult residents of mental health facility, including:

- Art therapy assessments
- Individual art therapy
- Individual psychotherapy
- Group art therapy

*Alternative High School* Portland, Oregon  
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Psychology and People Living With HIV/AIDS:  
A Critical Review of the Literature

## ABSTRACT

The implications of living with Human Immunodeficiency Virus (HIV) have evolved over the last 30 years. The view of HIV infection as an imminent death sentence has largely disappeared. From a practical perspective, HIV positive status is now medically treated as a chronic illness rather than as a terminal diagnosis. In response, the focus of psychological research and therapeutic practice has evolved to reflect the changing implications of living with HIV. This study documents how psychological literature regarding people living with HIV has changed over the course of the epidemic.

## Chapter 1

The implications of living with Human Immunodeficiency Virus (HIV) and/or being diagnosed with Acquired Immune Deficiency Syndrome (AIDS) have evolved over the last 30 years. Advances in medical treatment have dramatically improved mortality rates for infected individuals in the US. Many people living with HIV/AIDS (PLWH) are living longer and in turn, the view of HIV infection as an imminent death sentence has changed. Though often missing from lists of chronic illnesses (Swendeman, Ingram, & Rotheram-Borus, 2009) from a practical perspective, HIV positive status (HIV+) should now be viewed as a chronic illness rather than as a terminal diagnosis. Accordingly, the focus of psychological research and therapeutic practice has shifted to reflect the changing implications of living with HIV. This study will document through a review of academic literature how the field of psychology has evolved its ways of addressing HIV over the course of the epidemic.

AIDS was first reported in the medical literature in 1981 (Gottlieb et al., 1981). Specific diagnostic criteria were established prior to discovery of the viral cause, based primarily on the presence of opportunistic infections in the absence of an identifiable cause of immune suppression (Current trends, 1982). Within two years of the initial disease description, the viral cause of the syndrome had been identified (Barre-Sinoussi et al., 1983). The ability to test for antibody to the virus spurred epidemiological research and allowed widespread screening of at-risk populations (Casareale et al., 1984; Goudsmit, Tersmette, Kabel, Miedema, & Melief, 1983). Through the 1980s and 1990s, as the disease was intensively studied, the Centers for Disease Control (CDC) and the World Health Organization (WHO) periodically revised diagnostic criteria (1993 revised

classification, 1992). Distinctions were drawn between viral infection and the progressive stages and categories of AIDS or AIDS-related syndromes (Official authorized addenda, 1994). In the early years of the AIDS epidemic, with no effective treatments for HIV infection, progression through the stages was viewed as the norm for most patients (Moss et al., 1988). The CDC and WHO have continued to elaborate and distinguish stages and progression of the disease, from exposure, infection, through various diagnostic classifications (Revised surveillance case definitions, 2008).

The overall annual rate of new HIV infections in the US has decreased only slightly (HIV/AIDS epidemiology, 2010), yet while new infections continue to increase in certain populations, medical interventions have improved mortality rates for infected individuals. Azidothymidine (AZT) was the first drug approved for treatment of AIDS in the US, and received federal approval in 1987 (Molotsky, 1987). Yet it would take a decade to develop medications that substantially reduced mortality rates from HIV infection (Palella et al., 1998). For most HIV infected individuals Highly Active Antiretroviral Therapy (HAART), a combination of drugs, is the current standard of care (AIDSinfo - HIV guidelines - adult and adolescent).

During the early years, AIDS as a new disease entity carried uncertainty in treatment and a poor prognosis. As early medical interventions were pursued, clinicians recognized a concurrent need to address the psychological well-being of infected patients. The earliest articles in psychological journals (Loewenstein & Sharfstein, 1983) encouraged clinicians to address the general psychological distress of an AIDS diagnosis and the emotional responses associated with the grief process (Nichols, 1983). Twenty-five years later, journal articles have shifted focus away from existential distress to the

behavioral aspects of prevention and treatment adherence (Burton, Darbes, & Operario, 2010; Comulada et al., 2010; Konkle-Parker, Erlen, & Dubbert, 2010; Safren et al., 2010).

### **Purpose of the Study**

This study will document the evolution of psychological knowledge and clinical practices with PLWH through a critical review of the literature of 30 years. The focus will be limited to efforts to address the HIV epidemic in North America and Western Europe.

### **Guiding Questions**

What have been the organizing themes that have guided psychological research in the area of HIV? How have those themes changed over time? Have new themes arisen while others have disappeared? How can the evolution of psychological literature regarding HIV be interpreted as a reflection of advances in the medical management of the disease? How can the evolution of psychological literature regarding HIV be interpreted as a reflection of broader social changes? Are there documented current *best practices* for providing psychotherapy for PLWH?

### **Delimitations**

HIV infection is now recognized as a worldwide epidemic. Yet important characteristics of the epidemic vary widely across the globe. HIV infection rates are increasing in some geographic regions while decreasing in others (UNAIDS outlook report: 2010, 2009, p. 7). The same is true for death rates from AIDS. Populations vary in their understanding and description of disease per se, and in what constitutes culturally viable responses to prevention and treatment. Even within North America, HIV has a different character among sub-populations based on factors such as ethnicity and race or

mode of transmission, such as sexual, needle sharing, or maternofetal (Wilson & Miller, 2003). Controversial and contradictory views regarding how HIV should even be defined have varied among academic disciplines (Taylor, 2007). Naturally then, wide ranges exist in prevention and treatment efforts and their results (Bingenheimer & Geronimus, 2009).

Psychology has been criticized for an over-reliance on narrow and ethnocentric populations for research (Teo & Febraro, 2003; Triandis, 1992). The criticisms include holding implicit assumptions of generalizability to populations not studied and ignoring or marginalizing minority populations. Psychotherapy as delivered in the US is not a globally recognized practice (Wampold, 2001), having developed mainly in Europe and North America in the last 100 years. As an adjunct practice to managing the impact of HIV, psychotherapy's scope is likewise geographically and culturally limited. While acknowledging variability across borders and within subcultures, research on psychotherapy practices will necessarily retain a limited geographical and topical focus. This study has reviewed literature limited to topics addressing populations in Western developed geographies.

### **Significance of the Study**

Due to improved survival rates for PLWH, a wider range of psychotherapists are more likely to treat such clients. Understanding historical research, thought, and current practices can help therapists utilize the accumulated knowledge of experienced practitioners. Identifying gaps between academic research and clinical practice can assist efforts to close those gaps, either by clarifying needs for future research or by promoting improved clinical education. Understanding how the practices have developed in the

context of a shifting clinical and social environment can contribute to theory-building as it applies to practical issues in clinical psychology.

## Chapter 2

### Plan of Action

#### Theoretical Framework

Selecting a research methodology should be based on the nature of the problem investigated, the purpose of the research, and the characteristics of the data (Mertens, 2005 pp. 230-231; Roberts, 2004 p.116). Quantitative methods are generally appropriate to test specific and detailed hypotheses, when the data about a number of variables can be counted, and if possible, when those variables can be carefully controlled or manipulated under experimental conditions. Qualitative methods are more appropriate to study experience from a phenomenological perspective, with a focus on process, individual outcomes, and to build theory from those descriptions of personal experience.

For this study, the nature of the research questions and location of data lend themselves to a qualitative methodology. In particular, a qualitative approach is appropriate to document the type of understanding that arises through community consensus in an evolving context. Roberts (2004) and Rudestam and Newton (2007) note that in qualitative research the data consists of the words used to describe people's knowledge and opinions. Academic literature represents understanding through an evolving process that builds over time through mostly written exchanges and responses between researchers. Thus, a historical review of an academic field's literature is an appropriate method to understand and document that community's formal evolution in thought.



## **Type of Design and Underlying Assumptions**

This study has incorporated a hermeneutical approach and implemented a content analysis to interpret relevant literature to answer the research questions. Hermeneutics has been traditionally focused on the interpretation of historical texts, but social science researchers have also used the same approach to understand modern writings (Rudestam & Newton, 2007). Content or text analysis consists of detailed and systematic reviews of a set of writings to discover and identify the organizing themes presented (Leedy & Ormrod, 2005; Rudestam & Newton, 2007). For this study, the content analysis consisted of a systematic review of relevant articles published in academic psychology journals to identify primary interests to researchers during various epochs of the epidemic. While a literature review is typically used to provide a short summary as background or introduction to new research, Mertens (2005) stated that a literature review can be conducted as an *end in itself*. It can be used to provide a comprehensive understanding of a body of knowledge developed over time. In such a case, the literature review process is typically longer than when used as summary and introduction to a topic. This study has used such an approach, utilizing the extensive academic journal articles as the primary source of data from which to document the evolution and current state of psychological perspectives on HIV in America.

## **Role of the Researcher**

Qualitative research methods have been criticized on grounds of the inherent subjectivity in the process. Proponents of qualitative methods counter that quality is enhanced through a personal and dynamic relationship with the data (Meulenberg-Buskens, 1997; Morrow, 2005). Management of researcher subjectivity in qualitative

methods typically includes an upfront and explicit description of the researcher's experience and attitudes towards the research topic and study participants.

The researcher for this study has been personally and professionally involved with agencies that provide a variety of social services to PLWH. Following the death of an immediate family member from AIDS he served as a volunteer Personal Active Listener (PAL) for Cascade AIDS Project in Portland, Oregon. The role of a PAL was to provide emotional support through long-term commitments and weekly face-to-face conversations with people in the later stages of AIDS. He volunteered as a social worker with Camp Laurel in Pasadena, California, part of The Laurel Foundation whose mission is to provide educational and support programs to children, youth, and families affected by HIV/AIDS. The role of social worker was to provide emotional support to families and individuals affected by HIV during summer and winter camps. As part of the training for a doctoral degree in clinical psychology he engaged in a one-year practicum placement conducting psychotherapy with PLWH at AIDS Services Foundation of Orange County in Irvine, California. Each of these experiences provided opportunities for in-depth conversations not only with people living with HIV, and in some cases dying from AIDS, but with other professionals engaged in providing psychotherapy and other support services.

The researcher is a doctoral student in clinical psychology and has successfully completed multiple graduate level classes in research processes and methodologies, including qualitative methods. In the process of completing the requirements for a course in research design and analysis, the researcher carried out a pilot project for this dissertation. The pilot project included conducting two semi-structured interviews with

therapists experienced with PLWH. Transcripts of the interviews were coded, themes were identified, and major concepts were organized and presented. Reflections on the process were recorded in order to improve the process for this study.

### **Selection of Articles**

AIDS has been an identified disease entity for almost 30 years. The primary data source has been academic journal articles spanning the entire course of the epidemic. A focus on North America has been delimited as described below. Mertens (2005) noted that while primary research articles usually contain 20 to 30 references, a literature review as part of a dissertation is typically more extensive. She provided examples of dissertations in which the literature review serves as an end in itself, providing a comprehensive current understanding of a topic. In those cases the literature review contained from 200 to 400 references. This study has such a depth of description as its goal, and has included a set of references exceeding 200 sources.

### **Data Collection Strategies**

The primary source of data tapped for this study has been the literature of academic psychology. Additional written sources focused primarily on the psychology of AIDS treatment were accessed when deemed relevant and rigorous. Using *PsycINFO*<sup>®</sup> to identify relevant literature, database searches generated a list of academic journal articles related to psychology and HIV from each of the three epochs of the epidemic. Search terms included variations and combinations of *HTLV* (HTLV is an acronym for Human T-lymphotropic Virus, the early name of the virus that causes AIDS), *HIV*, *AIDS*, *therapy*, *psychotherapy*, and *counseling*. The *PsycINFO*<sup>®</sup> database is a product of the American Psychological Association (APA), containing the world's largest collection of individual

abstracts of psychology-related literature (EBSCO – EBSCOhost online research databases). *PsycINFO*<sup>®</sup> then represents the primary source of mainstream thought regarding what has been of primary scholarly interest in each of the defined epochs of HIV disease. An additional rich source of relevant literature was discovered during the research process. FOCUS: A Guide to AIDS Research and Counseling is a publication that addresses HIV and mental health. FOCUS is published by the AIDS Health Project, University of California San Francisco. It is a monthly publication that summarizes research on HIV and mental health, and has been published since 1985. While FOCUS does not implement the rigorous peer-review processes of academic journals, it represents valuable information gleaned by and for front-line providers of HIV medical and mental health services. For this researcher, FOCUS articles provided a more direct touchstone to many of the practical real-world issues confronting service providers that is sometimes absent from more traditional academic research journal articles.

A note on search terms and mental health terminology: Psychotherapy, therapy, and counseling are often interchangeable terms. In this literature review a fairly consistent distinction was revealed. While not universally or consistently applied, counseling generally referred to activity of frontline providers of antibody testing. In fact the activities of testing and counseling were so often paired that they inherited a common acronym, T+C. Those counselors have often had the role of addressing antibody testing, the impact of testing results, safe sex practices, substance abuse treatment, and medication adherence. Psychotherapy generally referred to activity of those providers of mental health therapy. Those therapists have often had the role of addressing issues such

as depression and anxiety. This dissertation has generally held to that distinction between the terms counselors and therapists.

### **Data Analysis Strategy**

In the literature review below, the text of the literature has been examined. Specific content of the literature has been categorized by identifying prominent themes relating to psychological approaches to HIV. Emergent themes have been related and organized into meaningful groups. The table of contents reveals the resulting organization of identified themes. Themes were organized into the following main categories:

*Populations of Focus, Testing, and Psychotherapy. Sub-categories under Populations of Focus were: Gay Males, Women, Children and Adolescents, Drug Users, Diverse Ethnicities, and Others. Sub-categories under Testing were: Psychological Impact, and Prevention Efforts. Sub-categories under Psychotherapy were: Coping with Death, Theoretical Approaches, Diagnostic Approaches, and Other Issues. With some exceptions, each sub-category was then generally organized in a sequence to facilitate elaboration of the evolution in writing over time.*

The results section synthesizes the literature review to address the guiding research questions presented earlier: What have been the organizing themes that have guided psychological research in the area of HIV? How have those themes changed over time? Have new themes arisen while others have disappeared? How can the evolution of psychological literature regarding HIV be interpreted as a reflection of advances in the medical management of the disease? How can the evolution of psychological literature regarding HIV be interpreted as a reflection of broader social changes? Are there documented current *best practices* for providing psychotherapy for PLWH? The

discussion section also addresses the clinical implications of the results for the treatment of PLWH.

## Chapter 3

### Literature Review

#### Populations

One way of documenting how the psychological literature of HIV has evolved is to simply track how the population of focus has shifted over time. The shifting focus seems to have paralleled the presence and spread of the disease over time from gay white males outward to other populations including women, children, intravenous drug users, and ethnic minority populations and to more finely-described sub-cultural groups such as Latina prisoners. The shift in population of focus also parallels the development over time of the awareness of sociocultural complexities of sexual behavior, and the limitations (failures) of so many prevention efforts that were naïvely misapplied to large groups.

**Gay males.** The third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), having been issued in 1980, was current when AIDS was first diagnosed. Homosexuality was only a few years removed from the DSM list of disorders (listed in DSM-II, removed in 7<sup>th</sup> edition in 1974). Less than a decade from that controversial event, the field of psychology was sensitive and responsive to the social realities of prejudice and stigma. AIDS arose within a larger sociocultural and medical context, and researchers urged broader interdisciplinary approaches (Feldman & Johnson, 1986; Herek, 1987; Martin & Vance, 1984).

In order to combat perceived mass hysteria regarding AIDS, psychologists positioned their research efforts in the midst of both scientific and political battles (Mandel, 1986). Even though the virus responsible for AIDS had been identified in 1982,

etiologic uncertainty and skepticism remained through the early years (Joseph et al., 1984; Martin & Vance, 1984). A clear and strong association between AIDS and sexuality, homosexuality, promiscuity, prostitution, and illicit drug use generated condemnation, prejudice and discrimination (Hanson, 1986). In view of traditional psychology and psychiatry's fairly recent abandonment of pathological views of homosexuality, there remained significant distrust of mental health providers in the gay community. After a decade of social change, there was a fear that AIDS would result in a backlash against gay liberation (Joseph et al., 1984). Rather than seeing psychologists as a potential resource in dealing with AIDS, the gay community was understandably concerned that the field of mental health might revert to stigmatizing and blaming gay men for this disease (Coates, Temoshok, & Mandel, 1984; Joseph et al., 1984; Macks, 1986; Mandel, 1986). Researchers were cautioned not to allow stereotypes to drive research toward an overly-narrow focus on sex and drugs (Coates et al., 1984).

Irrational fears of contagion were documented by studies showing healthcare providers' reluctance to engage with AIDS patients, who were at that time overwhelmingly represented by gay males (Coates et al., 1984; Herek, 1987; Macks, 1986; Mandel, 1986). In a 1986 study of 1,149 hospital employees, it was reported that 50% believed in the possibility of transmission via casual contact, 20% believed it could be transmitted by coughing/sneezing, more than 50% donned masks and gowns when approaching AIDS patients, 25% avoided public places such as swimming pools out of fear of contagion, 49% reported spending less time with AIDS patients, while 35% actively avoided involvement with them. Another study of health care workers revealed that 10% believed that AIDS patients were simply "getting what they deserve" (Macks,



1986, p. 2). Some psychologists, however, identified these attitudes as projections of clinicians' distress, and pressed treatment providers, including counselors, to confront their own anxieties, fears, prejudices, denial, and countertransference when dealing with AIDS patients (Coates et al., 1984; Herek, 1987; Mandel, 1986; Nelson & Jarratt, 1987; Price, Omizo, & Hammett, 1986).

Biomedical researchers focused on the infectious nature of the disease and on characterizing the identified viral cause. The rapid pace and success of such research generated confidence that treatment and vaccines would appear within a short period of time (Matthews, et al., 1987). On the other hand, some psychosocial researchers were not convinced by a theory that focused on a simple infectious disease model (Coates et al., 1984; Martin & Vance, 1984; Solomon, 1987; Wheatley, 1987). Infectious disease theory was criticized for its narrow approach, which ignored lifestyle factors affecting health. Psychosocial researchers argued for a broader view that would acknowledge the multifactorial and interactional nature of disease (Batchelor, 1984; Coates et al., 1984; Solomon, 1987). Important factors not addressed by biomedical approaches included psychosocial variables such as personality, stress, delays in seeking treatment, behavioral compliance, personal isolation, social support, finances, and nutrition (Coates et al., 1984; Solomon, 1987). A broader approach with alternative theories of causality was suggested: An immune overload theory hypothesized that the gay lifestyle in general was responsible for overwhelming the immune system (Martin & Vance, 1984); AIDS was hypothesized as another opportunistic infection capable of inflicting harm only in the presence of a pre-existing immunosuppression due to multiple infections, drug uses, repeated viral assaults, and the use of antibiotics (Coates et al., 1984; Martin & Vance,

1984), as well as other undetermined interactions between the virus and host susceptibility (Martin & Vance, 1984).

A number of researchers believed that psychoneuroimmunology provided a more comprehensive explanation of AIDS, accounting for many psychosocial factors. Psychoneuroimmunology theorizes bi-directional interactions between the nervous system and the immune system (Coates et al., 1984; Martin & Vance, 1984; Solomon, 1987; Wheatley, 1987). Some suggested that links between stress and AIDS should be studied similar to what was being documented at that time for other diseases such as cancer or Hepatitis B (Coates et al., 1984; Mandel, 1986). Prior research linked anxiety and stress to both physical and mental health (Herek, 1987; Joseph et al., 1984). Immune suppression was specifically linked with depression, life dissatisfaction, hopelessness, and lack of social support (Coates et al., 1984). The emphasis at that time was specifically on the immunosuppressive nature of stress, and in this case, the stress of coping with cultural homophobia. Essentially, the belief was that AIDS was the end-result of a causal chain that began with homophobia-induced stress in gay males, and that stress resulted in the suppression of the immune system characteristic of AIDS. That provided the causal chain explanation for the *acquired* nature of the disease, rather than a mainstream view of acquiring the disease through viral infection.

Whether or not accepting a stress-based etiology of AIDS, psychologists nevertheless focused on the heavy psychological toll generated by receiving and living with a diagnosis of AIDS or AIDS-related complex (ARC). ARC was the name given to a set of symptoms that were viewed as *pre-AIDS*. It represented a shift from asymptomatic infection to the development of physical symptoms such as fever and weight loss prior to

the onset of the immune deficiency that characterized AIDS. The epidemic was purported to induce unique psychological distress (Hanson, 1986; Macks, 1986), including anxiety, depression, and low self-esteem (Mandel, 1986). Seventy-eight percent of ARC patients and 56% of AIDS patients met DSM criteria for a formal diagnosis of mental disorder. The predominant diagnosis was an adjustment disorder with depressed mood, anxiety, or mixed presentations (Macks, 1986). The distress was attributed primarily to social difficulties such as fears of rejection and anti-gay discrimination (Coates et al., 1984; Macks, 1986; Mandel, 1986). Others attributed a generalized distress throughout the gay community due to recommended lifestyle changes in response to AIDS, especially new fears and prohibitions against sexual behavior and the disruptions and disappearances of traditional gay male institutions (Martin & Vance, 1984).

Gay liberation was included in the civil rights movement of the 1970s and 1980s. By the late 1980s, gay affirmative psychotherapies had developed in order to assist gay and lesbian individuals to cope with social prejudice, including discriminatory practices in psychotherapy (Langdridge, 2007). Gay affirmative therapies are characterized by acknowledgement of the unique challenges faced by lesbian gay bisexual and transgender (LGBT) individuals such as stigma (including internalized stigma), difficulties coming out, and generalized oppression. Affirmative therapies assume that LGBT individuals will benefit from a psychotherapeutic approach that understands those challenges, one that positively affirms LGBT identity, and that affirmatively opposes pathological views of homosexuality (Glassgold, 2009; Harrison, 2000; Langdridge, 2007).

The APA provided guidelines in 2000, revised in 2012, to help psychologists take an affirmative attitude towards LGBT individuals in therapy, education, and research (Guidelines, 2012). The guidelines reflect the principles described above, including respect

for gay identity, cautions against therapies that attempt to change sexual orientation, affirmation of homosexuality as a normal variant of sexual orientation, opposition to discrimination, and sensitivity to the impact of HIV/AIDS on gay populations.

By highlighting the psychosocial factors of AIDS, whether pointing to theoretical stress-linked causes or focusing on stigma-based stress, the psychological literature of early years often described AIDS in the context of hysterical public reactions and the potential psychological impact on PLWH. The development of gay affirmative approaches in later years could be seen as an attempt by psychologists to protect gay clientele from perpetuating the bias and prejudice from which psychology had only recently been distanced.

**Women.** As more women became infected, epidemiological studies revealed a poorer prognosis for them relative to men (Siegel, Karus, & Raveis, 1997). Already aware of the social issues regarding HIV, researchers sought to distinguish biological from social components of HIV in women (Sherr, Petrak, Melvin, & Davey, 1993).

Beevor and Catalan (1993) noted that at the time there was a lack of reliable data on the impact of HIV on women. They and Sherr et al. (1993) called for a research focus on women's concerns, pointing to the unique reproductive issues and the need for prenatal care of HIV+ women. AZT had been approved to treat HIV in 1987, and by the early 1990's AZT treatment had been shown to reduce maternofetal transmission (Chrystie, Zander, Tilzey, & Wolfe, 1995). Routine prenatal antibody testing was encouraged as way to detect and treat infected mothers and at-risk infants (Chrystie et al., 1995; Meadows, Jenkinson, Catalan, & Gazzard, 1990; Sherr & Hedge, 1990).

However, relying on testing as a primary prevention effort presented concerns due to a variety of behavioral, social, and emotional barriers for women seeking health care.

Siegel et al. (1997) cited various studies documenting that women generally sought health care later than men, faced a variety of obstacles, and on the whole received fewer services. They speculated that women's concern for practical needs and their roles as caretakers for others might contribute to delays in seeking care for themselves. Beevor and Catalan (1993) reported similar avoidance and delays in seeking antibody testing by HIV+ women. They attributed the delays to women's general lack of empowerment regarding health care decisions. Meadows et al. (1990) described a type of no-win situation regarding antibody testing of women, pointing to the risk of economic loss following a positive result against the false sense of security that might follow from a negative result. Siegel et al. (1997) pointed to fear of the results contributing to delays in seeking testing. Beevor and Catalan (1993) cautioned that routine testing of women, such as during prenatal screenings and perhaps without explicit consent, might leave women unprepared for the implications of a positive result, leaving them without an opportunity to rally the emotional or social support that such a result would require.

Sherr et al. (1993) acknowledged the importance of prenatal testing, but cautioned that focus on women's reproductive issues represented a too narrow perspective. They compared women's responses to HIV infection to the earlier experiences of gay men. They listed familiar psychological concerns such as anxiety, depression, death anxiety, suicide, and bereavement.

Nevertheless, the primary focus in the literature has been how to help women prevent transmission of the virus through testing and safe sex practices. Mays and Cochran (1988) had reviewed the literature on AIDS risk in Black and Hispanic/Latina women and noted that at that time AIDS was generally perceived as a disease of white

males and substance abusers. Meadows, Catalan and Gazzard surveyed 318 women in a prenatal clinic and found that most (83 %) believed they were at very low risk of infection (Meadows, Catalan, & Gazzard, 1993). Women's attitudes at the time reflected a general sense of being at low risk. Thus, interventions aimed at encouraging safer sex through condom use were deemed unlikely to have significant impact. Male condom use remained low, presumably due to women's financial reliance on men and the challenge of insisting on men changing sexual practices (Bevor & Catalan, 1993; Hankins, Gendron, Tran, & Lamping, 1997). Hankins et al. (1997) encouraged practitioners to extend interventions beyond behavioral management strategies, and consider the socio-cultural context of women's sexual practices.

Later, Morrill and Noland (2006) and Walker (2002) noted the steady increase in HIV infection in heterosexual women. Walker noted that while AIDS deaths had declined in men they had increased in women. Carvajal, Ross, Byrd and Shelton (2005), focusing on incarcerated women, noted that research up to that point had focused on men rather than women, in spite of the fact that HIV infection was higher among females in prison than among male prisoners. Walker attributed the increased mortality rate to women's relative lack of access to health services, including antiretroviral medications, women's use of silence as a way to cope when feeling disempowered, and gender role expectations of mothers as selfless and sacrificing their needs for their children. Morrill and Noland and Carvajal et al. identified high risk heterosexual contact as the primary method of infection.

Morrill and Noland (2006) concurred with prevalent theories that knowledge of one's serostatus was important in prevention efforts. They explored communication

patterns between women and their male sexual partners as an important factor, especially communication regarding serostatus. They identified *testing by proxy* as a commonly employed, yet dangerous, strategy used to avoid the challenges of open communication between women and their male partners. *Testing by proxy* is the assumption that a negative test result for one partner after having unprotected intercourse implies that the others partner's status is also. They suggested that public health informational campaigns may have inadvertently generated false beliefs regarding an instantaneous or highly contagious nature of HIV. Thus, a *testing by proxy* strategy offered false assurance.

Morrill and Noland (2006) explained that interpersonal relationship factors including gender roles and power differentials are significant factors regarding sexual risk behaviors. They pointed out that these factors trump knowledge in their influence on risk behavior. They cited studies showing that reluctance to introduce safe sex practices is based greatly on perceptions that such a conversation and change in practices would have negative consequences on the relationship, requiring a change in sexual practice or raising questions of fidelity.

Ickovics et al. (1998) pointed out that most theories on HIV prevention had not considered gender-related issues, or many other sociocultural domains. They said that studies had focused on men who have sex with men (MSM), and they referenced research that showed that popular educational interventions do not work with women studied. Simoni, Martone, and Kerwin (2002) looking at spirituality reported that research at that time had focused primarily on gay white men. Icovics et al. also critiqued prior research for lack of longitudinal data, hypothesizing that short term follow up may be insufficient to indicate effectiveness of testing and counseling (T+C) interventions. They focused on

long term effects of T+C on women. They found that little to no change in risk behavior was detected, though there was an increase in psychological distress (anxiety, depression, and intrusive thoughts about AIDS) among tested women. Increased awareness and even a mental preoccupation with the risk of contracting AIDS did not change risk behaviors.

Walker (2002) critiqued the research on women and AIDS as having a dominant focus on urban women. She documented challenges that were of particular concern to rural women, including social isolation, greater caregiving burden, more stigma, and limited access to medical services, medication, and psychological resources.

Simoni et al. (2002) noted gender differences in the use of spirituality in coping. They described that in general, spirituality had been shown to be associated with better coping. However, among partners of HIV+ gay men, they suggested that formal religiosity (membership in one's childhood religion, or regular attendance to services) might instead be related to greater anxiety, possibly due to inherent homophobia found in many traditional religions. Among African American and Puerto Rican women with HIV, however, spirituality was frequently used to cope with the distress of such a diagnosis.

Bucharski, Reutter, and Ogilvie (2006) studied aboriginal Canadian women to understand particular issues regarding their relatively high incidence of HIV. They identified unique sociocultural influences, including aboriginal women's experience of oppression, poverty, substance abuse, and domestic violence as contributors. They performed a qualitative study to facilitate development of culturally appropriate HIV prevention programs.

**Children and adolescents.** The growth in HIV infection in the heterosexual community affected not just women, but entire families including fathers, young children,



and adolescents. Pediatric AIDS represented a new and complex set of issues (Landau, Pryor, & Haefli, 1995). Because children became infected primarily through maternofetal transmission, one or both parents were likely to be infected as well (Landau et al., 1995). Due to the high mortality rates of early years, AIDS created orphans, with the naturally occurring set of issues, including uncertainties regarding food, shelter, medical care, emotional support, and guidance (Levine, 1995). Though research was sparse at that time, the presumption was that children affected by HIV would experience a similar set of psychological challenges as adults. HIV orphans were deemed at high risk of developmental and behavioral troubles (Levine, 1995). Children infected by HIV were presumed to face challenges similar to other children with terminal diseases including physical impairments and losses, death anxiety, isolation, and social rejection (Landau et al., 1995; Levine, 1995).

Ryan White's experience in Indiana made national news throughout the mid to late 1980s. At 13 years of age Ryan was barred from public school attendance after public disclosure of his AIDS diagnosis generated protests by local students and parents. He had been diagnosed with AIDS following transfusion of blood products to treat his hemophilia. His public struggle for access to education generated wider awareness of AIDS in children including the associated fear and social stigma (Johnson, 1990). Schools eventually responded by initiating education campaigns to both prevent further transmission and to reduce stigma associated with infection. School psychologists were asked to provide HIV-related instruction, counseling, and emotional support (Landau et al., 1995; Levine, 1995). Schools were asked to include HIV education in programs directed toward preventing sexually transmitted diseases, and to modify materials to be

flexible and responsive to younger audiences (Landau et al., 1995). In addition to focusing on lowering risk-taking behavior, interventions were added to enhance the social reactions to children with AIDS (Landau et al., 1995).

Following the initiation of mandatory prenatal HIV test counseling in California, Ruiz, Molitor, Prussing, Peck, and Grasso (2002) surveyed providers and patients to examine the frequency of such counseling. Their surveys revealed discrepancies between the frequency reported by care providers and that reported by patients. While 98% of care providers reported that they offered testing to patients, only 80% of patients reported receiving that offer. And, while 77% of providers reported that they offered counseling regarding the risks and benefits of HIV testing, only 56% of patients reported having had such a conversation. Ruiz et al. (2002) offered hypotheses regarding the discrepancies. They suggested that providers likely needed to give testing and counseling a higher priority in their prenatal care routines and to make information more relevant to their patients.

Following recommendations for routine, but voluntary, prenatal HIV testing, Ethier, Fox-Tieryn, Nicholas, Salisbury, and Ickovics (2000) looked at organizational factors influencing women's decisions to be tested or not. Their study showed that when counseling regarding testing was performed by primary care providers (PCPs), more women received counseling but also more women refused testing than when the organization maintained a staff dedicated to providing the testing. They hypothesized that a dedicated staff of non-primary care providers would take more time and be able to re-offer testing to women who initially refused.

Gunther, Crandles, Williams, and Swain (1998) focused on adolescents that were coping with the infection of their parents. At the time of their writing (1998), HIV was the number one cause of death among mothers of young children and adolescents. They described support groups specific to the needs of adolescents coping with illness and potential loss of parents to HIV. They pointed out that acting out behavior was common among affected adolescents as a way of coping with their parents' status. They described the stigma and subsequent secrecy associated with the diagnosis as a form of *double abandonment*, wherein the adolescent is left by the parent as well as shunned by society. Using a developmental model they pointed to parallels between group processes and adolescent individuation processes to justify group therapy as a favored intervention.

Stephens, Braithwaite, and Taylor (1998) also described a group intervention to improve prevention efforts aimed at African American youth. Based on adolescent sexual attitudes and documented high-risk behavior they indicated the possibility that then-current adolescents likely represented the majority of future HIV infections. They identified a need for innovative approaches to prevention efforts with adolescents. They also emphasized the need for culturally-relevant approaches, including understanding the culture of African American youth. They described the use of music therapy, and in particular, the use of hip-hop music as a way to pass along more enduring safe-sex messages.

**Drug users.** A substantial rise in HIV infection of IDUs prompted a shift of attention towards that population (Gallagher, Cottler, Compton, Wilson M., & Spitznagel, 1997). As the epidemic began to spread beyond gay male populations, IDUs were seen as the purported source of heterosexual infection (Gallagher et al., 1997; Liebman, Brooks,

Bonilla, & Kotranski, 1996). High risk behavior among drug users was blamed on a lowering of inhibitions when using drugs and the prevalence of engaging in prostitution for drugs (Gallagher et al., 1997; Liebman et al., 1996).

Drug treatment programs relied on behavioral modification and educational interventions, with varying degrees of reported success. Some studies appeared to show a positive link between HIV awareness and behavioral change in this population, while most did not (Gallagher et al., 1997). Martin (1988) reported changes in needle sharing behavior, but little or no change in sexual behavior. Study participants that tested positive for HIV antibody were found to be more likely to make behavioral changes than those who remained uninfected (Martin, 1988).

Serpelloni, Carrieri, Rezza, and Morganti (1994) studied changes in high risk behavior among IDUs engaged in methadone treatment, and reported improvement among participants. The degree of improvement was correlated to both the dosage of methadone and to time spent in treatment. Because the treatment included providing both methadone and counseling, it was difficult to separate the individual effects of each intervention. Liebman et al. (1996) doubted the effectiveness of simply testing IDUs to provide serostatus as a method of education to promote behavioral change. They urged counseling as the top priority for IDUs.

People with co-occurring diagnoses present complex challenges to treatment providers and systems of care. Differences in treatment approaches, systemic culture, and priorities had been documented between the worlds of HIV medical care and substance abuse treatment. It seemed that if a patient entered the health care system for HIV treatment, the substance abuse or mental health issues might be under treated, while if

they entered the system for substance abuse treatment, the HIV issues might be under treated (Korthuis et al., 2008; Proeschold-Bell, Heine, Pence, McAdam, & Quinlivan, 2010; Tobias, Brown, Rajabiun, Drainoni, & Young, 2005). Integrated approaches designed to address issues of substance abuse, mental health, and HIV were described with combined aims of decreasing substance abuse to prevent further HIV transmission as well as improving self-care and medication adherence for PLWH.

It has been recognized that substance abuse could interfere with appropriate management of HIV (Pisu et al., 2010; Pollack & D'Aunno, 2010). Substance abusers are less likely to access HIV care and to maintain adherence to HIV treatment (Pisu et al., 2010; Tobias, Wood, & Drainoni, 2006b). The obvious problem with a lack of medical management means that substance abusing people living with HIV would suffer higher morbidity from HIV and likely be a continued source of transmission to others (Tobias, Wood, & Drainoni, 2006a). Burnam et al. (2001) documented that while a majority of adults (61%) receiving medical care for HIV had also received mental health or substance abuse treatment, substance abuse treatment represented a small portion of that care.

The Ryan White CARE Act of 1990 provided for grants to states and large metropolitan areas to improve medical care and support services to underserved populations affected by HIV (Hayes, Gambrell, Young, & Conviser, 2005). Tobias, Wood, and Drainoni (2006b) pointed to a historical lack of efforts to link HIV primary care with substance abuse treatment. They (Tobias et al., 2006a; Tobias et al., 2006b) conducted surveys to identify the degree and nature of services provided by Ryan White CARE Act grant recipients. Their 2006 surveys showed variability in the effective use of the funds. They noted that most grantees did use some of the funds to provide substance

abuse treatment for people with AIDS, but were not addressing identified obstacles to care.

Pollack, D'Aunno, and Lamar (2006) and Pollack and D'Aunno (2010) tracked how HIV-related care had been integrated into outpatient substance abuse programs between 1995 and 2005. They found that outpatient substance abuse treatment programs had indeed included HIV-related preventive measures, especially testing and behavioral counseling. While those services were provided for clients in treatment, there was a lack of outreach efforts. They found a variability of offerings, and the offerings depended on the percentage of IDU clients (higher risk), resources available, and external and internal organizational support. In the later survey Pollack and D'Aunno (2010) confirmed that the availability and offering of T+C in outpatient substance abuse treatment clinics had remained stable. They noted, however, that still only a minority (29%) of clients had actually been tested in that setting. They identified the barriers to higher rates of utilization as high ratios of clients to staff, incomplete needs assessments, and inconsistent use of clinical protocols that include HIV assessment. Spector and Pinto (2011) pointed to *culture-based countertransference* as another obstacle. They suggested that substance abuse counselors were reluctant to address HIV-related issues due to biases against clients with different sexual behaviors, especially those engaged in same-sex behavior.

Abraham, O'Brien, Bride, and Roman (2011) noted literature that suggested publicly funded substance abuse programs were more likely to offer HIV related services. They surveyed privately funded treatment facilities to characterize HIV-related services in that setting. They found a greater likelihood of service availability in hospital-based

settings, other settings where medical services were available onsite, and settings with higher percentage of African American patients.

Rather than look at HIV services offered by substance abuse programs, Pisu et al. (2010) studied an urban HIV clinic to characterize the substance abuse offerings and clinical outcomes of providing such treatment. Unfortunately, and contrary to intuition, they found that in spite of utilizing substance abuse treatment, there was no significant effect on the clinical indicators of HIV disease progression. They saw no improvement in either CD4 T-cell counts or HIV viral counts. This finding may be limited by the focus on a single clinic where clients are already accessing medical care. Nevertheless it raises fundamental questions about the presumed link between substance abuse treatment and HIV-related medical or behavioral outcomes. Could this represent another case of theoretically sound strategies that are practically ineffective? On the other hand, might the value of linking HIV services and substance abuse treatment be found in preventing high risk behavior to reduce transmission, rather than as an adjunct to medical treatment of those already infected?

Substance abuse has been linked to increases in high risk sexual behaviors. Suggested explanations include drug and alcohol lowering inhibitions, lowering desire or ability to use condoms, impairing judgment, or link with sensation-seeking behavior, all which can increase the likelihood of high risk sexual behaviors (Jones, 2004; Mitchell & Oltean, 2007; Palepu et al., 2005). The literature documents substance abuse treatment strategies targeted primarily at prevention of further HIV transmission, other strategies targeted at improving medical outcomes for those already infected, and integrated approaches designed to address both issues. There has been a modest preponderance of

attention paid to prevention strategies targeting links between substance abuse and high risk sexual behaviors. To address high risk behaviors in substance abusing PLWH, a variety of behavioral change strategies have been employed, with mixed results.

Palepu et al. (2005) reported that substance abuse treatment was ineffective at lowering sexual or drug use risk behavior among a study population of HIV+ alcoholics. They hypothesized that addressing risk prior to infection may be more potent as the risk is personal, while addressing risk after infection risk may be less potent because it requires attention and concern for others. Stevens, Leybas-Amedia, Bourdeau, McMichael, and Nyitray (2006) combined substance abuse prevention and HIV prevention trainings with youth. They reported no change in substance abuse or sexual risk behaviors. They did show improvements in measures of self-esteem, which, while presumed to be related to the risky behaviors, did not translate into behavioral change in measured drug use or sexual activity.

Addressing the difficulties in bringing about behavioral change in spite of the widespread availability of interventions, Mitchell and Oltean (2007) noted that many substance abusers remained unaware of how to protect themselves. Their research examined substance abuse counselors' knowledge, ability, and willingness to include HIV prevention practices in their treatment approaches. Half the counselors they surveyed admitted to being dissatisfied with their level of HIV knowledge. They and others (Daughters, Magidson, Schuster, & Safren, 2010) suggested that the role of HIV risk assessor may not seem consistent with providers' primary identity or training as substance abuse counselors. The researchers suggested that counselors could enhance



their effectiveness by acquiring more HIV training and taking on more of an educational role with clients.

Other studies have reported more effective outcomes in risk-reduction. St. Lawrence, Crosby, Brasfield, and O'Bannon (2002) showed success when an HIV risk-reduction intervention was integrated with residential substance abuse treatment for youth. They utilized a combination of psychoeducation and behavioral skill training. Likewise, Copenhaver, Lee, and Margolin (2007) demonstrated effective behavioral changes in their study participants when adapting a manualized behavioral intervention aimed at helping outpatients in community-based substance abuse treatment decrease HIV-related high risk behavior. Their report commented on the differences between evidence-based practices developed in the research setting and the real-world implementation of such approaches. They attributed their success to having substantially modified and simplified the manualized treatment, adapting it to the realities of treatment in community-based settings. Wong et al. (2008) reported success with a 15 session case management approach to decrease substance abuse among PLWH. Their objective in treating the substance abuse was to indirectly decrease high-risk sexual behavior (transmission prevention). Meta-analysis showed HIV risk-reduction interventions combined with substance abuse treatment produced better outcomes than substance abuse treatment alone (Jones, 2004).

Besides substance abuse treatment strategies targeted primarily at prevention of further HIV transmission, strategies have been reported that prioritize improving medical outcomes for those already infected who have a co-morbid substance abuse problem. Substance abuse interferes with access to medical care as well as adherence to medical

treatment, including medication regimens (Andersen et al., 2003; Proeschold-Bell et al., 2010; Willinger, 2010). Andersen et al. described an application of a nursing model of care with HIV+ substance abusers. The model they implemented assumed that treating the client for substance abuse issues would indirectly facilitate all forms of self-care, including better compliance with medical treatment for HIV.

Several researchers have described the complexities of treating clients with dual or triple diagnoses (Daughters et al., 2010; Proeschold-Bell et al., 2010; Willinger, 2010). Willinger addressed treating those with HIV, substance abuse, and personality disorders. She criticized primary care providers (PCPs) for not appreciating the barriers to medication adherence created by co-occurring substance abuse and mental health illnesses. She also pointed out the potential negative impact that providers' countertransference may have when dealing with clients with personality disorders. Daughters et al. described similar complexities for those with HIV, substance abuse, and depression. Both of the above researchers described how they integrated multiple existing interventions to address a complex client situation. They described using a combination of cognitive behavioral therapy (CBT) for mood, personality issues, and medication compliance, and harm reduction, stages of change and motivational interviewing for substance abuse. They deemed as critical the integration of interventions and coordination of services between providers. Note the focus of the interventions described above was not on prevention of transmission to others through behavioral change, but was intended for the direct and immediate benefit of the individual client and his/her health care.

A more pointed critique of systemic conflicts was provided by Tobias et al. (2005). They described the historical and cultural differences between substance abuse treatment and HIV medical care. They pointed out how common interventions within the two systems of care could be in conflict. For example, substance abuse treatment is often provided by peers in group settings, and programs often invoke strict behavioral requirements in order to maintain enrollment. Medical care, on the other hand, is provided by professional clinicians with a priority on maintaining patient engagement with treatment, including harm-reduction approaches. Tobias et al. and Proeschold-Bell et al. (2010) advocated for systems-level interventions to facilitate a coordinated and integrated approach.

**Diverse ethnicities.** By the late 1980s and early 1990s AIDS had become the leading cause of death among young males of all ethnicities in New York and New Jersey, with the heaviest impact upon African Americans. Likewise, in the same geographical area it had become the leading cause of death among African American females aged 15–44 (Spigner, 1993). During the same period, HIV infection was increasing in the Latino population and was predicted to become a major problem (Flaskerud, Uman, Lara, Romero, & Taka, 1996).

Researchers cautioned against focusing prevention efforts on individual behavior without considering the impact of cultural attitudes and sexual practices (Flaskerud et al., 1996; Spigner, 1993). They urged consideration of socio-cultural factors including poverty, discrimination, and risk of deportation in the case of Latinos (Flaskerud et al., 1996; Spigner, 1993).

Flaskerud et al. (1996, 1997) focused on documenting challenges to HIV prevention efforts within the Latino community. They pointed to particular implications of machismo attitudes, which included expectations that men would have a high level of sexual activity and a wide variety of sexual practices with many partners. While male-to-male sexual contact might be prevalent, machismo men would likely conceal that activity due to homophobia within Latino culture. Such men would probably not consider themselves to be gay, and would have sex with women as well. This behavior was the presumed source of most heterosexual transmission of the virus, as condom use was not considered to be macho. Flaskerud et al. (1996) acknowledged that modifying sexual behavior that is based on long-standing cultural attitudes would pose a great challenge.

Writers and researchers continued to elaborate on the need for cultural and systems-level perspectives when addressing HIV prevention and treatment. Parker (2001) noted the general failure of behavioral, medical, and individual psychological interventions to significantly impact sexual behavior. He noted the silence of anthropological research into HIV, in spite of anthropology's theoretical strength in studying complex problems embedded within variable sociocultural settings. He identified the lack of fully appreciating the sociocultural meanings of sexual behavior as a constraint on the effectiveness of two decades of behavioral and medical approaches to HIV prevention and treatment.

Researchers continued to broaden and deepen the definitions and implications of culture and sub-culture when it came to HIV. Parker (2001) and Harper (2007) both encouraged a broader definition of culture, to include more than race and ethnicity. Parker noted that although the AIDS epidemic had begun in the homosexual community,

gay subculture had been neglected in much of the subsequent formal research and prevention efforts. He noted that the majority of prevention programs have been targeted at heterosexual communities. He pointed out that gay culture included a distinct and complex set of behavioral norms regarding sexual identity, communication, and negotiation of sexual encounters.

With an evolving appreciation of cultural nuance, researchers generally maintained racial, class, and ethnic categories while looking deeper at sub-cultures of populations studied. A number of researchers addressed how HIV should be addressed in Latino, African American, and Native American populations.

Russell, Alexander, and Corbo (2000), West (2001), and VanOss Marin (2003) identified how specific Latino cultural values combined with external forces such as homophobia, racism, and poverty to influence HIV risk among Latinos. They described how traditional gender roles (machismo), sexual silence (taboos against discussing sexuality), and age differences in sexual partners, generally older males with young females, were culturally intrinsic contributors to power imbalances in sexual relations. West pointed out how the Catholic Church's traditional views of women and injunctions against the use of condoms contributed to the mix. These were seen as barriers to Latina women's ability to assert themselves in demanding safer sexual behavior from partners. Those intrinsic factors were seen to combine with extrinsic discrimination to contribute to a general disempowerment of Latinos, especially Latina women.

Russell et al. (2000) and West (2001) both acknowledged the difficulty, and perhaps the futility, of either encouraging assertive behavior that is contrary to longstanding cultural traditions or overturning religious and cultural values. They

encouraged researchers to gain a thorough understanding of Latino culture in order to develop culturally appropriate assertiveness skills training. West also repeated earlier suggestions by Yeakley and Gant (Yeakley & Gant, 1997, as cited in West, 2001) to disconnect education and training programs from the Catholic Church, and to reframe responsible behavior in culturally appropriate terms. Examples of how to do this included using pharmacists, barbers, or other community resources to distribute condoms with a message that using a condom is “the ‘macho’ and ‘manly’ thing to do” (p. 37).

In an interesting parallel, researchers working with young African Americans, especially young girls, identified similar needs for culturally sensitive ways to encourage assertiveness and reframing the use of condoms (Horner et al., 2008; Shambley-Ebron, 2009). They both mentioned that younger girls are more likely to begin having sex at an early age and with older males. Shambley-Ebron described an intervention based on indigenous concepts of African womanism and African worldviews to induce individual empowerment through boosting self-esteem and cultural pride. Horner et al. focused on both male and female urban African American youth, emphasizing the need to understand the nuances of the rules of interpersonal relationships in urban adolescent sub-culture in order to encourage delays in initiating sexual relationships and the use of condoms.

Similar concerns for culturally-aware interventions were suggested in a setting quite distinct from urban population centers. Duran et al. (2010) identified historical barriers to HIV treatment in rural tribal settings of Native Americans. They pointed out that a history of forced assimilation had contributed to the breakdown of American Indian culture, and had generated a long history of mistrust. In particular, they described past

government programs that were presented ostensibly to help but were out of touch with tribal customs and culture. They warned against being unaware of or unconcerned with the history of negative interactions between whites and American Indians.

Levy et al. (2007) surveyed a sub-culture of Latinos, namely, recent immigrants in Northern California to understand apparent delays in seeking treatment for opportunistic infections due to HIV. They identified barriers such as a lack of HIV knowledge, social stigma, secrecy, and waiting for the appearance of symptoms to seek treatment. They reported that immigrants were 6 times more likely to delay seeking treatment than native born Latinos

**Others.** Blood banks began screening donors and donated blood when it was recognized that blood from infected donors could transmit the virus to transfusion recipients. Following recommendations by CDC and WHO, and FDA licensing of test methods, mandatory screening of donated blood began in 1985 (FDA licensed testing, 1986; WHO recommendations, 1985). Miller, Donegan, Curran, and Shelley (1990) documented that in spite of several years of widespread education, both blood donors and transfusion recipients were poorly informed regarding risks of HIV transmission. He recommended ongoing and specific education for those groups.

Carey, Weinhardt, and Carey (1995) collected data from nine studies showing that infection rates within the seriously mentally ill population were greater than in the general population, with the homeless at highest risk. They recommended developing enhanced and specific HIV-related services for this population.

Pagliari and Pagliaro (1992) raised concerns regarding HIV in prison populations. They noted the extremely high rates of infection within prisoners, and that AIDS was the

leading cause of death among inmates at that time. Homosexual behavior was not the major risk factor. Rather, they identified the sharing of needles for male prisoners and pre-incarceration prostitution among females as primarily responsible. The authors urged prevention steps be taken, including the possibility of mandatory testing of inmates and prison staff.

### **Testing**

The ability to test for exposure to HIV became one of the central aspects of HIV diagnosis and prevention efforts. Testing's central role in HIV management, and the significant personal impact of testing positive, created an early and long-standing connection between testing and counseling (T+C). Counseling in this sense is not the same as psychotherapy. Nevertheless HIV counselors have been called upon to provide the bulk of psychological support to the millions of individuals ultimately being tested. Most testing efforts have been aimed at prevention and have included some degree of psychoeducational counseling (Kelly & St. Lawrence, 1990; Phillips & Coates, 1995). The CDC encouraged education campaigns similar to those that had been previously developed to address sexually transmitted disease (STD) prevention (Grace, 1994). Modest change had been documented when testing and counseling were combined (Kelly & St. Lawrence, 1990; Landau et al., 1995). The success of such efforts, however, was minimal relative to the widespread educational efforts underway at that time. Serious doubts about the efficacy of psychoeducational counseling arose as social scientists witnessed ever-increasing infection rates in the midst of increasing rates of knowledge of transmission (Flaskerud et al., 1997; Gallagher et al., 1997; Kelly & St. Lawrence, 1990;



D. J. Martin, 1989; McCornack, 1993; Norton, Miller, & Johnson, 1997; Otten, Zaidi, Wroten, & Witte, 1993; Phillips & Coates, 1995).

The essential failure of educational campaigns to curtail high-risk sexual behavior led researchers to look deeper in order to identify factors that might influence safer sex practices (Salt, Boyle, & Ives, 1990). Educational programs were criticized for adopting simplistic approaches suggesting *safe practices* and *partner discussions* (McCornack, 1993). Salt et al. (1990) noted that most interventions at the time were limited by their emphasis on individual behavior, without taking into consideration wider contextual factors. Researchers began to appreciate the complex social systems in which sexual behavior, and therefore HIV, was a part (Bor, 1995; Hinman, 1991; Kelly & St. Lawrence, 1990; Phillips & Coates, 1995; Salt et al., 1990).

Education, the simplest and easiest approach (Kelly & St. Lawrence, 1990; Landau et al., 1995) was recognized as insufficient to the task. Researchers called for a broader range of interventions (Doll et al., 1990; Gaines, 1988; Hinman, 1991; Lorion, 1990). Acknowledging the complexities, social scientists began calling for strategic changes in HIV psychoeducational efforts. Suggestions included evaluation of individual readiness for behavioral change (Lorion, 1990; Martin, 1989; Norton et al., 1997), use of peer-group pressure and social learning methods (Kelly & St. Lawrence, 1990; Landau et al., 1995; Martin, 1989; Silverman, Perakyla, & Bor, 1992), and using psychotherapy research to improve counseling practices (Grace, 1994; Lorion, 1990).

**Psychological impact.** After scientists isolated and identified the specific virus responsible for HIV, it quickly became possible to screen individuals for exposure to the virus through the use of an antibody screening test. In the early days, test results

themselves had a potentially dramatic impact on an individual's life. Counselors and individuals attempted to balance legitimate public health concerns for containing the spread of disease with individual concerns for preserving privacy, lifestyle, and civil rights (Dlugosch, Gold, & Dilley, 1986; Goldblum & Seymour, 1987). Reluctance to undergo testing seemed reasonable, as people who tested positive were losing jobs, housing, insurance, families, partners, and friends (Goldblum & Seymour, 1987; Nelson & Jarratt, 1987). There was a natural distrust of the use of the test results. Individuals sought counseling to decide whether or not to be tested. Guidelines were established to facilitate decision-making and to assist in coping with results. Mental health professionals were advised to get the facts about the test in order to provide accurate information to a client, to understand the benefits and the risks of the test, to guide the client through a decision-making process, and to create an action plan to respond to positive results (Dlugosch et al., 1986; Goldblum & Seymour, 1987; Price, Omizo, & Hammett, 1986).

Initial reactions of testing positive often included shock, anger, panic, sleep disturbance, and sexual dysfunction (Dlugosch et al., 1986; Grant & Anns, 1988; Nelson & Jarratt, 1987; Price et al., 1986). Clinically, the distress could range from mild to full-blown anxiety or depressive disorders (Goldblum & Seymour, 1987; Nelson & Jarratt, 1987). Counselors were instructed to assess clients' perceptions of risk, degrees of anxiety, ability to cope, existing support systems, and drug and alcohol use (Dlugosch et al., 1986; Grant & Anns, 1988). Because of the multiple implications of testing positive for HIV, Dlugosch et al. (1986) emphasized the need for a non-directive process, and reminded counselors that the decision to test or not belonged to the client. Likewise, Goldblum & Seymour (1987) urged counselors to examine their own biases for or against

testing during the decision-making process. They noted that it might take several sessions before the client became ready to make a decision. For counselors who were responsible for delivering the test results, Dlugosch et al. (1986) suggested that the results be presented in a straightforward manner, with active listening, allowing clients to have their own reaction. Part of the disclosure session was to include appropriate referrals, especially to support groups (Dlugosch et al., 1986; Grant & Anns, 1988).

Those who tested positive moved from an initial short-term crisis reaction to the process of managing longer-term implications of such a diagnosis. In addition to the existential issues surrounding mortality and grief, psychotherapeutic interventions focused on a long list of adjustment difficulties, including anger and stress management, coping skills, abandonment and isolation, depression, guilt, spiritual alienation, relationship issues, and sexual functioning (Grant & Anns, 1988; Nelson & Jarratt, 1987; Price et al., 1986; Vitiello, 1987).

With early emphasis on gay male populations, Grant & Anns (1988) emphasized the impact that an AIDS diagnosis at that time could have on self-esteem and sexual identity, noting the power of a diagnosis that combines issues of sex and death. They pointed to the risk of regression in the coming out process, a re-emergence of past issues, and advised that substantial time in counseling can be spent affirming gay identity. Price et al. (1986) likewise recommended counselors accentuate the humanism in gay male bonding.

Nelson & Jarratt (1987) recognized the impact of an AIDS diagnosis on the individual as well as “the rippling effect” (p. 484) on an individual’s larger social sphere. They described a therapy program that included crisis intervention, psychotherapy,

psychiatric consultation, and various group therapy offerings. Separate groups included people with AIDS, parents of people with AIDS, and parents of gays. They also noted that a patient's close community often experienced similar reactions to a positive test result, including fear, anxiety, depression, and guilt.

Apart from the focus on efficacy of T+C strategies on prevention, researchers continued to note the psychological implications of learning one's serostatus. A range of reactions was noted, from denial, stunned shock and silence, to anxiety, angry outbursts and tears (Gaines, 1988; Hicks & Rundell, 1996). Sherr and Hedge (1990) and Beevor and Catalan (1993) noted that the distress associated with testing could even lead to suicidal ideation and behavior. Such reactions were characterized as normal and expected (Hicks & Rundell, 1996; Martin, 1989; Sherr, Davey, & Strong, 1991). The role of counselors began to shift from being providers of psychoeducational information toward becoming providers of safe havens and emotional support (Hicks & Rundell, 1996). Miller, Bor, Salt, & Murray (1991) suggested that time invested in counseling upfront might reduce time spent in subsequent crisis response.

By the later years, researchers and practitioners had gained much experience in the broad processes and issues regarding HIV testing. Myers, Worthington, Haubrich, Ryder, and Calzavara (2003) identified the *best practice* components of the testing process as including the following elements: education, individual behavioral risk assessment, delivering results face to face, providing appropriate referrals, and easing the process of partner notification. However, writers continued to encourage awareness of and appreciation for the complexities of the overall testing process, including especially the broader social implications. Mattson (1999) criticized prior CDC guidelines (from

1994) as ineffective and out of touch with real-world clients and situations. In particular, the guidelines were criticized for being too removed from the human situation, and not truly client-centered in spite of prior recommendations. Obermeyer and Osborn (2007) and Anaya et al. (2008) echoed those criticisms of testing practices, adding that social factors continued to complicate patient receptivity to T+C. They emphasized that testing was not a uniform process, and that differences in intent and setting must be considered. Important contextual distinctions were cited, such as mandatory vs. voluntary testing, or medical diagnostic testing vs. epidemiological surveillance. The situational diversity of the real world made for difficulty in defining and implementing effective broad guidelines and training (Sheon, Lee, & Facente, 2010).

Koo, Begier, Henn, Sepkowitz, and Kellerman (2006) attributed some of the problems with testing to processes based on a traditional conservative model that had been adopted from practices used for genetic counseling for untreatable conditions. Consistent with those models, laws had been developed that required complicated pretest counseling, in spite of the lack of evidence that pretest counseling had any significant positive effects on behavior. Multiple researchers commented on the low rates at which patients returned for their test results (Ekwueme, Pinkerton, Holtgrave, & Branson, 2003; Obermeyer & Osborn, 2007; Smith, Buzi, & Weinman, 2005; Spielberg, Branson, Goldbaum, Kurth, & Wood, 2003). In addition to the simple distaste for waiting, explanations included psychosocial factors including fear of stigma associated with testing itself, as well as anticipated stigma associated with a positive result such as the potential need to take medicines or inform sex partners. Mattson (1999) criticized what passed for counseling as being overly judgmental, blaming, and guilt-provoking. Failure

to test or return for testing was blamed for many infected people remaining undiagnosed or diagnosed late after symptoms began to appear (Anaya et al., 2008; Koo et al., 2006). Smith et al. (2005) tested the hypothesis that a pre-test assessment and discussion of risk factors would motivate patients to return for test results. They found that the assessment had no impact on rates of return for test results. These complications prompted Koo et al. to advocate for simplifying the process, requiring simple verbal informed consent for testing, and moving counseling from pre-test to post-test for those found to be HIV+. Simple knowledge of risk factors and prevention measures, even coupled with an HIV negative test result, had not been shown to effectively change sexual behavior. They noted evidence showing that an HIV+ test result was one of the few conditions that preceded behavior change.

Efforts to improve T+C processes received more focus as the CDC revised their guidelines in 2006 (Branson et al., 2006) in which they recommended routine testing of all general medical patients. In order to facilitate the recommendation to broaden testing, major revisions to the guidelines included streamlining the process by eliminating the need for a separate written consent and dropping the requirement for prevention counseling as part of the testing process.

Such broad testing recommendations resulted in efforts to enhance the efficiency and effectiveness of associated processes. Sheon et al. (2010) described a method to streamline the process by utilizing an electronic assessment of risk behavior to be performed prior to face-to-face counseling. Separating that data gathering from the personal encounter with a testing counselor reportedly improved both the efficiency as well as quality of counseling. Researchers investigated the use of rapid testing methods in

order to overcome obstacles to delivering test results (Anaya et al., 2008; Ekwueme et al., 2003; Obermeyer & Osborn, 2007). Ekwueme compared the cost effectiveness of various approaches to testing in medical settings, and described efficiencies and effectiveness of simpler rapid testing protocols.

Simplifying informed consent, altering the sequence of counseling from before to after testing, and implementing cost effective rapid testing methods served to facilitate implementation of CDC's recommendation to broaden testing. Nevertheless, new protocols were not without complaint. Criticism included familiar themes regarding the failure of such economically and epidemiologically broad efforts to address the personal and social impact of testing. Sheon et al. (2010) noted that rapid testing increased workload on counselors due to increased paperwork and laboratory tasks. They identified the protocols as up-front obstacles to rapport building with clients when it is most important and most available. Mattson (1999) similarly criticized then-current approaches as too clinically based, more "information giving" than "knowledge sharing" (p. 334) and recommended a reemphasis on client-centered approaches. She recommended a harm reduction approach to break from the traditional medical model of doctor to patient interaction, favoring a more egalitarian, nonjudgmental, and collaborative process between client and counselor.

It seems that there will continue to be tension between the need for efficient broad testing of general populations and the responsiveness to the sensitive nature and contextually unique needs of individuals receiving what remains potentially life-threatening and most certainly life-changing news.

**Prevention efforts.** Widespread testing for HIV was initiated in large part to promote change in high risk sexual behavior (Otten, et al., 1993). Because testing was viewed as an essential component of prevention efforts, there were calls for routine mandatory testing in many situations (Beardsell, 1994). Evaluation of testing efforts looked at the behavioral and psychological impact of testing (Doll et al., 1990). At that time, the effect of testing on behavior was unclear (Doll et al., 1990; Otten et al., 1993). Beardsell (1994) cautioned against widespread testing for prevention based on a lack of evidence. Balmer (1992) explained that modifying sexual behavior is difficult due to the private nature of sex, the taboo nature of discussion, and the context of longstanding cultural traditions in which sexual behavior is embedded. Balmer surmised that educational sessions are unlikely to generate long-term behavioral changes, even when the information is clearly grasped.

Beardsell (1994) elaborated on the complexities between behavior and T+C efforts of the time. She critiqued the assumption of a linear relationship between the two, and explained that behavior is complicated and flexible, ranging between safe and unsafe practices and depending on many factors. Doll et al. (1990) determined that simple awareness of one's serostatus was not sufficient to generate behavioral changes. Evaluating the wisdom of routine testing of pregnant women, Meadows et al. (1990) noted that no relationship had as yet been found between awareness of serostatus and behavior change in other populations. Liebman et al. (1996) interviewed test participants after they had learned of their status, and reported that very few indicated any intention of changing behavior, regardless of whether the test was positive or negative. Gaines (1988) found that those who tested negative were somewhat unwilling to discuss behavioral



methods of lowering risk. Some researchers found that a negative result might even lead to higher risk behavior, based presumably on an irrational sense of personal immunity (Otten et al., 1993; Sherr & Hedge, 1990). That led some writers to question the practice of routine testing of low-risk populations (Liebman et al., 1996).

Though there were no calls to abandon testing altogether, behavioral researchers began to view as naïve the idea that long-standing sexual behaviors could be influenced by the simple awareness of one's serostatus (Beardsell, 1994; Kelly & St. Lawrence, 1990; Phillips & Coates, 1995).

As stated above, T+C had been used for a variety of purposes, including initial diagnosis, epidemiological screening and surveillance, and as a component of broader prevention efforts, often tied to education campaigns. Weinhardt, Carey, Johnson, and Bickham (1999) identified T+C as the most widespread and costly effort directed at prevention. They noted that sexual behavior remained the primary mode of transmission, and joined others continuing to point out the body of literature documenting the psychosocial, gender and cultural complexities of sexual behavior (Ickovics et al., 1998; Weinhardt et al., 1999). Researchers continued to confront the failure of the original and primary assumption that risk assessment and education would drive change in risky sexual behavior (Ickovics et al., 1998). It had repeatedly become clear that lack of knowledge was simply not the problem. Gay and bisexual men in particular were well educated about the risks, modes of transmission, and mechanics of condom use. Knowledge and safe sex attitudes were continually found to be inadequate to drive behavioral change (Coury-Doniger, Levenkron, McGrath, Knox, & Urban, 2000; Rutledge et al., 2001). Focusing on women, Ickovics et al. (1998) documented the failure

of T+C to drive behavioral change. They noted however that compared to untested women, tested women were more anxious, more depressed, and battled more intrusive thoughts regarding their risk of acquiring HIV. As education alone had not produced the expected behavioral changes, psychological researchers pointed out that the simple models had not been informed by behavioral science theory (Coury-Doniger et al., 2000; Weinhardt et al., 1999). They pointed out that in addition to information, individual motivation and skills were necessary components to behavioral change (Ickovics et al., 1998; Kalichman et al., 2005).

Prevention efforts in the last decade have been influenced by the effectiveness of anti-HIV medications. The success of medication regimens has meant that there are many HIV+ people living longer who remain sexually active (Rutledge, 2007). Despite the frustrations of decades showing that receiving negative test results had little to no generalized affect on behavior, it seems to have been the case that receiving a positive result had been more associated with decreases in risky behavior (Amaro, Morrill, Dai, Cabral, & Raj, 2005; Ickovics et al., 1998; Weinhardt et al., 1999). A paradoxical result of the effectiveness of medications, however, may have been a diminishing awareness and/or perception of risk among the uninfected, and a diminished vigilance among HIV+ individuals to prevent further spread (Rutledge et al., 2001; Rutledge, 2007). As a result, several researchers called for and noted a shift in prevention efforts by focusing on the HIV+ population (Golin et al., 2010; Rutledge, 2007). Indeed, the CDC had recommended such a shift in 2003 (Incorporating HIV prevention, 2003). It was noted, however, that interventions focused on uninfected populations did not translate well to already-infected populations (Golin et al., 2010; Rutledge et al., 2001; Rutledge, 2007).

Such interventions did not address issues unique to the positive population, including stigma, disclosure of status to partners or motivation to protect others (Golin et al., 2010). Prior approaches taken with HIV+ individuals were criticized as having had an attitude of *blaming the victim* (Gerbert et al., 2006; Rutledge et al., 2001; Rutledge, 2007). Coury-Doniger et al. (2000) pointed out that PCPs, those most involved in care and most available to counsel patients, had little knowledge or skills as behavioral health providers or counselors.

In response to calls both to focus on already infected individuals and to incorporate behavioral change theories, various theoretical approaches were suggested, including stages of change models and motivational interviewing techniques. Coury-Doniger et al. (2000) noted PCPs frustration with patients' resistance to behavioral change from traditional approaches. They suggested that a stages of change model could address providers' tendency to avoid confrontation with patient resistance, so long as the interventions were translated into appropriate language for PCPs to administer. Amaro et al. (2005) also pointed to the historical success of stages of change approaches and recommended integrating such a model when addressing HIV+ individuals. Based on similar theoretical underpinnings, Rutledge (Rutledge et al., 2001; Rutledge, 2007) and later Golin et al. (2010) pointed to motivational interviewing as a method to deal with patient ambivalence. Both pointed to the non-confrontational approach inherent in motivational interviewing, noting how important such an approach is with those in early stages of change readiness. Rutledge (2007) emphasized that an HIV+ population was likely already dealing with stigma, and may have experienced prior negative judgments and heavy-handed demands for behavioral change. Golin et al. added that motivational

interviewing had a good track record with health-related behaviors. They conducted a study of HIV+ participants' experiences when PCPs utilized a motivational interviewing approach. They reported that participants recalled having prior negative experiences with counselors and in spite of continued concern about counselor's attitudes there was a positive response to the overall content and experience of the motivational interviewing intervention.

Gerbert et al. (2006) focused on issues of trust between PCP and patient. In particular they warned that a shift of focus towards HIV+ populations would require confronting stigma. They suggested that PCPs would resist dealing directly with HIV+ patient's behavior due to fear of stigmatizing patients and thereby eroding trust. Of particular concern was the possibility of dealing with partner notification and PCPs duty to warn. This was a reasonable concern as HIV+ individuals were being prosecuted for failure to notify sexual partners of their status. Mattson and Roberts (2001) described controversial ways in which deception, rather than disclosure, might be employed as a way to help HIV+ patients initiate safe sex practices with primary sex partners who were unaware of the patient's status. Gerbert et al. (2006) warned that any interventions that pose a threat to PCP/patient trust and relationship would not succeed. They recommended shifting the conversation away from preventing danger to others and focusing instead on general health benefits of safe sex behavior to the individual patient. Such a strategy was hypothesized to preserve a trusting relationship by focusing the conversation on the individual patient while indirectly encouraging behavior that would prevent the further spread of HIV.

Consistent with efforts to streamline testing procedures, brief models of counseling for prevention were suggested. Shorter counseling sessions were theorized to be potentially effective based on a history of effectiveness in other situations such as alcohol use (Kamb et al., 1998). Several studies did indeed demonstrate some effectiveness of relatively brief interventions (Belcher et al., 1998; Gibson, Lovelle-Drache, Young, Hudes, & Sorensen, 1999; Kalichman et al., 2005; Kamb et al., 1998). Aware of the poor track record of simple education-based interventions, while also studying streamlining the process, Kalichman et al. (2005) dissected a comprehensive approach to identify which individual components of HIV counseling were associated with behavioral change and which components might be discarded. They found that a comprehensive approach continued to produce the best outcome. According to them, effective interventions needed to include counselor provision of factual information combined with sufficient patient motivation and acquisition of behavioral skills.

Mattson (1999) had expressed similar concerns regarding the limitations of simple information-based interventions and their lack of basis in broader behavioral science theory. She explored the Health Belief Model (HBM) of behavioral change with regards to HIV. HBM research historically focused on mass media campaigns to change health behavior. Briefly the model describes the following components of change: (a) perceived risk appraisal, (b) perceived benefits and barriers, (c) perceived self-efficacy and (d) cues to action. She used an HBM to assess mass media campaigns and found them to be inadequate in their effectiveness in dealing with HIV. Mattson criticized mass media AIDS campaigns as being successful in improving *general awareness* of risk while lacking in effectively addressing *personal perceptions* of risk.

Earl and Albarracín (2007) and Mattson (1999) looked at the hypothetical and practical aspects of fear-based motivational efforts. While fear tactics seemed to increase immediate and personal perceptions of risk, they seemed to actually prohibit knowledge acquisition and safe sex behavior. Mattson hypothesized the mechanism of failure of fear-based approaches, suggesting that clients/patients reacted to minimize the distress of fear by immediately seeking to deny, avoid, and stop listening to the counselor. Earl and Albarracín suggested that rather than attempt to induce fear, efforts should be extended to reduce fear in order to facilitate receptivity to information, motivation, and skills-building components of more comprehensive interventions.

### **Psychotherapy**

The wide ranging psychological issues associated with the disease have been well documented. In the early years, emotional responses to living with HIV included fear and uncertainty (Bor, Miller, Goldman, & Scher, 1993), coping with loss (Bor et al., 1993; Martin, 1989; Peräkylä & Bor, 1990), including loss of control and feeling vulnerable (Bor et al., 1993; Coleman & Harris, 1989), and facing end of life decisions, death, and grief (Bor et al., 1993; Martin, 1989; Peräkylä & Bor, 1990). Social issues were documented, including changes in personal relationships (Martin, 1989), which may have included a loss of independence (Bor et al., 1993). Stigma, discrimination, and loss of social support were well known and commonly faced (Bor et al., 1993; Coleman & Harris, 1989; Levine, Bystritsky, Baron, & Jones, 1991; Martin, 1989; Sherr et al., 1991). Questions of identity, such as a re-emergence of internalized homophobia and low self-esteem (Martin, 1989) have often resulted in isolation and withdrawal (Coleman & Harris, 1989).

Difficulties coping with the emotional and social impacts described above generated a variety of psychiatric diagnoses. Anxiety disorders were common (Levine, 1995; Martin, 1989; Sherr et al., 1991), some included panic attacks, obsessions (Coleman & Harris, 1989) and posttraumatic stress disorder (Martin, 1989). Not surprising, Adjustment Disorder was the most frequent diagnosis (Bor, 1995; Levine, 1995; Levine et al., 1991). Depression was common, with specific symptoms including anhedonia, excessive guilt, addictions and increased self-destructive behavior and suicidality (Coleman & Harris, 1989; Levine, 1995; Martin, 1989; Sherr et al., 1991).

Medical issues and treatment were a further source of distress. These included pain (Bor et al., 1993; Peräkylä & Bor, 1990), sleep disturbances, appetite problems, nausea, and sexual dysfunction (Coleman & Harris, 1989). Early treatments for HIV were difficult and could include hospitalization (Levine et al., 1991; Martin, 1989; Sherr et al., 1991). As HIV progressed, some patients experienced neurological impairment, including difficulty concentrating and impaired judgment (Bor et al., 1993; Coleman & Harris, 1989).

Counselors that had been dealing with testing and psychoeducational efforts were often ill equipped to deal with the level of psychological distress encountered by their clients. Counselors initially faced challenges discussing sensitive issues such as sexuality and death (Peräkylä & Bor, 1990; Silverman & Bor, 1991). Sherr et al. (1991) encouraged counselors to be trained to at least recognize and begin to address anxiety and depression in HIV.

By the later years of the epidemic, clinicians had built on two decades or more of research that described the needs and challenges of providing psychotherapy to people

with HIV. Previous studies had documented the need for mental health services to this population. Bottonari and Stepleman (2009) noted studies suggesting that 50% of PLWH likely qualified for a diagnosis of mental disorder, and that 40% of them used illicit drugs other than cannabis. They identified typical presenting issues such as depression, anxiety, substance abuse, relationship distress, grief, and HIV-related stress. By these later years, many researchers were distinguishing the mental health needs of the early days from those of the current day (Farber & McDaniel, 1999; Frederick, 2004; Harding, Gray, & Neal, 1993; Pobuda, Crothers, Goldblum, Dilley, & Koopman, 2008; Rousaud et al., 2007). They noted that psychotherapy in the early years was often focused on coping with imminent death and pervasive loss. The arrival of effective medical treatment generated a shift from coping with a terminal illness to managing the day-to-day issues of living with a chronic illness.

Wallis (2004) attributed the availability of effective medication to creating an essentially new population—HIV *survivors*. Long-term survivors presented with a different and often more complex set of issues. Noting the broad spectrum of current needs, he suggested that while there may have been a typical person with HIV in the past, that situation had certainly changed. Frederick (2004) noted that while complicated grief and mourning still exist, an additional and new set of challenges faced those PLWH. He and others (Farber & McDaniel, 1999) listed the new set of issues associated with day to day problems: medication complications, side effects, and adherence; changes in issues regarding partner notification and negotiation of sexual behavior; changing self and role definitions, including social status change from *special* to *ordinary*; and managing new possibilities in life, including regrets about past choices.



R. Harding (2003) noted new issues for parents of infected children who were now expected to live. He noted research detailing parents' fears of disclosure and stigma, and expectations of long-term emotional distress among their infected children. Garcia, Forrester, and Jacob (1998) noted that providing therapy to HIV+ survivors brought a new set of ethical issues as well, including career decisions and workplace issues, sexual decision-making among clients and therapist duty to warn. They noted that some earlier ethical issues remained salient such as those around death, suicide, and assisted suicide.

### **Coping with death.**

**Mortality.** Lack of available treatment for AIDS in the early years led to exponential growth in rates of infections and deaths. In those days, exposure, as revealed by a positive antibody test, was interpreted as a certain death sentence (Ferrara, 1984). The certainty of death was combined with unpredictability in timing and processes of dying, and hopelessness due to a lack of effective treatments (Hanson, 1986). Psychological literature included discussions of existential concerns such as anxiety regarding mortality and coping with multiple losses (Grant & Anns, 1988). Individuals and families were left to cope with the death of many young people. In response, psychological literature included descriptions of grief processes (Shearer & McKusick, 1986), and included interventions directed towards helping AIDS patients search for meaning in their condition (Nelson & Jarratt, 1987). Some infected individuals facing a progressively debilitating disease sought *death with dignity*, and counselors advocated sensitivity to this right when dealing with AIDS-related suicide assessments (Goldblum & Moulton, 1986).

Individual and community response to AIDS was characterized by fear. Dubbed “afrAIDS - an acute fear regarding AIDS” (Redouty & Brady, 1986, p. 17), it represented the fear of contagion and death. Psychological literature attempted to address the fears on an individual basis and on a community basis by summarizing existent knowledge and battling myths, especially myths about modes of transmission (Batchelor, 1984; Carter, 1986). Throughout its history in the United States, AIDS has had the most devastating impact on the gay male population. Psychologists focused early writings on efforts to minimize the misperceptions, stigma and fear associated to what was seen as a modern-day black plague, primarily striking the gay population (Ferrara, 1984; Morin, 1984).

*Anxiety.* Much of the psychological literature during the late 1980s and into the mid 1990s continued to focus on death, the processes of dying, and how to help those infected and affected by HIV to cope with what was seen as an inevitable outcome. Initial drug therapies were introduced during this period. Azidothymidine (AZT) was the first drug approved for treatment of AIDS in the US, and received federal approval in 1987 (Molotsky, 1987). Not a cure, and with significant side effects, the initial treatments did at least prolong the survival of some patients. Longer, yet still ultimately limited survival, meant that AIDS patients had an opportunity to explore and attempt to resolve deeper questions. Existential concerns such as confronting mortality, creating meaning, leaving a mark on the world, and even designing *a good death* became important themes in therapy (Hines & Peura, 1995; Krupnick & Shill, 1989; Templer & Greer, 1996).

Templer and Greer (1996) encouraged a clinical understanding of death anxiety— anxiety focused on illness and death. Hines and Peura (1995) described common defenses against that anxiety, including denial, anger, and depression. Krupnick and Templer

(1989, 1996) suggested that helping clients manage the natural stress of receiving a terminal diagnosis involved clients establishing some level of knowledge about their disease, performing a life review, and developing a non-obsessive preparation for death. Follansbee (1996) also noted that death with dignity requires preparation. Peräkylä and Bor (1990) explained some of the difficulties associated with such preparation, noting that talking about fears of death is not easy and pointed out cultural taboos against such discussions. Bor et al. (1993) added to the list of difficulties by noting that most HIV+ people were young, facing a shortened life-span, and had little hope for the future.

***Process of dying.*** Faced with the certainty of clients' ultimate and usually premature death, clinicians were encouraged to understand the process of dying itself. Stage theories, such as those popularized by Elisabeth Kübler-Ross (Gaies & Knox, 1991; Jones & Dilley, 1993), were recommended as helpful frames of reference. Follansbee (1996) described the extended path toward disability and death as beginning with the positive antibody result. He distinguished psychological dying from physical dying, and described the psychological impact as the beginning phases of the overall process.

He and others (Follansbee, 1996; Gaies & Knox, 1991; Rose, 1996) recommended against postponing death-related conversations, and against denying the realities of the situation. They suggested that counselors communicate clearly regarding the limitations of treatments, and acknowledge the approach of death gently but clearly. Within the limitations of existing treatment protocols, Gaies and Knox (1991) suggested reducing stress and fostering a realistic sense of the situation in order to generate whatever sense of control was possible. Hines and Peura (1995) recommended framing

the process of dying as a meaningful stage of life, even though patients might initially refuse such a view. Peräkylä and Bor (1990) encouraged the early discussions of death preparations so that patients would be less likely to cut off social supports in the process.

Psychologists were aware, and warned, of the difficulties in having such conversations. Besides the natural difficulties of discussing impending death, it was noted that the process of dying from HIV was complicated by stigma, blame, youth of the populations, memories of others' death, lack of support/abandonment, and the sense that for HIV patients, death equaled a failure (Follansbee, 1996; Gaies & Knox, 1991; Hines & Peura, 1995). Because issues might vary between individuals, therapists were encouraged to be flexible in their approach, not to rely on pat techniques. Openness regarding traditional boundaries was encouraged, including openness around physical contact and respect for non-traditional family members (Gaies & Knox, 1991; Hines & Peura, 1995; Rose, 1996).

Therapists were warned that engaging in such conversations with these patients would require confrontation with the therapists' subjective and troubling responses, including feelings of helplessness and anticipatory grief (Gaies & Knox, 1991; Hines & Peura, 1995; Rose, 1996). Gaies & Knox (1991) suggested that therapists should understand and appreciate these responses as normal, and that they should be accepted, supported, and not manipulated. They and Rose (1996) cautioned against therapist burnout during this process. Respecting the totality of the experience, they reminded clinicians to accept and complete the process by including some form of saying farewell to clients.

**Dignity.** Because a prolonged process of dying seemed a certainty for most clients, caretakers began to recognize and advocate for clients to make choices regarding the practical aspects of the process (Martin, 1988). Rather than adopt a simple passive attitude towards death, dying patients and their caretakers began to advocate for choices regarding where, when, and how one should die. Practical issues called for attention to issues such as insurance, wills, and power of attorney (Martin, 1988). This was occurring at the same time there was a broader effort to provide terminally ill patients with rights to make decisions about their own end-of-life choices. In June of 1990, Dr. Jack Kevorkian made headline news with his first assisted suicide (Belkin, 1990). Later that same year the Patient Self Determination Act was signed into law (United States, 1990). That act required informing patients of their rights regarding accepting or rejecting treatment (Hunt, 1992). Hunt encouraged physicians and therapists to hold discussions with their patients, and to support the difficulties around complex practical issues.

Movement toward advance directives and self-determination led to examining suicidality among AIDS patients, and in particular *rational suicide*. According to Motto (1994), in the decade between 1984 and 1994 suicide was the leading cause of death behind AIDS itself in this population. Jones and Dilley (1993) reviewed studies of the prevalence of suicide in this population and found mixed results. Their study showed that most AIDS patients at that time were supportive of a person's right to suicide. They also pointed out that suicidal ideation and depression in this population were not always linked. Dunshee (1994) framed the situation as presenting three possible choices to AIDS patients at the time: fighting the end, fighting to the point where quality of life is too far gone, or actively choosing to end their lives prior to suffering the ravages of full blown

AIDS. Self-determined and possibly physician-assisted, rational suicide became visible and non-stigmatized during this period. It was viewed as *death with dignity*, and as a *final right* (Dunshee, 1994; Jones & Dilley, 1993; Motto, 1994; Slome & Moulton, 1991).

Therapists were asked to help clients through such a decision-making process. Slome and Moulton (1991) identified challenges a therapist might face, including determining whether or not the decision was indeed a rational choice. They suggested that therapists explore the natural ambivalence of such a choice by guiding clients through a comprehensive review of their factual situation, and evaluating clients' mental status and motivations. Others suggested including an exploration of alternatives as well as evaluating the level of family support (Dunshee, 1994; Jones & Dilley, 1993; Motto, 1994). Martin (1989), Dunshee (1994) and Motto (1994) suggested that working through issues via a defined protocol would assist the grieving process of loved ones, helping families, partners, and friends come to terms with their loss. In spite of a desire for careful protocol, therapists were cautioned that what is deemed *rational* is often an intuitive judgment call, and that no reliable and entirely objective standard was in place (Motto, 1994; Slome & Moulton, 1991).

At the time, legal and ethical codes for therapists presented some challenges (Motto, 1994). The AIDS epidemic contributed to an evolution of the codes towards more tolerance of death with dignity, but at the time the ethical codes forbade active euthanasia (Slome & Moulton, 1991). Motto (1994) encouraged therapists to base their decision to assist not by adhering strictly to codes, but rather by humane principles of compassionate care. Therapists were cautioned to look closely at their own values, to manage natural countertransference, to remain non-judgmental and non-interfering (Jones

& Dilley, 1993; Slome & Moulton, 1991). Assisting a client through such a decision-making process was described as potentially worthwhile and rewarding when seen as providing the client with relief from ongoing suffering (Dunshee, 1994).

***Grief and coping.*** Regardless of the manner of death, during this period considerable attention was paid to the emotional toll from the mounting deaths among urban gay men (Burke & Miller, 1996; Grothe & McKusick, 1992; Martin, 1988; Schoen & Schindelman, 1988). Increasing yearly levels of depression were reported in San Francisco, with an anticipation of even higher levels as death rates escalated (Grothe & McKusick, 1992). Unfortunately, those at highest risk of death were the same people affected by witnessing multiple deaths in their own community and the same people serving as the primary support system (Martin, 1988).

Grothe and McKusick (1992) suggested that bereavement theory could help frame the problem and provide an appropriate therapeutic model. They described four progressive tasks of bereavement: to accept the reality, to experience the pain, to adjust to a new situation, and to reinvest energy in new relationships. However, a particular challenge was identified in the HIV community at that time. Grothe, McKusick and Martin explained that due to the frequent and widespread deaths that were occurring at that time, survivors were frequently unable to move beyond a stage of acute grief (Grothe & McKusick, 1992; Martin, 1988). Grothe and McKusick describe the numbness that follows an overwhelming flooding of grief. Equating the process to post traumatic stress disorder, a type of exposure therapy was recommended for those in a numbed state (Grothe & McKusick, 1992; Martin, 1988; Schoen, 1992).

Besides responding to challenges of overwhelming grief, psychologists were admonished to refine some theories in response to the particular psychological issues of gay men and AIDS (Kaal, 1992; Schoen & Schindelman, 1988). In particular, a *gay affirmative* therapy was suggested, which takes into account gay psychological development, relationships, struggle for identity, social positions, homophobia and stigma (Kaal, 1992; Schoen & Schindelman, 1988).

Along with the immediate impact to partners and other gay associates, other individuals and groups were attempting to cope with the magnitude of loss. Schoen and Schindelman (1988) described the complicated grief of parents coping with feeling responsible for both their child's gayness and therefore their subsequent death. They described how wives of AIDS victims were often confused, hurt, and angry.

Mirroring the response of individuals and families, service organizations were impacted and often unprepared for crisis (Santek & Kuller, 1992; Schoen, 1992). Many support organizations were staffed with HIV infected individuals, and therefore further stressed due to the fact that the support system itself was vanishing just when needed. Naturally the deaths were felt very personally. Schoen (1992) described the mixture of emotions of the survivors, including shock, helplessness, rage, and survivor guilt. Those left behind in service organizations exhibited behavioral symptoms at work related to the stress, including taking on increased responsibility, failing to set limits, working long hours, and not taking time off. Among the organizations, there was increased conflict, discord, blame, diminished morale and staff turnover (Santek & Kuller, 1992). Support organizations were encouraged to address the stress by encouraging staff to take more leave, set work limits, engage in quiet time as well as have social events. Administrators



were encouraged to set a tone of openness, allowing staff permission to grieve, to talk about feelings, and to give and receive peer support (Santek & Kuller, 1992; Schoen & Schindelman, 1988; Schoen, 1992).

**Theoretical approaches.** The psychological literature on psychotherapy theory and HIV is represented by traditional schools, including existential, humanistic, psychodynamic, cognitive behavioral, systems, and transtheoretical models. Early writings were not focused on theory per se, but had a natural emphasis on humanistic supportive and existential approaches. Later, in what might be a counterintuitive movement, given the shift of focus from *death sentences to life sentences*, proponents of existential, spiritual, or religious approaches were more strongly represented in the literature (Farber, 2009; Frame, Uphold, Shehan, & Reid, 2005; Holt, Houg, & Romano, 1999; Hopcke, 2004).

**Existential.** Existential themes run throughout the HIV literature. That may come as no surprise given some of the historical origins linking existentialism and the holocaust, and the parallel experiences of early 20<sup>th</sup> century European Jews and late 20<sup>th</sup> century PLWH. Shared themes include stigma, isolation, powerlessness, abandonment, widespread death, loss and bereavement, survivor guilt, and efforts to create meaning out of immense suffering. Existential psychotherapy provides a theoretical framework capable of containing the intensity and depth of such experiences.

In the midst of the focus on death and bereavement described above, it is not surprising that an existential approach would arise as a workable psychotherapy with HIV+ individuals. Burke and Miller (1996) believed that working with HIV+ clients required a more robust set of clinical skills, able to meet the challenge of intensity and

depth required to work with people facing death in the particular social milieu of the time. Other existentially-oriented writers concurred in doubting the efficacy of simple guidelines, suggesting that life is often more complicated, and that in the spirit of Victor Frankl, clients were to be helped to create meaning out of their suffering (Grothe & McKusick, 1992; Kaal, 1992; Milton, 1994; Schoen & Schindelman, 1988). A therapist's role was viewed as being a witness to pain, as supporting clients when emotionally overwhelmed, as helping clients come to terms with the dilemmas of living, and as assisting in their creating meaningful rituals (Grothe & McKusick, 1992; Milton, 1994).

Burke and Miller (1996) focused on a spiritual approach to address classic existential issues such as death, powerlessness and aloneness. Because at that time an HIV diagnosis eliminated the illusion of immortality, they suggested that therapy could help individuals build dying into their perception of living. A sense of powerlessness was seen as a natural result of the confrontation with the reality of human limits to treat the disease and avoid impending death. They pointed to an existential/spiritual approach in therapy as a way to address these issues as well as the existential aloneness resulting from the stigma, harassment, and discrimination that followed the diagnosis.

Holt et al. (1999) and Frame et al. (2005) acknowledged the perspective shift arising from advances in medication. They nevertheless characterized an HIV diagnosis as ultimately *terminal*, with the natural arising of existential issues. Other researchers agreed that an existential approach to therapy with HIV+ clients was especially applicable (Farber, 2009; Hopcke, 2004). In addition to the confrontation with premature death that had previously been written about, they focused additionally on the existential issues around uncertainty, social isolation and stigma, the discovery/creation of meaning

in illness and suffering. Farber especially pointed out that existential approaches are particularly suited to help clients confront limits of what is and is not realistically possible given a chronic and possibly terminal condition that requires lifelong treatment with attending complications and complexities.

Addressing specifically spiritual and/or religious approaches in therapy, Hopcke (2004) asserted that most therapists were unprepared to take such perspectives due to the secular nature and empirical frame of modern psychology. He described religion and spirituality as coming from a dimension greater than psychology. He and Holt et al. (1999) noted however, that HIV+ therapy clients may themselves resist religious or spiritual approaches due to histories of negative experience with religious communities. In particular gay men and drug users were likely to have been negatively judged and marginalized by mainstream religious organizations. Holt cautioned that therapists needed to be not only sensitive to clients' history but should check their own biases and countertransference reactions, remembering that therapy may be the first or best opportunity for clients to experience non-judgmental encounters with caring others.

Frame et al. (2005) pointed out that prior research had suggested positive connections between spirituality or religion and improvements in both physical and mental health. They conducted a study to examine if elements of spirituality or religion would positively affect health-related quality of life among PLWH. They found that spirituality was indeed associated with improvements in psychological well-being among study participants, though religion per se (church attendance or bible reading) was not. They distinguished between *spiritual coping* and *spiritual growth*, noting that what they called spiritual coping (relying on religion-based coping techniques) did not improve any

health-related issues, while spiritual growth (feelings of connection with a force greater than oneself) had a positive impact on psychological function. They did not find that either form of spirituality had an effect on physical function or pain management.

Holt et al. (1999) recommended that therapists working with HIV+ clients include the role of spirituality in their initial assessment. They suggested that therapists demonstrate acceptance, work on existential issues of meaning and purpose, and address client histories of multiple losses and survivor grief. They also suggested that therapy may differ based on the stage of illness, recommending a contextual and systems perspective. Farber (2009) likewise recommended an existential approach and provided descriptions of specific strategies. He also cautioned that such a framework would not likely benefit all clients, especially those with cognitive limitations, those with psychotic or manic symptoms, or those whose high impulsivity which would require more directed interventions.

***Psychodynamic.*** Jeffrey Weiss (1997) described how a psychodynamic approach was especially suited to address particular issues with PLWH. While there was awareness of how HIV was no longer strictly limited to a single demographic population, the disease was still primarily associated with gay males. He pointed to how an HIV diagnosis could have an impact on sense of identity, touching on at least two core issues that psychodynamic therapy has traditionally addressed: the overall integration of sexuality into one's sense of self, and the development and maintenance of overall identity, including sexual orientation.

Weiss (1997) identified sexuality as a core theme in psychotherapy with gay males. Because unprotected sexual activity may have generated the infection, he pointed

out that therapy may serve as a focus in bringing to light previously unresolved conflicts. The client might struggle with feelings of sexual guilt, shame, and have a sense of deserving to be punished. Weiss suggested that therapists needed to be clearly affirming of the client as a sexual being.

He described the process of accepting an HIV diagnosis as a form of a *second coming out* process for many gay male clients. He suggested that the process of accepting an HIV diagnosis depended on the client's prior experience of coming out and integrating a gay identity. For clients that had remained in the closet, an HIV diagnosis which would likely soon become public, often prompted a complicated first coming out. He pointed to psychodynamic theory as especially able to deal with the narcissistic injuries that such coming out processes might awaken.

***Cognitive behavioral.*** Cognitive behavioral therapy (CBT) was represented in a variety of contexts, not dealing with the essential issues of HIV per se, but rather as methods to address associated particular challenges, such as substance abuse, medication adherence, chronic pain, and the need for brief interventions.

Daughters, et al. (2010) pointed to the value of a CBT approach when dealing with the complexities of substance abuse treatment for PLWH. They suggested that CBT could be utilized to focus on the mood, personality, and medication adherence issues, while at the same time utilizing more traditional treatment approaches such as stages of change and motivational interviewing to address the substance abuse components. Cook, McCabe, Emiliozzi, and Pointer (2009) also recommended a combination of CBT and motivational interviewing to assist PLWH compliance with medication regimes. Evans, Fishman, Spielman, and Haley (2003) found relatively better results with CBT as

compared to supportive psychotherapy in assisting PLWH to manage chronic pain.

Rousaud et al. (2007) reported positive outcomes on measures of general psychosocial adjustments following a time-limited cognitive behavioral group intervention with PLWH.

**Systems.** Sensitive to the various sociocultural implications of an HIV diagnosis at that time, systems theorists emphasized the importance of taking the broader social context into account when providing therapy for this population (Bor, Miller, & Perry, 1988; Stynes, Lipp, & Minichiello, 1996). Relevant themes to consider included the social stigma, homophobia, and the resulting secrecy, isolation and fear surrounding an HIV diagnosis (Bor, Miller, Scher, & Salt, 1991; Stynes et al., 1996). Therapy from this perspective focused on analyzing networks of contacts in order to address and facilitate improved interactions between individuals and the systems in which they were embedded (Bor et al., 1988; Stynes et al., 1996). Clinicians were warned not to overlook the impact of HIV on health care systems, families, and significant others (Stynes et al., 1996).

**Groups.** Group therapy was seen as one way to address some of the psychosocial issues related to an HIV diagnosis, including prevention efforts, individual psychological distress (Levine et al., 1991), and social support (Hedge & Glover, 1990). Hedge and Glover (1990) pointed to evidence that social support was correlated with disease progress and mortality. Coleman and Harris (1989) described a structured group therapy process they had developed. Members in their groups were divided based on the time since an individual had received a positive test result. For those within the first three months of diagnosis, the group was focused on psychoeducation, including information about how to access and manage resources such as insurance. For those who had had

more time to process the implication of a positive test, the group had a psychosocial support focus.

Hedge and Glover (1990) pointed out that many with the diagnosis were hesitant to engage in the sharing of fears and feelings that characterized traditional support groups. They described a strategy in which they created informational groups in order to recruit members and indirectly facilitate needed social support. They attributed better results in individual therapy for group members, hypothesizing that the indirect and natural process of the group experience had prepared their clients for a deeper confrontation with therapeutic issues.

**Others.** Other theoretical orientations have been represented, with a strong emphasis on brief approaches in the era of managed care (Pobuda et al., 2008; Rabkin, 2004; Rousaud et al., 2007). Pobuda suggested that many clients simply wanted symptom reduction rather than in-depth personality or psychological exploration. Rabkin noted that brief psychotherapy had been shown to be effective with depression, a common presenting symptom among the HIV+ population.

Pobuda et al. (2008) studied the effectiveness of Time-Limited Psychodynamic Therapy (TLDP) to address emotional distress among HIV+ men who have sex with men (MSM). They detailed the unique set of psychosocial issues challenging that population, including the grief and demoralization from experiences of repeated loss, survivor guilt, and recognition of internalized homophobia and sense of self as flawed or deficient. They also pointed out the challenges inherent in taking prescribed anti-viral medications, including fear of stigmatization and discrimination at work, the constant reminder of HIV during daily doses, adherence resistance, and financial concerns for some. They noted

that TLDP has increasing empirical support, and reported that their study showed significant improvement in emotional distress after 20 sessions.

Rousaud et al. (2007) studied the effectiveness of a time-limited cognitive behavioral group intervention with HIV+ clients. They reported improvement in various outcome measures related to general psychosocial adjustment after 16 weekly 2 hour sessions.

Wallis (2004) and Himelhoch, Medoff, and Oyeniya (2007) reported that group interventions were both effective and cost-effective. While early group interventions focused on death and dying, they noted the complexity and broader set of needs represented by current survivors. They recommended a careful assessment to match clients to appropriate groups. They described a spectrum of groups ranging from support groups that combine problem-solving and information sharing, to psychoeducational and psychotherapy groups. In particular they noted the value of peer-support groups that can provide information not always available in individual therapy, especially personal experiences with community resources, insurance companies, and different medications or HIV treatments.

Harris and Larsen (2007) pointed to the value of peer counseling at generating hope, especially in the early days following first diagnosis. They noted that hope is an important therapeutic construct common to all theoretical orientations. They described peer counseling as one-to-one education or counseling between a recently diagnosed client and a veteran trained in such counseling. They reported that newly diagnosed clients benefited by forming a non-judgmental accepting connection with others, receiving emotional support, and gathering relevant information and referrals. The



participants in their study reported significant emotional benefits, including the development of a positive view of future, appreciating a sense of humor, and support in maintaining dreams, goals, and meaning in life. Those who participated as peer counselors also reported positive gains from filling that role.

Barrows (2006) described a group intervention focusing on a mindfulness meditation approach to stress reduction. Referring to well-established research demonstrating connections between stress and the immune response, and between meditation and stress, he explained how such an approach might benefit an HIV+ population. In particular he focused on stress relief and the Buddhist notion of suffering arising as a consequence of cognitive appraisal of pain. He described mindfulness stress relief groups meeting weekly for two to three hours sessions, for eight weeks, including a seven-hour silent retreat during week six. Barrows explained that while instructors usually had a degree in mental health, it was more important for them to have ongoing mindfulness practice.

In a series of articles, Ingram et al. (Ingram, Flannery, Elkavich, & Rotheram-Borus, 2008; Rotheram-Borus et al., 2009; Rotheram-Borus, Ingram, Swendeman, & Flannery, 2009) surveyed a number of empirically supported HIV prevention efforts to identify a set of common factors ostensibly responsible for the positive outcomes. They noted that community-based programs often deviated from strict implementations of manualized treatment due to real-world challenges of maintaining fidelity to program specifics and to the implementers' experience and sensitivity to local populations. They suggested that the theoretical models identified in the treatment manuals, while plausibly accounting for some of the outcome, failed to account for much of what actually

transpired during service delivery. Using qualitative methods they suggested a set of common factors active among all successful approaches. Their 2009 study (Rotheram-Borus et al., 2009) included five shared common factors among successful programs:

- (1) establish a framework to understand behavior change;
- (2) convey issue-specific and population specific information necessary for healthy actions;
- (3) build cognitive, affective, and behavioral self-management skills;
- (4) address environmental barriers to implementing health behaviors;
- and (5) provide tools to develop ongoing social and community support for healthy actions.

They advocated for flexibility in implementing the many specific elements of manualized approaches while maintaining fidelity to this shorter list of broader high-level common factors.

**Diagnostic-based approaches.** Many researchers have based their approach to the psychological treatment of PLWH on the presence of mental health or medical diagnoses, with special focus on assessing and treating depression (Farber & McDaniel, 1999; Himelhoch et al., 2007; Rabkin, 2004). Rabkin encouraged efforts to take depression seriously by screening for, monitoring, and treating depression in PLWH. Himelhoch noted some of the unfamiliar consequences of depression in this population including the likelihood of delayed treatment initiation and poor adherence to daily medication regimens.

Rabkin (2004) discussed the challenge of making a clear diagnosis of depression in PLWH. She noted that the clinical presentation is often complicated by medical illness and medications, side effects, and shared somatic symptoms. Additionally, she pointed out that it may be hard to properly ascribe the role of HIV in depression since many

PLWH have a history of depression, often occurring in adolescence, during a coming out process, or related to substance abuse history. She noted that research does not show depression worsening with progression of HIV/AIDS. She recommended standard treatment for depression, including antidepressant medication and/or brief focused psychotherapy. She cautioned that demoralization and lack of motivation are typical barriers in any treatment of depression.

Researchers addressed specific therapies to address chronic pain that often accompanies HIV/AIDS (Evans, et al., 2003; Nicholas et al., 2007). Pain can be a significant symptom in AIDS patients, with attendant psychological distress and diminished quality of life. Up to 60% of AIDS patients suffer some impairment from pain, up to 30% due to peripheral neuropathy (Evans et al., 2003). Numbness and/or burning sensations in the feet are common presenting symptoms. The peripheral neuropathy can be caused by the inflammatory processes of HIV infection per se, as well as by the neurotoxic side effects of HIV medications (Evans et al., 2003; Nicholas et al., 2007). Although the pain and psychological distress is usually primarily treated with analgesics (Evans et al., 2003), Nicholas et al. (2007) pointed out the pain can be conceptualized as both a physical and perceptual phenomenon. As such, various approaches to pain management in this population were described. Nicholas et al. listed a variety of self-care techniques including meditation practices. Evans et al. compared CBT with supportive psychotherapy. In their study both interventions were somewhat effective in helping participants better manage chronic pain. The participants undergoing CBT demonstrated somewhat better results. Nevertheless, in spite of positive outcomes, the dropout rate for both groups in this study was significant and raised questions about the effectiveness of

psychotherapy in general to address pain management. Evans et al. noted that participants had presented for treatment expecting and anticipating analgesic prescriptions to manage their chronic pain.

In addition to the peripheral nerve damage from HIV infection and/or treatment, AIDS-related neurocognitive decline, including dementia, had been part of the clinical picture for years. Fortunately, introduction of medications had dramatically decreased the incidence and severity of HIV-associated neurocognitive disorder (Treisman & Angelino, 2004). Nevertheless it remained a concern as some mild cognitive impact was found in approximately 30% of asymptomatic HIV infected persons, and approximately 50% in those with AIDS (Treisman & Angelino, 2004). According to Triesman and Angelino 18% of patients at first appointment to Johns Hopkins clinic for HIV care had a primary diagnosis of cognitive impairment.

A literature search for psychotherapy as treatment for HIV-associated neurocognitive disorder (HAND) did not produce any results. Nevertheless, mental health clinicians were encouraged to be aware that HAND could still be a concern and they should include cognitive function as part of routine assessment (Marcotte, 2008). HAND can be assessed using standard neurocognitive testing methods. Assessment practices included mini-screens, brief screens, automated computer screens (Cysique, Maruff, Darby, & Brew, 2006), brief batteries and comprehensive batteries. All had been designed to target the deficits most commonly associated with HIV.

**Other issues.**

**Disclosure.** An important element of most preventive efforts included encouragement of PLWH to disclose their status to potential sex partners. Yet researchers

noted that a significant percentage of PLWH continued to elect not to disclose (Arnold, Rice, Flannery, & Rotheram-Borus, 2008; Frye et al., 2009). In order to enhance interventions aimed at preventing further spread of the disease by people who know they are infected researchers sought to understand the dynamics of decision making regarding disclosure. Surveying the literature of disclosure one immediately is faced with researchers noting the complexity of this particular decision (Arnold et al., 2008; Bairan et al., 2007; Frye et al., 2009; Klitzman et al., 2007). A search for factors that influence disclosure decisions reveals a multitude of factors embedded in a complicated psychosocial context. Arnold et al. described a simple starting point for characterizing disclosure strategies by identifying three broad approaches: *disclose to all*, *disclose to none*, or *disclose to some people*. They characterized the first two strategies (all or none) as providing a simplified decision making process, eliminating the ongoing need for repeated or real-time contextual evaluations. This is not to say that initially arriving at one or the other of these approaches is simple, but once adopted, they relieve one of a burden. In exchange for that relief, however, those approaches require accepting the consequences of the decision. The pathways of evaluating the consequences and arriving at a decision are elaborated by a number of studies cited below. Researchers have attempted to understand why or why not PLWH disclose to others, and if they do, to whom and when.

Researchers acknowledge a wide variability in disclosure strategies and practices (Arnold et al., 2008; Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Rutledge, 2009). The principle dynamics appear to be highly contextual personal evaluations of risk and rewards (Derlega et al., 2004; Frye et al., 2009; Rutledge, 2009; Serovich, Craft, &

Yoon, 2007) with the nature of personal relationships a dominant influence in the calculations. The risk/reward dichotomy is essential between balancing the risk of exposure to stigma with the reward of receiving social support from important others (Arnold et al., 2008; Bairan et al., 2007; Frye et al., 2009). Bairan et al. (2007) proposed a model that broadly summarized the nature of social relationships and their influence on disclosure. They made an important distinction between sexual and non-sexual relationships. Within sexual relationships PLWH were likely to decide to disclose based on the temporal nature of the relationship, with briefer encounters less likely to involve disclosure while longer more committed relationships were more likely to include disclosure. For non-sexual relationships, PLWH were likely to decide to disclose based on closeness of the relationships, with relative strangers being less likely to be informed while those in closer relationships (family and close friends) more likely to be informed. Those findings are hardly surprising, essentially showing that the longer and more intimate a relationship is, sexual or not, the more likely there will be disclosure of serostatus.

The particular issues that are evaluated and combined to tip the scales are elaborated by a number of studies (Bairan et al., 2007; Derlega et al., 2004; Klitzman et al., 2007; Rutledge, 2009). There is considerable overlap among these studies all based on interviews and questionnaires surveying PLWH. Reasons for disclosure included: It's the right thing to do, out of duty to protect others, process of self-affirmation, to recruit social support, process of catharsis, to educate others, to seek help, to test others, in the context of a pre-existing supportive relationship, as part of dealing with the disease, and the fear of arrest. Reasons for non-disclosure included: to avoid stigma, out of fear of

rejection, to maintain personal privacy, to avoid potential loss of income, to avoid disclosing substance abuse, too difficult to explain, denial of HIV status, low viral load making infection less likely, certain types of sexual encounter making infection less likely, the fear of arrest, use of a condom making infection less likely, a sense of fatalism, community norms discouraging disclosure, to avoid confronting feelings of self-blame, and a perspective that sex is not that important. The preceding lists demonstrate the complexity and the range of personal issues that are considered when deciding what, when, and with whom to disclose. As an example of that complexity, note that while not a dominant concern, the fear of arrest is cited by some as a reason to disclose and by others as a reason not to disclose.

Bairan et al. (2007) correlated demographic and personal characteristics that influenced disclosure decisions. They found that those more likely to disclose: Were younger, were female, had high ethical and moral standards, were more spiritual, were involved in serodiscordant relationships, had participated in interventions that encouraged disclosure, and had more advanced disease. Those less likely to disclose: Identified as gay, were ethnic minorities, experienced depression or loneliness, or were sex workers. Although there are apparently some predictive correlations such as above, it is important to realize that variability is more the rule when it comes to demographic or personal characteristics influencing individual decision making.

Using interviews and questionnaires as part of a longitudinal study of HIV+ African American women, Serovich et al. (2007) sought to characterize the timing of disclosure to immediate family members. While disclosure was frequently made within the first year of diagnosis, the overall average time to disclose was seven years. The

pattern of disclosure was first to mothers, then sisters, followed by brothers and lastly to fathers. Their study participants reported that in general immediate family members and friends had positive and supportive responses to the disclosure. They noted that the progression of disease did not correlate with time to disclose. This was in contrast to earlier studies that theorized that disease progression would prompt disclosure. In separate studies Klitzman et al. (2007) and Serovich, Lim and Mason (2008) also showed that disease progression was not related to disclosure, and that an evaluation of the consequences of disclosure (stigma vs. support) were more influential in driving the decision to disclose or not.

**Bug chasers.** Gauthier and Forsyth (1999) introduced the academic community to a phenomenon known as bug chasing, described as the act of an HIV negative (HIV-) MSM seeking unprotected sex with an HIV+ partner for the purpose of intentionally acquiring infection with HIV. The mainstream media were alerted to this questionable practice when Rolling Stone Magazine (Freeman, 2003) published an article focusing on bug chasing subculture and include interviews with an individual who described himself as a bug chaser. A handful of academic studies followed to investigate the phenomenon (Adam, Husbands, Murray, & Maxwell, 2005; Grov & Parsons, 2006; Moskowitz & Roloff, 2007; Tewksbury, 2006). Except for Adam et al., the studies focused on a subculture of MSM's who utilized websites devoted to *barebacking*, the act of unprotected anal sex. The websites included the ability to generate personal profiles and ads for website viewers in search of sexual partners. Using the data available from the personal profiles and ads, researchers sought to characterize bug chasers and their



counterparts, *gift givers*, who were HIV+ and expressed a willingness or desire to intentionally infect another.

In their initial study, Gauthier and Forsyth (1999) sought to explain the motivations of individuals in this subculture. They generated four speculative explanations: Fear and Relief—the belief that HIV infection was inevitable and that acquiring the virus sooner rather than later would simply relieve one of the worry. That relief would allow for more satisfying sexual relationships while managing the subsequent disease through available medication therapy; Risk Taking as Eroticism—the simple idea that sexual excitement is enhanced by breaking the rules. In this case, the rules are the clear social prohibitions against unsafe sex; Loneliness and Group Solidarity—the search for inclusion, or re-entry, into an important community. The community in this case consisted of newly-empowered and socially accepted MSM with AIDS; Political Actions—Attempts by politically active MSMs to assert their presence and worth in the midst of a homophobic and stigmatizing wider culture. Moskowitz and Roloff (2007) surveyed the online profiles posted on a barebacking website to characterize differences between bug chasers and gift givers. They explained the practice as an example of sexual addiction, rejecting the explanations described above.

Grov and Parsons (2006), and Tewksbury (2006) also surveyed online profiles in attempt to characterize self-identified bug chaser and gift givers. Both of their studies indicated that the phenomenon reflected a small minority of the population of MSM, only 6-10% of those identified as barebackers, that group already representing a minor subculture of MSM. The low numbers and the nature of personal ads, providing anonymity and possibility of posing, caused some to question whether the phenomenon

was in fact a reality. Adam et al. (2005) had previously questioned the veracity of the online self-reports. In a study examining reasons for engaging in unprotected sex they conducted in-depth personal interviews with 102 MSM. They noted that not a single one of their interviewees described either a desire to acquire or to give an HIV infection. This is consistent with the more extensive literature on disclosure by HIV+s described and cited above. Not one of the studies cited above mention bug chasers and gift giving. While acknowledging the practice of unprotected sex, Adam et al. based their explanations on face-to-face interviews rather than website profiles. Their explanation was far simpler—for most of their respondents, eschewing the use of condoms was because condom use frequently resulted in a loss of erection. Far from speculative psychological explanations or incomprehensible desires to intentionally spread the virus, their survey participants reported that, among other reasons, they were mostly and simply choosing between having unprotected sex or having no sex at all. The researchers contrasted these simpler explanations with those based in sensational portrayals of barebacking and bug chasing found in popular press.

***Training therapists.*** The complexities of providing psychotherapy to PLWH prompted several researchers to comment on the paucity of specific counselor training related to HIV. Domenic (2003) attributed much of new counselors' anxiety to a lack of training. Kukafka, Millery, Chan, LaRock, and Bakken (2009) correlated levels of training to gaps in counselors' knowledge of HIV-related processes, issues, and treatment. Britton, Cimini, and Rak (1999) noted that most prior research on training had surveyed licensed psychologists, while the majority of counseling was actually provided by masters level Licensed Professional Counselors (LPCs). They noted that surveys revealed

that only 19% of counseling and clinical psychology programs accredited by the American Psychological Association (APA) offered HIV-specific coursework, while only 14% of social work programs did so. Britton et al. (1999) described what such a course would cover, including: medical overview, community resources, ethical legal and professional issues, assessment and diagnosis, diversity, therapist attitudes, intervention, death and dying, and countertransference.

Various suggestions have been made to address therapist lack of knowledge or confidence, including recommendations for more formal training in graduate schools. Some states have added HIV-specific training requirements for mental health licensure (HIV/AIDS Spectrum Training, 2012; Washington State Credentialing Requirements, 1998). The American Psychological Association (APA) has developed specific training offerings through their APA Office on AIDS (HIV Office for Psychology Education Program, 2012). Kukafka et al. (2009) described developing an online decision support tool (HIV Tips) to assist counselors. They noted that such tools were commonly used in medicine, but not yet popular in psychology. Britton et al. (1999) described an experiential method for teaching HIV counseling, while Domenic (2003) described a conversational model of time-limited therapy that could be used to allay new counselor anxiety. Noting that a conversational model can apply across various theoretical orientations, he described therapy as a special kind of conversation, noting that most people know how to have a conversation.

***Duration of therapy.*** Bottanari and Stepleman (2009) noted that while psychotherapy was demonstrably helpful, premature dropout was a common problem. Reece, McBride, Shacham, and Williams (2005) questioned inexperienced counselors'

sense of the social complexities involved in living with HIV. They noted that inexperienced counselors consistently underestimated the expected duration of therapy relative to estimates by experienced therapists. Bottonari and Stepleman demonstrated that the amount of therapist experience correlated positively to duration of therapy. Reece et al. noted that therapists they surveyed expected a longer duration of therapy for clients with an HIV diagnosis compared to patients without a diagnosis, regardless of therapist theoretical orientation. Bottonari and Stepleman surveyed prior research and suggested the strongest predictor of time in therapy was client expectations of how long therapy should take. Reece suggested that understanding the complexities of living with HIV was critical to setting realistic client expectations regarding duration of therapy, especially since brief therapies were becoming popular to contain costs.

Bottonari and Stepleman (2009) attempted to identify which complicating factors of an HIV diagnosis were associated with premature termination of therapy. They noted prior research showing that patient demographics did not correlate, but that complications from comorbid illnesses, substance abuse, and personality disorders did correlate with early termination, while combining therapy and psychotropic medication correlated with longer therapy. Their study showed longevity in therapy to be positively correlated with living with a supportive partner, proximity to treatment facility, concurrent psychotropic medications, the presence of a personality disorder (a finding contrary to prior research they had summarized), and an ethnic match between client and therapist.

**Assessment.** Recognizing the complexities of living with HIV, researchers cautioned therapists to appreciate the difficulties of performing a comprehensive differential diagnosis (Frederick, 2004; Rabkin, 2004). Specific assessment components

were defined by a number of researchers, including: psychological adjustment, substance abuse, transmission-risk behaviors, medication adherence, access to resources, intimate and family relationships, other social support, employment status, overall physical health and cognitive function (Farber & McDaniel, 1999; Kukafka et al., 2009; Rubenstein & Sorrentino, 2008).

***Adherence.*** As repeatedly noted above, the effectiveness of medications to treat HIV has resulted in a perspective shift, with an HIV+ test result no longer implying an automatic and premature death sentence. As also noted above, those longer survival rates have generated a new set of complexities for those living with HIV. Ironically, one of the complications of living with HIV in an era of effective medication became the perplexing challenge of maintaining adherence to a regimen of the very medication that provides extended survival (Cook, et al., 2009; Frame et al., 2005).

Swendeman et al. (2009) looked at chronic disease management, distinguishing common factors from HIV-specific challenges. A common element in managing chronic illness includes the general area of self-management practices, including maintenance of sometimes costly and complex medication adherence. They identified HIV-specific challenges including the inability to independently and directly monitor one's physical state (immune system indicators), ongoing stigma, and potential legal liability of transmission. Nevertheless, much of the self-management issues in HIV, including medication adherence, are common across chronic illnesses. They noted that many lists of chronic illnesses did not include HIV, potentially contributing to a lack of recognition of successful intervention strategies already in place for other chronic conditions.

Specifically addressing common challenges to medication adherence would be included in those shared strategies.

Research had demonstrated low levels of medication adherence (de Bruin et al., 2010), including a significant percentage of diagnosed individuals who never even began treatment (Cook et al., 2009). Some researchers (Bottonari & Stepleman, 2009; Himelhoch et al., 2007) attributed poor adherence to the interference of depression and substance abuse in the infected population. The impact of partial adherence to medication regimens varies according to disease, but for HIV has a significant impact on the individual's illness as well as subsequent demands on the overall medical system (Cook et al., 2009). Efforts to develop effective medications and vaccines have primarily been hampered by the virus' ability to mutate, creating an evolving moving target (Huang & Wooley, 2005). Studies have shown that 95% adherence to HIV drug therapy was required to avoid drug resistance (de Bruin et al., 2010), and estimates were that on average only 50-70% adherence was achieved during the first six months after diagnosis (Cook et al., 2009; Dybul, Fauci, Pau, Bartlett, & Kaplan, 2002).

In 2002 the CDC provided revised treatment guidelines that directed physicians to include adherence counseling when prescribing antiviral medications for HIV (Dybul et al., 2002). Golin, Smith, and Reif (2004) later surveyed physicians to monitor their compliance with such guidelines. They determined that many patients were not receiving adherence counseling per the recommendation, though they found that basic information was being provided. They speculated that physicians may have perceived that such counseling was not within the scope of their role, or that they lacked time, training, or reimbursement for such activity.

Other researchers studied ways to encourage patient adherence to medication schedules. de Bruin et al. (2010) studied the effectiveness of using automated electronic data gathering combined with nurse counseling to improve adherence. With this technology, using a prescription bottle cap that automatically and electronically tracked dates and times of opening, nurses could download and chart the data during counseling/review sessions with patients. They found that in their study adherence was significantly improved. They reported that the intervention required minimal nurse training and could be administered during routine clinical visits. Cook et al. (2009) studied an intervention based on a combination of CBT and motivational interviewing delivered over the telephone. They reported that they improved adherence to a 95% rate.

Kenedi (2006) focused on adherence challenges among those HIV+ patients diagnosed with borderline personality disorder (BPD). He described how the impulsivity and self-destructive acts common to BPD can be particularly dangerous among those with HIV infection, leading to unsafe sex and needle sharing. He linked levels of medication adherence to levels of chaos and crisis in the lives of those with both HIV and BPD. He recommended that clinicians refer any patients with the emotional instability and impulsivity characteristic of BPD to seek mental health assessment, suggesting they might benefit from dialectical behavior therapy.

## Chapter 4

### Discussion

Summarizing and synthesizing an extensive literature spanning 30 years can be a daunting task. An essential organization to this data has already naturally emerged through the process of selecting, organizing, and summarizing the literature as presented in the preceding chapters. That outline, revealed by the table of contents, already reflects an organization that emerged independent of a pre-existing anticipated structure and can be viewed as one high-level identification and summary of thematic categories and sub-categories of this body of literature. Nevertheless, a variety of alternate valid approaches could be taken. What follows is an integrated summary of the preceding outline approached by answering the research questions that were originally posed prior to surveying the literature, including another view that addresses two new higher-level themes that seem to cut across the body of literature, all with an additional eye and focus on the evolution of the literature.

### Research Questions

**Themes.** What have been the organizing themes that have guided psychological research in the area of HIV? As described above, the first high level thematic organization to emerge is revealed in the table of contents: populations, testing, and psychotherapy, with the associated sub-themes previously detailed. Two additional high-level themes have emerged that cut across the literature. These represent what could have been one alternative way of organizing the data but would not have been apparent by a simple review of article titles or abstracts. Those themes are *stigma* and *complexity*.



**Stigma.** Awareness and management of the stigma of AIDS is frequently mentioned from the earliest through the latest literature. It is addressed when viewing the literature from the perspective of populations, testing, and psychotherapy. *Stigma* or variations on the term is mentioned 30 times above, distributed throughout the literature review chapter--every other page on average. Yet it is not found in the title of a single of the 200+ references cited.

Stigma is addressed in virtually every aspect of the literature. Early writings point to the stigma of homophobia, followed by the stigma of substance abuse, the stigma of children with AIDS, the stigma of any positive antibody result. Therapists have been continually urged to check their own countertransference to avoid stigmatizing clients in all settings. The primary issue in models of decision making regarding disclosure of one's status is to balance the risk of stigma against the potential for social support.

Though not explicitly addressed in any of the titles of articles cited, an important finding is that one has not been able to engage in meaningful discussions about HIV/AIDS without awareness of and accounting for stigma. Stigma remains a critical underlying theme both to understand the experience of PLWH and to provide meaningful therapeutic interventions with such clients.

**Complexity.** While awareness of stigma may have been present and appreciated throughout, awareness of the complexity of managing all aspects of HIV/AIDS has unfortunately been a more gradual and painful process. Simplistic models have continually shown to be inadequate. Early models of the disease were viewed as analogous to other infectious disease outbreaks, with little to no appreciation of sociocultural influences on viral transmission. Early assumptions that AIDS was a disease

limited to gay males may have resulted in the silent spreading of the epidemic to other populations as many people were caught unaware and continued to engage in unprotected sex. On the other hand, perhaps the biggest lesson to be learned from the failure of many public prevention campaigns is that awareness per se, even widespread awareness, has been dismally inadequate to prevent the epidemic. Messages to *know how it is spread*, *know your status*, *know your partner*, and *use a condom*, strategies that are unarguably logical and effective on paper, were found to be woefully inadequate to change real-world sexual behaviors that are deeply embedded in complex and widely divergent cultural settings.

Today we understand the psychological implications of being tested, the impacts of both positive and negative results, the futility of testing as a primary preventive measure, and the futility of widespread mandatory testing of low-risk individuals. But these have been lessons learned slowly and with difficulty, while spending tremendous efforts to encourage everyone to *know their status*.

The literature does demonstrate the awareness of the personal, interpersonal, and cultural complexities of managing HIV/AIDS. And it may even be that psychology as a field was on the relative forefront of advocating for more elaborate models and consideration of sociocultural influences. Nevertheless, the very fact that so many writers seemed to call for more considerations of cultural complexity, and the fact that cultural and sub-cultural complexities were only gradually elaborated over time point to the deficiencies of early models.

This may be, however, the only way it could have proceeded. This process may serve as an example of the scientific method in operation. Early models of intervention,

for example, were proposed and implemented. As the epidemic spread, the gaps and deficiencies in those models were identified and newer more robust approaches were suggested. Those in turn were pressed to the limits while the epidemic continued. Still more elaborated and comprehensive models were generated. The danger today may be that a simple view that HIV is now treatable as a chronic condition may lull some into believing that HAART and insulin are analogous modes of treating two different chronic illnesses. This is one of the important points contained in Swendeman et al.'s (2009) study of common factors in chronic disease management—in addition to the value of viewing HIV as a chronic illness it must be combined with sensitive awareness to HIV-specific challenges. HIV is both like and unlike other illnesses.

An example of the complex challenges of addressing real clients in a real world setting is illustrated: This researcher recalled working with a therapy client that had difficulty maintaining adherence to his regime of anti-HIV medications. His primary care physician referred him to psychotherapy out of frustration, essentially complaining, “I can’t get him to take his med’s. Maybe you can . . . .” In therapy, the client acknowledged his understanding of the purpose of the medication. He was clear in his knowledge of the potential fatal consequences of non-adherence. In fact, he promised weekly that he would initiate his prescribed course of drugs, and apologized weekly for his failure to do so. Behavioral interventions in the form of daily cell phone reminder alarms were ineffective. This client provides an example of how sociocultural complexities affect mental health and therefore medication adherence. The client was an undocumented immigrant. Earlier in his life he had been a star athlete, playing semi-professional baseball. He came to the US, married a woman, and developed a successful business career and active social life.

He was a devout religious believer and had achieved significant social esteem and broad popularity as a paid speaker and lay minister. He also had a history of alcohol abuse and infidelity. Over time he lost his physical fitness, his job, his social standing, and his circle of religious friends. His marriage was laden with conflict and estrangement. At some point in therapy the client was able to provide a coherent explanation for his resistance to taking medications. He explained his belief that God was humbling him with HIV, and that his current physical illness prevented him from returning to his prior sinful ways, with alcohol and promiscuity. This client demonstrated the real world complexities of living with HIV. Religious beliefs, culture of origin, immigration status, legal risks, family stress, financial troubles, social stigma, medical complications, and significant losses all contributed to this client's complicated and intractable depression. Simply following prescribed medication schedules was not so simple. Unfortunately the client dropped out of therapy without making any discernable changes in mood or behavior.

The past several decades of psychology literature in general have emphasized the problems that result from applying a dominant culture's perspective to culturally diverse situations. It seems that the more finely we sort through issues of culture and sub-culture the more complexity is revealed. Such seems to be the case with HIV as well.

**Epochs and evolution.** As suggested early in this document, the evolution of effective medication to treat the virus provides one set of milestones to mark the evolving nature of the literature. Based on that, the history can be roughly broken down into three periods which can serve as the defined epochs for this study: The first epoch, from early to late 1980s (pre-medication), the second, the late 1980s to late 1990s (AZT and others),

and the third, late 1990s to current day (HAART). Table 1 presents a broad summary of how the main themes and sub-themes have appeared over the course of the three epochs.

Table 1

*Evolution of Themes by Epoch*

Epoch 1 (Early to Late 1980s)	Epoch 2 (Late 1980s to Late 1990s)	Epoch 3 (Late 1990s to Current)
Populations		
Gay Males Others	Women Children Drug Users Diverse Ethnicities Others	Women Children/Adolescents Substance Abuse and HIV Diverse Ethnicities
Testing		
Impact of Testing	Impact of Testing Testing for Prevention	Impact of Testing Testing for Prevention
Psychotherapy		
Mortality and Fear of Death	Death Anxiety Existential Theory Psychodynamic Theory Systems Groups	Existential, spiritual, or religious Other Theories Diagnostic-based Approaches Disclosure Bug Chasers Training Therapists Duration of Therapy Assessment Adherence

How have those themes changed over time? Have new themes arisen while others have disappeared? Reviewing the themes and sub-themes relative to the defined epochs, changes over time can be described for each category.

**Populations.**

**Gay males.** HIV was first recognized in US gay male populations. The early literature on affected populations was almost entirely limited to a focus on gay males. During the early years of the AIDS epidemic, psychologists were responsive to the obvious needs of individuals reacting to an unexpected medical diagnosis, perceived at that time as 100% terminal. In addition to therapeutic approaches to the adjustment needs of their clients, psychologists also responded with awareness of and sensitivity to the

unique psychosocial challenges of being both gay and HIV+ in a homophobic culture. Some of the mistrust and skepticism towards the biomedical community may seem misguided from the perspective of nearly 30 years hindsight. Psychoneuroimmunological explanations have long ago been replaced by traditional models of infectious disease transmission. That approach represents, however, a significant way in which psychology initially reacted to the HIV epidemic by attempting to address individual distress while also protecting a vulnerable and recently liberated yet still-stigmatized community.

Gay males have continued to be the group most impacted by HIV in the US, and have maintained some presence in the literature throughout. Yet the strictly limited focus on gay males in psychology literature diminished over time due to the expanded awareness of other effected groups. Focusing on the complexities of cultural diversity, researchers expanded on more specific groups affected. Indeed later in the epidemic researchers were noting how prior research had become focused on heterosexual populations, questioning the applicability of some interventions to a gay male population.

**Women.** The psychological literature on women and HIV evolved from its virtual absence in the beginning, through a focus on prenatal testing for prevention of maternofetal transmission, to a more sophisticated and broader approach to gender issues. A focus on women's issues was first seen in the second epoch as it became clear that prenatal transmission of HIV was not only possible, but posed a significant health issue for women and children. A focus on prenatal testing to prevent transmission brought attention to the unique health care challenges for women, including sociocultural barriers to access. Arising from the studies relating to women's access to care researchers began to also appreciate the sociocultural and interpersonal complexity of sexual practices when

attempting to understand and encourage condom use. The situation for women seemed to grow worse over time. By the third epoch of the epidemic while the rate of AIDS deaths had declined for men, it had increased for women. Researchers continued to grapple with the sociocultural complexities of public efforts to modify individual sexual behavior. Testing as a preventive measure had clearly failed, as women were well-educated in HIV transmission, yet infection rates remained high. Researchers continued to detail the many ways that gender issues played a role in interpersonal relationships, including differences in power, communication patterns, and the ability to implement preventive measures.

***Children and adolescents.*** The psychological literature on children and HIV evolved from its virtual absence in the beginning, through a focus on pediatric AIDS and to the larger impact of HIV on families. The spread of HIV through the heterosexual population created children with AIDS as well as orphans who had lost parents to AIDS. Researchers addressed both the individual and community impact of HIV in new populations.

***Drug users.*** The psychological literature on drug abuse and HIV evolved from its virtual absence in the beginning, through a focus on intravenous drug users (IDUs), to a more generalized appreciation for the complex interrelationships between substance abuse, mental health, and HIV transmission and treatment. The focus on IDUs raised the first broad awareness of the transmissibility of the disease in a heterosexual population. Public health workers met with substantial frustration in their efforts to prevent transmission through behavioral management. They were forced to confront the inadequacy of public education efforts to modify complex individual behavior. At the same time, the first evidence appeared that testing might have some impact on behavior,

albeit in a surprising way--a positive antibody screen seemed to have a slight impact on decreasing high risk behavior while a negative antibody screen offered some sense of safety, resulting in more high risk behavior.

Substantial efforts were made to integrate HIV education and counseling into substance abuse treatment programs, while HIV care providers attempted to include substance abuse prevention efforts. Neither effort met with much success. Substance abuse treatment did not have much effect on sexual behavior, while HIV medical treatment and risk management did not seem to impact substance abuse. Researchers had to confront differences between theory and practice. This pushed them to take more of a systems perspective, noting the historical cultural differences between substance abuse treatment and medical treatment, and seeking realistic ways to integrate the two.

***Diverse ethnicities.*** The psychological literature on ethnic diversity and HIV evolved from its virtual absence in the beginning, through an initial inclusion of African Americans and Latinos, to deeper cultural explorations of culture, poverty, discrimination, and specifics of sub-cultures. By the second epoch, AIDS had become the leading cause of death among American minorities. It fell heaviest among African Americans, but also greatly impacted Latinos. This served as an additional prompt for researchers to shift their focus from individual choices, such as the decision to use a condom, to broader cultural influences on behavior. Researchers explored Latino cultural norms of machismo, the influence of the Catholic Church, and general disempowerment of Latina women.

**Testing.** In the early days testing was neither mandatory nor necessarily encouraged. At that time one of the counselors' roles was to provide assistance to clients in deciding whether or not to be tested. That role gradually shifted to being the person to



deliver bad news, on through to sometimes becoming the sole psychological support to the dying. As testing became central to public efforts to prevent transmission, counselors filled the role of attempting to persuade individuals to use knowledge of their serostatus to modify high risk behavior. As stated above, with the exception of some small to moderate effect produced by a positive antibody screen, efforts to utilize T+C as a preventive strategy, while a logical and primary public policy strategy, were mostly failures.

***Psychological impact.*** The literature on the psychological impact of HIV testing evolved from descriptions of its potential as the means of discovering an inevitable death sentence to descriptions of best practices that included an appreciation of broad social and contextual implications of testing in the era of HAART. The early years presented significant challenges to individuals being tested, their counselors, and important others such as family and friends. Counselors focused on managing the range of reactions to a positive test result. The potential social impact, including loss of jobs and housing, drove counselors to assist clients in deciding whether to even risk testing or not. Counseling included psychoeducation about the risks and benefits of knowledge. Systemically, researchers attempted to explore the balance between protecting an individual's interest in privacy and self-direction with the public's interest in preventing further spread of the disease.

As antibody testing became more widespread, even routine or mandatory in many settings, counselors moved from the role of educators to that of psychological comforters. Due to the sensitive nature of the information and potential impact on an individual's life, a rather cumbersome, expensive, and sometimes lengthy set of processes had developed.

In an era of widespread availability of testing, counselors discovered that many individuals never returned to receive test results. In response, clinics undertook efforts to simplify and streamline test processes.

**Prevention efforts.** The psychological literature on HIV testing for prevention evolved from an initial focus on its use primarily for diagnosis, to a focus on educating people who were uninfected, to a focus on the already-infected population. The literature documents well the evolution from an optimistic public policy strategy, to doubts about naïve reliance on simplistic models of behavior, to a reliance on more sophisticated models that attempted to utilize behavioral science theory. This evolution represents one of the most important lessons to be learned from this study.

Over most of the course of the epidemic, testing was relied on as a primary vehicle for preventive efforts. Testing was often coupled with educational efforts encouraging the use of condoms. The clear failure of widespread testing to impact behavior forced researchers to more fully confront the sociocultural complexities of sexual behavior, especially with low-risk populations of uninfected people. Researchers shifted efforts in two ways: First, they focused attention on the HIV+ population as sources of ongoing transmission, and second, they encouraged the use of more scientifically based behavioral approaches. *Real world* interventions were advocated, including harm reduction models, stages of change models and motivational interviewing.

**Psychotherapy.** The psychological literature on psychotherapy and HIV evolved from a focus on dealing with mortality in the beginning, through a focus on existential issues of uncertainty during the second epoch, including emphases on death with dignity, to a focus on the issues of managing day to day complexities of treatment for a chronic

illness. Changes in psychotherapy most closely reflect the impact of effective medications. Contrary to expectations, however, the availability of effective medical treatment of HIV did not eliminate the need for psychotherapy. Barring an effective cure, long term survival with HIV brought a new and complicated set of issues given the historical experience of survivors, diffuse guilt, shifting life plans, ongoing stigma, and medication side effects. Long term survival with HIV also generated new ethical issues for clients as well as for therapists.

Psychotherapy in the early years was almost entirely focused on how to provide compassionate care for clients facing certain and often premature death. Therapists guided existential explorations of mortality, isolation, guilt and meaning. Therapists in the early days became acquainted with the difficulties and psychological complexities of conversations linking identity, sex, and death.

***Coping with death.*** The psychological literature on death and HIV evolved from an initial focus on confronting fear of contagion and death, to processing pervasive grief among survivors and witnesses, to a near absence of its mention after the introduction of HAART. The approach to death shifted from one of *panic* in the beginning to one of planning for *a good death* during the second epoch. The focus also shifted from individual processes to managing the impact of the epidemic on the broader community of family, friends, and community support resources devastated by the high mortality rate.

The first epoch was marked by fear and hopelessness. Gay males faced widespread stigma and fear from others. Public education was directed toward minimizing the panic by disseminating clear information regarding modes of transmission and debunking popular myths. In the meantime the gay community began to

cope with a mounting mortality rate, especially among young people. By the second epoch, the community was mostly focused on two issues, grief and death with dignity. The early medications for HIV were ineffective at preventing eventual development of AIDS, but did serve to extend the survival of many. That life extension provided time for individuals and the community to reflect on the situation. Psychological literature reflected a focus on understanding the process of death and helping to cope with almost overwhelming grief. The extended yet inevitable mortality also provided opportunities for individuals to plan their deaths. Alternative responses to suffering and death were also in the news during this epoch. Jack Kevorkian popularized assisted suicide, while patient self-determination, advance directives and death with dignity became common parlance in medical care. The situation posed a challenge to therapists and counselors. They were required to manage their own grief, ambivalence about assisted suicide, and the ethics of guiding clients through a new sort of decision-making process.

***Theoretical approaches.*** In the early years the psychological literature on HIV had essentially no focus on theoretical approaches per se. Those days were marked by an informal existential approach in therapy, naturally indicated by the confrontation with mortality that was at the forefront of the experience. During the second epoch researchers were engaged in longer-term therapy situations and began to reflect on traditional theoretical approaches to therapy with PLWH. That included more formal references to existential approaches, but also included psychodynamic and systems theories. Group therapy processes were popular and their benefits described. By the later years researchers had nearly three decades of experience providing therapy and assessing outcomes. Ongoing efforts to maximize positive outcomes focused on a number of issues

besides purely theoretical critiques. They included taking a diagnostic-based approach, concerns regarding disclosure decisions, therapist training, keeping clients in therapy, the challenges of differential diagnosis in complicated cases, and the inexplicable resistance to adherence to life saving medication regimens.

How can the evolution of psychological literature regarding HIV be interpreted as a reflection of advances in the medical management of the disease? This question reveals a hypothesis unstated at the initiation of this study. It was anticipated that the introduction and refinement in medical management of HIV would have had such a dramatic impact that distinct shifts in perspectives and psychological management of HIV would be immediately and starkly apparent. This has surprisingly not turned out to be the case. Shifts in perspective, where identifiable, have been delayed and subtle in presentation. Nevertheless there are three trends which can be identified in the literature traceable to advances in medication management of HIV.

First, regardless of the specific focus HIV-related journal articles in the later years have an almost standard introduction, similar to the first paragraph of this study. They begin by including some acknowledgements to the effect that “HIV/AIDS is now considered a chronic illness.” A new face of AIDS is almost never attributed to the success of prevention efforts or lifestyle changes, but rather to the development and availability of effective medications (HAART). That has truly been a success, despite the complications already discussed regarding self-management and medication adherence.

Second, the psychotherapeutic emphasis during the second epoch shifted from imminent death to a planned death with dignity. This may be a rather subtle shift, as both are death-focused. But focusing on imminent mortality is very different from having the

time to carry out the deeper existential tasks of making meaning-making out of suffering and to make choices regarding ones death. This shift can be mapped to the development of AZT which allowed some prolonged survival.

Third, death is essentially absent from the literature of the third epoch. HAART truly has allowed people to live with HIV as a chronic condition. Thus there is a clearly detectable fading away in the literature of what was once its early and primary focus.

But living and dying, while present in the literature, do not represent the majority focus by any means. This study has documented the wide-ranging nature of HIV-related issues in the psychology literature. It is probably a result of the development of effective medications and the existence of PLWH (people *living* with HIV) that have allowed such a range of writings to exist. That the literature exists is one thing. But, other than the absence of death topics in the post-HAART era, it is another and difficult thing to detect major shifts in tone or perspective that in any clear way can be mapped in time to the development of medications.

How can the evolution of psychological literature regarding HIV be interpreted as a reflection of broader social changes? Again this question reveals a hypothesis unstated at the initiation of this study. It was anticipated that due to 30 years of evolution in social perspectives on AIDS, especially regarding stigma and acceptance of gay liberation, that psychological literature would specifically refer to those new attitudes. It was anticipated that preventive or therapeutic interventions would be specifically reflective of such changes. That is not apparent from the literature. What may be present is a gradual emphasis on diversity that reflects psychology's focus on culturally competent attitudes and practices. That emphasis, however, is not identified as based in

or driven by changes in broader society. Psychology as a social science has likely rather been on the forefront of appreciating and encouraging broader social changes. In any case, there is no clear detectable links between broader social changes driving psychological literature on HIV. If it exists, that subtle link seems undetectable as it is rarely if ever specifically referenced as such in the literature.

Are there documented current *best practices* for providing psychotherapy for PLWH? Once again, based on an initial hypothesis, there was perhaps a naïve suspicion that after 30 years of treating PLWH theorists could provide a solid handle on the typical set of issues, for a typical client, in typical relationships, etc. As previously noted, Wallis (2004) summed up the situation by noting the lack of a typical person with HIV. That of course does not leave therapists without guidance at all. But the guidance surely does not resolve to some description of *best practices*, if by that it is meant any sort of formulaic approach to therapy with this population.

If there are summary overriding themes to hold in mind when working with this clientele it would be the two elaborated above, stigma and complexity. Stigma remains an ever-present concern for PLWH and should be acknowledged and openly addressed in therapy. Therapists should, of course, be ever mindful of their own potential biases and countertransference reactions in order to provide what may be a uniquely safe and stigma-free zone for PLWH in therapy. Managing complexity with this clientele starts from assessment through diagnosis and treatment. Therapists are presented with the common dialectic of any client encounter, diagnostic categories and demographics do matter, *and* they provide limited narratives and can therefore mislead. As a therapy client, each person living with HIV is in some ways like all people living with HIV, in some

ways like some other people living with HIV, and in some ways like no other person living with HIV.

### **Limitations**

Any researcher must acknowledge that the findings as presented are some approximation of *the truth*. They are more or less accurate due to the inherent nature and limitations of all approaches and methods. The specific literature reviewed here represents a sampling of a very extensive body of work that spans three decades. This sample has been selected purposively, not via some random sampling method. Articles were chosen based first on their relevance to the initial research questions posed. Those questions arose out of the researcher's prior and personal engagement with PLWH and their community support systems. That fact likely generated an idiosyncratic perspective that at various levels must have influenced the selection, organization, and interpretation of the literature. Another researcher may have generated a different set of readings for inclusion and review.

While chosen first based on their relevance to the research questions, many relevant articles were excluded based on a secondary strategy of convenience. Internet access to on-line databases provides simple contact with an enormous collection of data. Nevertheless many relevant articles, while identifiable on-line, were not easily accessible in full-text form. Some were excluded on that basis. Relevant and important perspectives may have been inadvertently excluded in favor of a degree of convenience. Nevertheless, as stated in the methods section breadth and depth were sought in this study and approached by including and citing more than 200 relevant sources. One measure of data penetration is encountering redundancy in the findings from study to study. While that



was not always achieved, nor formally tracked, it was apparent to this researcher that once a sizable set of articles were accessed in a particular category, redundancy was apparent. The appearance of that redundancy provides some level of confidence in these findings.

### **Recommendations**

Contrary to common approaches in research where one set of questions naturally leads to another, this study does not lend itself to identifying that sort of next step. However, given that the method taken with this study includes an inherent idiosyncratic focus based on prior engagement with the subject matter, future researchers could generate their own set of questions based on their experience and review the same or a similar body of literature. It would be interesting to explore similarities and differences in findings between such studies, based on a sort of qualitative meta-analysis.

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