Guidance for Counseling People Living with AIDS

The HIV epidemic has been raging for almost twenty years. Volunteers and mental health practitioners who counsel HIV-infected clients are often overwhelmed by the demands made of them by this complex and ever-changing pandemic.

The University of California San Francisco AIDS Health Project Guide to Counseling synthesizes fifteen years experience in working with people with HIV and highlights the medical and psychological issues they confront, presenting effective strategies for counseling the ever-growing HIV-infected population.

"This practical and state-of-the-art compendium is a rich resource that should be a 'must read' for every health professional working in the field of HIV. . . . The book is bound to instantaneously become the standard against which other books in the field will be judged."
—Michael Sherriff, editor of The Second Decade of AIDS: A Mental Health Practice Handbook and Counseling Chemically Dependent People with HIV Illness

"This is a startling book which eloquently presents insight and guidance on all levels of counseling around HIV issues. . . . Thorough, articulate, practical, and shows a depth of understanding which can only emerge at the confluence of excellent academia and extensive experience.”
—Lorraine Sherr, Churchill Fellow, Royal Free Hospital School of Medicine, University College London Medical School

"This volume is authored and compiled by some of the most experienced and thoughtful authorities in the field. In its detailed consideration of the behavioral aspects of the transmission and the mental health consequences of HIV infection, this volume provides an invaluable and welcome resource.”
—Richard W. Price, chief, neurology service, San Francisco General Hospital and professor of neurology, University of California San Francisco

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Guide to Counseling
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The UCSF AIDS Health Project
Guide to Counseling

Perspectives on Psychotherapy, Prevention, and Therapeutic Practice

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Robert Marks
Editors

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## Contents

**Introduction**  
Robert Marks  

**Prologue: Living with Therapy**  
Michael Helquist  

**Acknowledgments**  
xxiii  

**The Editors**  
xxvii  

**The Contributors**  
xxix

### Part One: Risk and Behavior: Helping Clients Remain Uninfected

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>HIV Test Site Counseling for Gay Men: Harm Reduction and a Client-Centered Approach</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>HIV Test Counseling: Does It Change Behavior?</td>
<td>25</td>
</tr>
<tr>
<td>3</td>
<td>Behavior Change Theory and HIV Prevention</td>
<td>50</td>
</tr>
<tr>
<td>4</td>
<td>A Developmental Perspective on Behavior Change</td>
<td>74</td>
</tr>
<tr>
<td>5</td>
<td>Prevention and Culture: Working Downhill to Change HIV Risk Behavior</td>
<td>101</td>
</tr>
<tr>
<td>6</td>
<td>Substance Use Case Management, Harm Reduction, and HIV Prevention</td>
<td>120</td>
</tr>
</tbody>
</table>
Part Two: Transformation and Psychotherapy: Helping Clients Live with HIV 137

7 HIV Disease as an Agent of Transformation: A Survey of Therapeutic Approaches 139
   Israel Katz, James W. Dilley
   Interpersonal Therapy: Albert
   Kathleen F. Clougherty, John C. Markowitz
   Self Psychology: Anthony and Helen
   Sharone Abramowitz
   Psychodynamic Psychotherapy: Robert
   Israel Katz
   Time-Limited Psychotherapy: Enrique
   Israel Katz

8 The Role of Psychotherapy in Coping with HIV Disease 173
   John Devine

9 HIV Disease over the Long Haul: Hope, Uncertainty, Grief, and Survival 197
   Avi Rose

10 Beyond Stereotypes: Stigma and the Counseling Process 209
    Mindy Thompson Fullilove

Part Three: Distress and Disorder: Helping Clients with Psychiatric Conditions 225

11 Anxiety and Depression: Mood and HIV Disease 227
    Dan H. Karasic, James W. Dilley

12 The Clinical Management of AIDS Bereavement 249
    Peter B. Goldblum, Sarah Erickson

13 Personality Disorders and HIV Disease: The Borderline Client 271
    Michele Killough Nelson, Rochelle L. Klinger
14  The Diagnosis and Management of HIV-Related Organic Mental Disorders  
Wilfred G. Van Gorp, James W. Dilley, Steve L. Buckingham

15  Addressing Substance Abuse in Clients with Psychiatric Disorders and HIV Disease  
Joan E. Zweben

Part Four: Therapeutic Practice and Countertransference: Personal Challenges for Therapists

16  Present in the Balance of Time: The Therapist’s Challenge  
JD Benson, Jaklyn Brookman

17  Multiple Loss and the Grief of Therapists Working with HIV  
Barbara E. Davis, David W. Cramer

18  Making Difficult Decisions  
Eric Glassgold, James W. Dilley

Epilogue: The Psychotherapist and HIV Disease  
James W. Dilley

Name Index  
Subject Index
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Introduction

Robert Marks

Today there are stacks of books about AIDS and a surprising number about the "psychosocial issues associated with AIDS." HIV professionals have been well occupied for fifteen years, not only as providers but also as authors, and the result of their efforts has been not just quantity of information and research but also quality. The UCSF AIDS Health Project (AHP) has been fortunate to be able to make useful additions to this library. But before undertaking each project, we have asked ourselves, "Does the world need yet another publication about HIV? What can our work contribute to this literature?"

The answer is experience. Founded in 1984, AHP is one of the world's oldest HIV-related mental health programs and has pioneered some of the most successful mental health responses to the epidemic. AHP is fortunate to be a part of an internationally renowned medical school, and as such has had the opportunity to work with others to develop and staff the number-one ranked AIDS clinical care program in the country at San Francisco General Hospital. AHP also works with a leading prevention research center, the Center for AIDS Prevention Studies.

Channeling Experience

Since 1984, AHP has provided a large proportion of the HIV-related mental health services in San Francisco. In almost fifteen years, we've helped more than one hundred thousand clients.

The AIDS Health Project formulated the first HIV antibody test counseling protocol and went on to develop one of the first counseling and testing programs, a service that counsels and tests
more than ten thousand people a year. We created HIV-specific psychiatric and social work services at the first outpatient and inpatient hospital AIDS wards at San Francisco General Hospital. We pioneered support-group programs for seropositive people and were among the first to recognize the need to offer emotional support to seronegative clients struggling with multiple loss and the challenge of sustaining safer behaviors over time.

We established the first hospital-based AIDS and substance abuse program, targeted toward providing risk-reduction counseling to those with primary substance abuse disorder, and piloted and refined an innovative substance abuse case management program. We developed a mental health crisis team and a mobile psychiatric consultation team that works with community hospice and home health care programs to keep people with HIV disease in their homes for as long as possible. Finally, we led the way in applying a brief psychotherapy model to counseling people with HIV disease.

AHP has also made publications and training a priority. We published the first books on HIV and mental health: Working with AIDS and Face to Face: A Guide to AIDS Counseling. Since 1985, we have published what is probably the longest-running AIDS newsletter in the country (and perhaps the world)—FOCUS: A Guide to AIDS Research and Counseling—certainly the grandfather of all HIV-related mental health publications.

We developed one of the first curricula for training antibody test counselors and have conducted training for both counselors and trainers of counselors throughout the state of California; as part of this effort, we pioneered what may be the only newsletter in the country that targets HIV test counselors, HIV Counselor PERSPECTIVES. We wrote the first book on AIDS and substance abuse and followed this up with a book on HIV and alcohol, and have developed a wide range of training for substance abuse providers. More recently, with the UCSF AIDS Health Project Monograph Series, we are publishing brief, pointed, and practical books on key topics, such as cognitive impairment and triple diagnosis.

**Mountain Climbing**

In geological time, the AIDS epidemic is barely noticeable, a blip of fifteen years. But in AIDS time, even six months can be an eon of revolutionary change, during which fundamental principles may
be reconceived and a new vocabulary invented. Things move too quickly for us to stop innovating; it’s stasis, not silence, that equals death. And we have felt compelled to share our insights with others, as they have shared theirs with us.

AHP’s experience is the foundation on which this book rests, but we have not been content to limit its reach to what we know. When we started developing an outline for the book, we began by searching for authors who we knew could bring expertise, insight, creativity, and clarity to the process of writing about issues that we believed were the most salient—and that we predicted would remain central over time. The result is a faculty of contributors from throughout the country as well as from our own backyard, from such research institutions as Columbia, Cornell, and Stanford universities as well as from frontline organizations in such places as Austin, Texas; Fremont, California; and New York City.

There are plenty of good books about HIV and mental health; our hope is that this book is different. It is not a primer, but it does embody the fundamental principles and central elements of HIV-related counseling. It is not a survey of the field, but it covers the key issues facing counselors working in the full range of settings that compose the front lines of the epidemic. It is not a handbook, but it abounds with case studies and practical applications of theory. It is not a research report, but it has made a concerted effort to offer a review of the relevant recent literature.

What this book is, then, is a compilation of perspectives that depicts the mountain range of HIV-related counseling and psychotherapy by mapping its highest peaks—its most prominent and difficult issues—a portrait of those viewpoints, themes, and topics that in some way define the current landscape of HIV-related care. It is conceived as a guide, a complement to the existing literature, a companion not merely to its AHP sibling Face to Face but also to the bulk of the counseling and mental health volumes in the AIDS archive.

Four Realms of Discourse

We have organized this book to focus on four realms that define the role of counselors working in the epidemic: risk and behavior, psychotherapy and transformation, distress and disorder, and countertransference and therapeutic practice. Another way of thinking
about these realms is in terms of the goal of the provider at each juncture: to prevent transmission, to help clients adjust to HIV, to manage psychiatric complications, and to sustain a practice in light of the unusual conditions HIV imposes. All clients and therapists are called by fictitious names.

Risk and Behavior

Prevention is most often discussed in terms of large-scale interventions focusing on providing information or changing community norms. But what has become increasingly clear over the past decade is not simply that information is not enough for everyone to make and maintain behavior changes—we learned that lesson very early in the epidemic—but also that the greatest barriers to risk reduction are individual psychological ones. Each of the chapters in the prevention section is ultimately about perspectives that can help counselors define the unique obstacles each individual faces and the ways in which the therapeutic relationship can be a tool to help clients identify and implement achievable risk-reduction goals.

Psychotherapy and Transformation

Adjusting to HIV is like aiming at a moving target. At each point in the epidemic, as more information refined definitions of the virus, the syndrome, the conditions, the treatments, and the prognoses, the task of adjustment has been closely related to the current state and limitations of our knowledge. When HIV was an emergency, it was about adjusting to terror, stigma, shock, fear, and not knowing—but this adjustment occurred in the context of medicine’s history of triumph, a history that engendered a belief that despite governmental inaction, the baffling array of symptoms, and the horror of young people dying, this was a crisis that would pass.

When it became clear that the crisis was here to stay, each bit of knowledge was met with enthusiasm, and each contradiction to that knowledge with despair; as we learned more and more, we realized that we knew less and less and, worse, that no amount of knowledge seemed to have meaningful practical applications. During this long period of time, adjusting to HIV was about adjusting
Prologue: Living with Therapy

Michael Helquist

Nothing from my experience of ten years of working with AIDS prepared me for the shock, confusion, and depression that came with my diagnosis of Pneumocystis carinii pneumonia (PCP) in 1992. It wasn’t for lack of familiarity that I felt so ill equipped. I had lost a lover to AIDS in 1983—he was one of the first hundred people with AIDS in San Francisco. There have been far too many other losses since: best friends, colleagues, roommates. For many of them I had been a primary caregiver. I knew about the devastation HIV disease brings upon others. I didn’t have a clue about the devastation it would bring upon me.

I had joined the “AIDS industry” in the early 1980s as a journalist and eventually took on assignments as a columnist, consultant, and editor of five books. I had interviewed researchers, medical doctors, and people with HIV disease and their families, lovers, and friends. For five years, I researched and modified international HIV prevention programs for use in developing countries and traveled extensively to help implement them. I was fully immersed in all facets of the epidemic. I had become an AIDS professional.

Yet AIDS, in the form of PCP, came at me like a hard, cold slap in the face. The shock I might have expected, but I could not have anticipated the confusing and threatening mix of new emotions. During the following four years, I continued to be jolted by the onset of new infections and disabilities. Now, however, I am less

surprised about what I do not understand. I know that I have to work very hard to grasp what is happening to someone else with AIDS, someone who is ostensibly in the same predicament but is, in reality, facing a condition different from mine. I recognize that my knowledge of the emotional and psychic effects of HIV infection is limited mostly to my own experience with the disease.

I believe that other AIDS professionals, including mental health practitioners, even those with many years of experience, may very well be in the same position. Just because we provide counseling to people with HIV disease, or lead group discussions, or write papers for publication, or generally “talk AIDS” does not mean we understand the experience. In the end, I have found that familiarity with AIDS is not enough. I fear that as providers immersed in the epidemic, we may develop an overblown sense of our own knowledge, and that many of us have come to think we understand more than we can.

Knowledge, Empathy, and Flexibility

Several months into my own therapy, I realized that I wanted to achieve a sense of being heard, of being understood in a way that is different, perhaps more profound, than a friend or lover might understand. As part of my own seeking, I came to identify what I consider some of the basic skills and knowledge that would facilitate this goal, that I would want and expect a therapist to possess.

Knowledge

The key medical facts about HIV disease are prerequisites. Familiarity with the primary treatments for HIV disease and its associated infections is essential, and this familiarity must be more than knowing about the primary antivirals and protease inhibitors. I would want a therapist to know of the dozen or so prophylactic drugs prescribed for various infections, their possible side effects, alternatives to these drugs, and the general track record of their effectiveness. I do not believe that it is sufficient for practitioners simply to refer clients to AIDS hotlines, health care providers, or treatment advocacy groups. Such referrals can be invaluable, but I think they should supplement the information therapists can give directly.
to disability and death. There were many ups and downs during this period: highs when AZT appeared to work, when vaccine studies suggested achievable cures, when combination therapy extended life; lows when the limitations of each advance were understood and when it seemed that progress was only about adding a year or two or three—precious time nonetheless—to what would still end as truncated lives.

Today, with the success of triple and quadruple combination therapy, more effective treatment and prophylaxis for opportunistic conditions, the identification of new surrogate markers such as viral load, and the compelling reality of people rising from near-death, adjusting to HIV for many has become about adhering to complex drug regimens, managing a chronic condition, and dealing with a newly extended future, interpersonal relationships, and life goals. There remains uncertainty, an ingredient that has always been part of the adjustment process. And for many, the failure or inaccessibility of these miracle treatments has made adjusting to disability and waning health all the more difficult as there arise feelings of inadequacy, isolation, abandonment, and deepening despair.

Whatever one’s perspective, HIV has always been about change. It could be no other way. And HIV-related psychotherapy has been about achieving a positive transformation no matter what the content of the adjustment. This is not a Pollyannaish response; it is the reality of human psychology. The chapters in the psychotherapy and transformation section offer a variety of perspectives on the wide range of approaches therapists have at their disposal. The section also includes chapters on two particularly difficult challenges that arise in psychotherapy: the psychosocial concerns that are arising in the context of the new treatment successes, and the effect of stereotypes and assumptions on the psychotherapeutic process.

**Distress and Disorder**

As overwhelming as HIV is, it is not the only influence on a person’s life. Each client brings to the experience a set of preexisting strengths and weaknesses. The third section of the book focuses on distress and disorder and, to a large extent, on the role of a person’s preexisting psychology in complicating the adjustment to HIV. The chapters in this section catalogue the range of disorders
that may arise in this context. They also discuss the extent to which HIV disease itself may lead to or create psychiatric disorders where none had existed before.

Therapeutic Practice and Countertransference

Surprisingly little has been written about the challenges therapists face as they work with HIV, both in terms of countertransference—the reflections of their own lives in the lives of their clients—and their experience of the epidemic as participants rather than providers. The section on therapeutic practice surveys the literature and looks at the ways in which HIV alters the therapeutic frame, the ways in which therapists undertake and respond to the process of practicing psychotherapy, the difficult decisions HIV requires therapists to make, and the monumental effect of grief and loss on burnout and care.

The goal of any book about HIV must be to help us all transcend the struggle. Most of the time, work in the field sweeps you along; there is a lot to do, and pausing appears to be a luxury that few can afford (even though, in reality, it is a necessity that few can afford to deny). But reading can be a reminder that there are others out there also struggling and sometimes even transcending the struggle in creative ways.

This book represents an opportunity for you not only to learn from the unique experiences of others but also to reflect on those experiences. If this book does nothing more than validate what you have learned over the years, it will have made a contribution. But we also hope it introduces you to ideas and approaches that foster new ways of thinking and doing, proving to be more than just a contribution and revealing itself instead as a gift and an inspiration to continue this important work.
For example, I have been greatly aided when my therapist has been able to explain some of the possible manifestations of different infections, especially when he has given me some perspective on the degree of discomfort or pain that might be involved. I have not looked to my therapist for medical advice; I have an excellent physician to turn to for that assistance. But my therapist has helped me manage my anxiety around certain medical procedures, and he has guided me in dealing with my fears about, for example, loss of vision, disfigurement, and dementia.

Empathic Surrender

Time and schedule demands for therapists can be restrictive and unrelenting, possibly interfering with their ability to learn about the HIV experience. A convenient and likely source of HIV-related information, especially the more subtle manifestations and implications, can be the client. If I had CMV retinitis, I would welcome a therapist acknowledging, for example, that he or she could not fully comprehend the reality of losing one's vision but was interested in knowing more about what I was experiencing. The therapist could follow this acknowledgment of limits and of being uninformed with questions to the client about the physical and psychological impact of vision loss.

I think practitioners may need to surrender themselves to particular experiences of their clients. In addition to listening, analyzing, and being supportive, therapists need to be willing, in a sense, to enter the world of their clients. For instance, three years ago I was diagnosed with an uncommon HIV-related blood circulation problem that resulted in bone cell death in my hip joints. Walking became difficult and often required my using a cane. Although I could identify for my therapist some of my feelings about these circumstances, his extra effort to enter my world allowed both of us to confront and feel my panic, fear, shame, and despair over my disability. During this time, each of us expressed, through silence and conversation, the pain of so many losses and the courage it required to surmount the embarrassment and shame of living with an AIDS disability in public. This experience emphasized for me that my therapist was truly present with me. I felt that I could trust him even more to accompany me on the journey I face with AIDS.
Flexibility

I have felt profoundly humbled by the challenges of living with AIDS. I never imagined that I would have such difficulty expressing my feelings. In therapy, sometimes I do not want to have to struggle to verbalize what I am experiencing on the deepest levels. I don’t want to be cognitive and rational and explanatory—a process that seems to glide over my feelings. In these instances, I do not want my therapist to exhort me to express myself simply. I want a therapist who understands the limits of language, who understands that there are no words to describe the profound nature of many feelings.

What I have found helpful is to define with my therapist ahead of time a way of conducting a session or part of a session in non-verbal ways, to explore my most profound feelings. For example, during one session, I acknowledged my belief in a Divine Spirit and talked with my therapist about my desire to find a way of more emphatically experiencing spirituality in my life. My therapist suggested that throughout my day I might invoke the Spirit and request help and guidance from it. We decided that I would also pursue this engagement with the Spirit in my next session.

I arrived the following week to find the lights dimmed and candles lit in my therapist’s office. I was quite moved by his willingness to alter the therapeutic environment and process. I sat this time on the couch closer to his chair. I asked that we hold hands to help me focus as we recognized the Divine Spirit among us. I asked the Spirit for help with specific personal struggles and for guidance in general. In the ensuing silence, I felt calm and grounded in my own reality.

During other sessions with my therapist, I found it helpful when he disclosed something of his own life that was relevant to the feelings I presented. For example, when I was talking about my fear of losing my mental abilities, my therapist mentioned that one of his close friends had experienced such a loss. We did not dwell on his friend’s fate, but the disclosure reduced my sense of isolation. I felt that he knew firsthand some of what I feared. Although some might fear that such a flexible and creative response would transform the therapeutic relationship into a “friendship,” I have found that my therapist’s actions have strengthened the thera-
apeutic bond. When further physical decline seemed imminent, I often felt separated and isolated, and I cherished any demonstration of understanding and empathy with heartfelt gratitude.

Treatment, Health, and Self-Esteem

With the increasing availability of protease inhibitors and other new medications, many people with HIV disease have watched their CD4+ cell counts climb and their viral loads plummet. The number of HIV-related deaths has dropped dramatically across the nation. Now that I have experienced the benefits of combination therapy and the protease inhibitors, my own self-definition as it relates to AIDS has changed. I have come to think of my HIV status not as positive or negative but as one of "extension": my life has been extended as a result of my treatment.

I have been immensely thankful, and a little stunned, by my shift to relatively good health. I know there are many others who have not received the same benefit from the new medications or who haven't had the chance to try out the treatments. Again, I realize that I cannot fully understand their experience, but I imagine many feel greater isolation from the "world of the well" and experience a sense of general abandonment. These clients especially will need reassurance that their therapists will remain focused on their difficulties.

Although the media has presented the phenomenon of renewed health in simplistic terms, the individual experience can be quite complex. I have faced a general disorientation about my new health status: having self-identified with my "end-stage" condition for so long, I have been unsure what meaning my new healthier life might hold. My everyday world of social contacts and experiences had shrunk so much during the years of illness that I have struggled—and stumbled—in my attempts to re-create a larger family of diverse relationships.

The opportunity to become more productive and creative also stymied me: What was meaningful to me now? I can laugh sometimes at the unexpected arrival of a human passage I thought AIDS had helped me avoid: a full-blown midlife crisis!

No matter how much my health has improved, I still feel like an outsider. The experience of declining toward death, and then
of an uncertain recovery, has changed me; I do not feel the same as those whose lives were not similarly disrupted. Therapists may need to try even more to understand these disparities once their clients with AIDS outwardly appear more similar to their general patient population.

During the course of the last fifteen years, mental health practitioners have provided invaluable assistance to thousands of people with AIDS. Working with AIDS may be professionally challenging and rewarding, but the generosity and compassion of the therapeutic spirit must get battered and worn down by these struggles with roller-coaster crises, dying, and death. I believe the best therapists are those who recognize their own limits of understanding and who commit themselves to greater learning and experience to bridge such gaps with their clients. In seeking therapy, I would make a commitment to a practitioner who was willing to alter standard practice to deal effectively with my unique issues and needs. Finally, I would question any practitioner who does not feel humbled by the invasive power of this disease and who does not feel awed by the endurance and courage of those who live with it daily.
Acknowledgments

Like many of the authors and editors of AIDS books who we know, we've fit the enterprise of creating this book into lives filled with clinical work on the front lines, research, program planning and management, and, of course, grant applications and fundraising. We could not have made this book come together without the help of many. Our most heartfelt thanks must then go to the contributors to this volume, also working on the front lines yet maintaining their composure and cooperation as we journeyed from revision to revision, deadline to deadline. Thank you for your patience, certainly; but more, thank you for your commitment, your knowledge, your openness, your insights, your help, your generosity.

The only way to undertake a project of such magnitude is to carve out time, and the only way to do this is with the support and commitment of allies. At the UCSF AIDS Health Project (AHP), three allies have been particularly important. Joanna Rinaldi, deputy director, played the delicate role of taskmaster, facilitator, sounding board, and cheerleader; more than any other, she was the person who helped us move forward with gentle prodding and a constant eye toward the task of managing multiple tasks. We offer her our heartfelt thanks. Shauna O'Donnell, publications assistant, must have bitten her tongue many times as she put up with the craziness that occurs over the final year of a process like this one. Her good sense, organization, ingenuity and creativity, and editorial expertise were invaluable. John Tighe, senior editor at AHP, was at our right hand, able to handle other publication projects and offer support to allow us, at times, to focus on this project to the exclusion of others.

There are many other people at AHP who were involved in the conceptualization, the production, or the support necessary to the successful completion of this journey. A while ago, we sat around a
table with JD Benson, Jackie Brookman, Paul Causey, Marcia Quackenbush, and John Tighe to plan the book, and their ideas form the backbone of what has evolved over time. JD, in particular, was very involved and was crucial to our efforts, not only in terms of developing the concepts for the chapters but also in seeking out authors who would ensure the quality and integrity of the book.

Michael Helquist and Steven Follansbee—each an outside volunteer adviser to AHP’s publications program—are ubiquitous in our publications process. Their beneficent influence and clinical insight are everywhere.

Julie Balovich, Meredith Faggen, Miriam Garfinkel, Israel Katz, Susan LaCroix, and Emily Leavitt, among others, helped us help authors of specific chapters, offering both clinical and editorial insights. Patricia Sullivan deserves special thanks for reviewing the whole book and offering many important comments. These individuals provided authors the feedback crucial to honing their work.

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Finally, we have been blessed in our personal lives with people of unfathomable patience, good cheer, and great wisdom. A special thanks to Jorge Morales and Saul Rosenfield, who offered not only their love and respect but also their advice, guidance, and good humor.
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The UCSF AIDS Health Project (AHP) is affiliated with the Langley Porter Psychiatric Institute of the world-renowned medical school at the University of California, San Francisco, and has been a leader in developing clinical services and professional education to meet the mental health needs of people living with HIV disease. Since 1984, AHP has been nationally recognized for pioneering programs in a variety of areas: HIV-related counseling and support, HIV prevention services including antibody testing and counseling, and HIV and substance abuse services. AHP publishes FOCUS: A Guide to AIDS Research and Counseling, one of the longest-running
HIV-related newsletters in the country; books, including *Face to Face: A Guide to AIDS Counseling*; and newsletters. It also publishes the UCSF AIDS Health Project Monograph Series, including short volumes on topics such as HIV-associated cognitive impairment; the triple diagnosis of HIV, addiction, and psychiatric disorder; bereavement; and the psychosocial implications of successful antiviral treatment.
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**Michael Helquist** was one of the first journalists in the world to cover the AIDS epidemic, publishing some of the earliest interviews with...

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The UCSF AIDS Health Project
Guide to Counseling
The UCEA AIDS Network Project
Guide to Condom Use
Part One

Risk and Behavior
Helping Clients Remain Uninfected

At first glance, preventing AIDS appears straightforward, even simple: HIV infection is a sexually transmitted disease, and as with any STD, protection from it requires that transmission be interrupted. Yet from the first moments of the epidemic, confusion has reigned about what was “safe,” “possibly safe,” and “unsafe.” It has also been clear that for many, changing behavior was going to be difficult and that maintaining these changes over time was bound to be an even greater challenge.

What may have seemed so simple in the context of an emergency became more complex as prevention practices became more normal. This might appear paradoxical, but of course it is not; having protected sex, even being abstinent, seemed an attainable goal when it was the prescription for only six months, or two years, or perhaps even a decade. But to accept as normal—forever normal—the loss of sexual practices that for many are fundamental to intimacy and pleasure stretches beyond the limits of imagination.

Gay and bisexual men responded heroically when HIV prevention was urgent; but grief, bewilderment, anger, and time have worn that resolution thin. Gonorrhea rates—one sign of the efficacy of HIV prevention efforts—are rising, even as the rate of death from AIDS is falling, a tribute to new HIV treatments and a sad commentary on the long-term efficacy of the HIV prevention interventions that have redefined sex for a generation of people. And despite significant decreases in seroprevalence among injection
drug users, it also remains true that for drug users, as for people who don’t use drugs, changing sexual behavior and maintaining those changes remain difficult.

These conclusions do not negate the fact that huge numbers of people have adopted safer sex practices and will continue to protect themselves. Nor do they overlook the fact that it has been and continues to be the failure of governments to support needle exchange, and not primarily the failure of drug users to change their behaviors, that has cost thousands of lives. Instead, these conclusions act only as reminders that the task of HIV prevention remains critical as the risk of HIV transmission endures.

In this part of the book, a number of authors discuss the need for mental health approaches to HIV prevention. They go on to suggest new perspectives and strategies for functioning in the complex and ongoing struggle to stop the epidemic.
Chapter One

HIV Test Site Counseling for Gay Men

Harm Reduction and a Client-Centered Approach

Walt Odets

Born in the emergency of the early and mid-1980s, HIV prevention for gay men has drawn intuitively on traditional public health approaches, which relied primarily on the provision of information. Since then, this approach has changed little, although it has been augmented with aspects of cognitive-behavioral learning theory (the Stages of Behavior Change,¹ the theory of reasoned action,² and the health belief model³) and “social marketing” concepts, particularly the work of Jeffrey Kelly.⁴ (For more information on these models, see Chapter Three.) These approaches to AIDS prevention have borrowed largely from work on “addictive” behaviors (substance use, overeating, and “addictive” sexual behavior), criminal behavior, and other nonsexual public health issues. Cognitive-behavioral learning theory and social marketing have been applied through media and clinically based prevention interventions, including the counseling opportunity provided by HIV antibody testing. All forms of intervention have almost invariably assumed the elimination of risk. We believed that we would stop the epidemic by preventing any new infections in informed—and properly “educated”—populations. Today, many still believe that we will stop the epidemic by applying these same approaches even more vigorously.
In the context of the emergency of the early years of the epidemic—which we hoped, if not fully believed, would be quickly limited by a medical solution to HIV infection and AIDS—the idea of risk elimination made sense. In fact, during these early years, many gay men heeded the message by adopting significant changes in sexual practices, including what was, for many, the radical solution of temporary abstinence. Many decided to avoid any possibility of exposure to a potentially fatal infection until there was treatment, and even the most conservative and emotionally costly measures against infection often felt appropriate and achievable in the short term.

The Unavoidable Truth of Continuing Transmission

For the first decade of the epidemic, newly discovered infections could be attributed to behavior that had occurred before we had knowledge of HIV and its transmission. Although the general public constructed its own definition of the “innocent victim of AIDS”—these were almost invariably nonsexual transmissions—in gay communities, innocent victims were those infected “before we knew.” As the epidemic matured, unabated and medically uncontrolled, through the remainder of the 1980s and into the 1990s, and as those who had once tested seronegative suddenly tested seropositive, it became increasingly apparent that short-term, risk-elimination approaches to prevention were falling far short of the relatively complete results we had earlier expected. At first, both educators and gay men themselves denied that informed gay men were continuing to allow themselves to be exposed to HIV or were exposing others. But there was substantial evidence as early as 1988—at the very time prevention programs for gay men were widely being abandoned because their “success” rendered them unnecessary—that as many as one-third of San Francisco’s gay men were willing to self-report that they were engaging in the most stigmatized of behaviors, unprotected anal sex.

From the perspective of public health traditions, which equated information with the elimination of risk, such behavior could be understood only as a result of continued ignorance, substance-induced impairment, sociopathy, or psychopathology. “There is,” a San Francisco educator said in 1990, “a lunatic fringe
we will never reach.” But as HIV providers finally began to acknowledge the inescapable fact that there were new infections among a broad cross section of “informed” gay men, we also came very slowly to acknowledge—but only sometimes understand—the relative complexity of the issues.

Certainly, a significant portion of new infections among gay men could no longer be attributed to ignorance of the transmission risks, and only a small percentage seemed causally attributable to substance-related impairment, sociopathy, or psychopathology. The message from gay men should have been clear. Social and psychological identifications with particular sexual behaviors, HIV, and AIDS were unexpectedly complex in a stigmatized minority community with seroprevalence rates as high as 50 percent in urban, gay male populations. Despite widely held assumptions that gay sex was substantially “recreational” and thus dispensable, sex and sexual intimacy between gay men came to be understood to have many of the same important meanings for gay men that it did for heterosexuals. The forbidden “exchange of body fluids” was not only a medical issue but one connected to fundamental feelings about intimacy.

Other feelings—about trust, relationships, and sexual communication—were affecting what gay men actually did in the privacy of the sexual encounter. Men were attaching importance to unprotected sex within relationships (or sometimes outside them) as evidenced by the practice of “negotiating” safety with partners of like serostatus. They were almost universally rejecting the use of condoms for oral sex, despite inconsistent but continuing suggestions by some prevention educators in the United States that it “might be risky.” In other words, even as it was becoming widely accepted that prevention, rather than the treatment of HIV infection, offered the only hope for controlling the epidemic, many compelling issues were motivating gay men to practice de facto harm-reduction approaches rather than the risk elimination assumed and expected by public health.

By definition, harm reduction is not intended to completely eliminate behavioral risk; instead, it aims to help minimize possibly adverse consequences of the behavior. Harm reduction assumes that some risks are not entirely avoidable and that others are risks that an individual does not wish to avoid because of the value he
or she places on the activity. But even by the standards of harm reduction, gay men’s attempts at minimizing HIV-related sexual risk during the first decade of the epidemic resulted in a high, probably unnecessary level of seroconversion. Unfortunately, this attempt was almost completely unsupported in public health messages, and gay men were thus left in ignorance of facts and approaches that might have facilitated their effort. Furthermore, many educators have used the results of this flawed effort to justify the retrenchment and redoubling of risk-elimination approaches, with little or no effort to understand why gay men had rejected risk elimination in the first place. Public health, in assumptively positing risk elimination, has insisted on values that many gay men do not share, and has thus withheld support that might save many lives.

**Balancing Risk Against Value**

In our daily lives, we attempt to completely eliminate risk only for those activities on which we place little or no value. For activities we do value, we routinely exercise harm-reduction approaches by weighing the relative value of the activity in our lives—the costs of not taking the risk—against the costs of the potential risk. A vast majority of Americans drive or ride in automobiles despite the knowledge that approximately forty-five thousand people—roughly the entire American death toll of the Vietnam War—are killed on the road annually. Because we value mobility, the costs of not taking the risk of *reasonably conducted* automobile travel are considered too high. We achieve a level of reasonableness through the safety engineering of automobiles, careful road design, and the exercise of personal responsibility in when and how we drive.

But we do not fully exercise known technology to manufacture automobiles that might nearly eliminate risk, because the price to the consumer, increased fuel consumption, and relatively poor drivability would be too costly. We do not require occupants to wear helmets because of cost, personal inconvenience, and vanity. We do not insist that drivers be alcohol free because of the personal and social costs of abstinence. In others words, we establish an expected way of going about automobile travel that allows a balance between the value we derive from it—and from related activities that increase its risk—and the potential costs of taking the risk.
This harm-reduction approach is expressed every time we enter an automobile.

Our behavior, if not always our public assertions, suggests that the majority of people value sexual expression at least as much as mobility. But most AIDS prevention work to date, rooted in the assumptions of risk elimination, has defined “safe” sexual expression in ways that large numbers of gay men are demonstrably finding unreasonable because it impinges too severely on the aspects of sexuality that gay men value. Contrary to a relatively broad acceptance of the necessity of vaginal sex for heterosexuals—and uncounted millions spent on contraceptive methods to allow it without pregnancy or condoms—we have consistently told gay men to use condoms or abstain from anal sex. Despite a paucity of evidence for HIV transmission through oral sex—and a huge body of data suggesting it is an extremely low risk activity on a par with many other daily activities—prevention organizations have persisted in instructing gay men to routinely “suck latex.” Many of the same educators who promote mutually monogamous relationships—which include ordinary, unprotected sex—as a “most effective” prevention approach for heterosexuals have insisted that, for gay men, such negotiated safety may simply be “negotiated danger.”

These unreasonable attitudes and prescriptions are rooted in many feelings. They often reflect authentic concern for the welfare of gay men and, thus, a belief that prevention should “err on the safe side.” Unfortunately, these cautious prescriptions also often express the public health official’s, educator’s, or counselor’s anxieties and unclarified feelings about both sexuality and risk. Too much of our educational approach for gay men reflects an erotophobic and homophobic dismissal of the importance of human sexuality and a deeply held American belief that longevity is more important than quality of life. “What I think about when I read the New York Times obituaries,” an official of the British National Health Service said to me, “is how long Americans live—and why they would want to.”

American society, which is now almost alone among Western countries in pursuing a risk-elimination approach to HIV prevention, has traditionally been reluctant to accept any costs for “socially unproductive” activity, particularly if it is experienced as sexual, sensual, or “indulgent.” This is an attitude that many gay
men, internalizing societal erotophobia and homophobia, are inclined to collude with, at least publicly. Thus it is the rare gay man in the United States who would not feel more comfortable about dying in an automobile accident—preferably while commuting to a respectable job—than by contracting HIV through sexual intimacy. It would also be the rare HIV counselor who would not feel similarly about those whom they have counseled. Unfortunately, such values fail to consider the serious costs in lives constrained by fear of censure and impoverished by excessive compliance with social expectations. For all the American dialogue about “individualism,” we have much less tolerance for certain kinds of differences among individuals than many, more apparently conformist, Western societies.

By its very nature, a risk-elimination approach to HIV prevention must provide minimum-risk behavioral guidelines and information and advice on how to adhere to those guidelines. In contrast, harm reduction assists people in the clarification of personal values and their expression in a life balanced between the costs of taking risk and not taking risk. In asserting that no risk is or ought to be acceptable, risk elimination assumes values for the individual: that the activity is never worth the risk. If the risk is connected to activity about which people are already acculturated to feel ambivalence, shame, or guilt—as many gay men are about their sexuality—many will publicly voice compliance with risk elimination, even as they retreat, sometimes unconsciously, into harm-reduction alternatives. Although unprotected anal sex has become the single most stigmatized behavior in the public rhetoric of gay communities, it is widely practiced, a fact evidenced by rates of new infection. This unfortunate consequence is not a result of inadequately asserted risk-elimination approaches. It is instead a result of dismissing the real values and needs of gay men and thus denying gay men the information, education, and counseling necessary for authentic, lifelong adjustments that reduce harm.

Without such assistance—and with the insistence that many obvious and widely practiced harm-reduction approaches may be “negotiated danger”—many gay men have been unable to make informed, conscious decisions about the balance between benefit and risk. Currently, gay men are in the same predicament in which we would all find ourselves if health and safety authorities decided
that any automobile travel over thirty miles per hour was unacceptably risky and prohibited it rather than educating the driving population about reducing risk while exercising the obvious, often desirable possibility of highway travel at higher speeds. The results of the restrictive approach—an unnecessarily large highway death toll as uneducated drivers flaunted the unreasonably low speed limit—would indicate not a need for more vigorous enforcement of the thirty-mile-per-hour limit but rather the need to examine the conflict between personal and publicly dictated values. As with gay men and sexual risk, to say that “speeders” acted solely out of incompetence or noncompliance—that they were, in the words of some AIDS educators, merely “unable or unwilling to immediately cease all risky behaviors”13—would miss an important point about useful approaches for health and safety promotion and about human life and its potential enrichment through mobility and interpersonal intercourse.

Client-Centered Counseling: A New Mandate

In May 1994, the Centers for Disease Control and Prevention (CDC) released new guidelines describing “client-centered” counseling for clients at HIV antibody test sites. Aware that information-based prevention—even with the addition of behavior change models and social marketing techniques—was falling short of expectations, the CDC hoped that client-centered counseling would be helpful in addressing some of the more complex individual issues, including so-called psychosocial issues.

Long before the new guidelines were released, many HIV test site counselors had gained substantial experience with the limitations of the traditional public health approaches they had been practicing.19 Historically having achieved poor results with sexual issues, public health was doing particularly badly with the AIDS epidemic in gay communities. “Risk assessment” and information and counseling derived from a structured behavior change model were producing startlingly poor results. By 1996, two in every three gay men who tested positive at a San Francisco alternative test site (ATS) had previously tested negative and received counseling at a California ATS.19 In gay communities, with seroprevalence rates as high as 50 percent, the social and psychological issues were deeply
rooted, complex, and unlike anything public health had ever been called on to address. Gay men were deeply identified with HIV and AIDS, and many seemed to experience HIV infection as inevitable, plausible, or even desirable. Many HIV-negative test results were producing bewilderment or overt distress, while some HIV-positive tests were appearing to provide resolution and relief. Such complex, ambivalent feelings about HIV were clearly unaddressed by simply counseling men about how to avoid HIV.

Many test site counselors, as well as others working with gay men, thus welcomed the CDC’s mandate for a client-centered approach that might help address psychosocial issues. But the relatively broad guidelines issued in support of the mandate left many counselors in a quandary about what exactly client-centered counseling was and how it might be implemented in the context of what had been a traditional public health risk assessment directed toward structured behavior change. There are, in fact, many assumptions intrinsic to a traditional public health approach and to cognitive-behavioral learning theory models that cannot be part of a truly client-centered approach. The CDC mandate may have thus implied more—and introduced more complexity and contradiction—than was appreciated or intended by its authors.

Client-centered counseling is, by definition, concerned with a process intended to help a client make personal clarifications (which may lead to individually desired changes and results), rather than with directing the client toward an assumed set of results.¹⁶ Although the process of client-centered counseling may help a client reframe his initial presentation of his experience, client-centered counseling always begins with acknowledgment of and unconditional respect for the client’s framing of his values, needs, and purposes. Client-centered counseling is thus largely incompatible with the intent to assess risk, provide information, and lead the client through a structured progression of expected behavior change.¹⁷

In contradiction to the assumptions and expectations of risk-elimination counseling, many clients do not experience themselves at risk, even when they clearly are; some unrealistically experience themselves at risk when, in fact, they are not, and some experience no desire or intent to change behaviors even when they perceive the risk. Some gay men may not even believe it desirable to avoid HIV infection. To simply describe such clients
as arrested in one of a progressive series of stages of behavior change posit assumptions and values many clients would not accept and ignores the complexity and variety of individual experience. A client-centered approach could only help such individuals clarify the reasons they framed their experience as they did, which might or might not result in the clients themselves beginning to reframe their values and purposes. Risk assessment, the provision of information, and a structured approach to behavior change could thus qualify as a client-centered approach only for those clients who clearly—and credibly—expressed their purpose as the change of any behaviors that entailed any risk, regardless of the value of that behavior.

In the context of HIV test site counseling for gay men, client-centered approaches will usually dictate a harm-reduction approach because HIV is usually contracted by gay men, as it is by heterosexuals, through behaviors that many value, sometimes considerably. The client-centered approach will help the client clarify his values and his feelings about risk and thus ultimately arrive at a personal balance between the value derived from the behavior—value suggested by the costs of modifying or abstaining from the behavior—and the potential risk entailed in the behavior. Most people will accept risk in some proportion to the value they place on the activity.

Helping an individual clarify his values about behavior and its potential risk is not always a straightforward process, and the process may be limited by the duration or setting of the counseling opportunity. Gay men seeking HIV testing and counseling very often experience a complex mix of conscious and unconscious feelings and desires, an anticipation of what is expected of them by public health personnel, and an awareness of social values and expectations that may be partially or wholly inconsistent with their own. The client's initial presentation of this complex mix of needs, desires, and internal and external expectations often obscures the real issues with which the client is grappling. Contradictions—for example, between a client's stated values and his actual behavior—often provide the clues that allow a counselor to begin to help the client clarify his situation.

More often than not, the strictly time-limited opportunity of HIV antibody test counseling will allow a client-centered approach
to do little more than introduce the client to the process of clarification and, when appropriate, refer the client to additional services. This effort may produce a wide range of results, including unexpected or even undesired ones. Time-limited counseling will only very rarely lead to a resolution of any issue, will often produce no behavior change whatsoever, and will usually not even result in an authentic decision to change behavior. Many clients will refuse referrals or not follow them through. The entire process of client-centered counseling is predicated on the counselor’s willingness to relinquish control of the outcome and place trust in the client’s own motivations and ultimate ability to live his own life as constructively and richly as he might. A client cannot be made to change—and can only rarely even be motivated to change—complex private behaviors by means of instruction or coercion.

Nevertheless, the time-limited client-centered approach will often initiate a process that may help the client ultimately generate his own clarifications about the desirability, possibility, and implementation of behavior change. The process can provide authentic, long-term changes in behavior that exposes the individual to unknown, unnecessary, or unintended risk.

**Case Studies: Client-Centered Counseling in Context**

The following case studies demonstrate a client-centered approach in time-limited HIV antibody test counseling. In addition, the vignettes illustrate some common issues encountered during HIV counseling for gay men.

**John: The Risk of Oral Transmission**

John is a twenty-four-year-old Latino man who has lived in San Francisco for one year and is not currently involved in a long-term relationship. On receiving his HIV-negative test results from a counselor, Ross, at an anonymous test site, he shows considerable relief. In response to his counselor’s question about why he came in for this test, John says, “I know all about safe sex, and I know that AIDS is not going to be part of my life.” He also reports that he has tested for HIV “maybe six or eight times” and that he came in for this test because, “I guess I have a lot of oral sex and I just wanted to be sure I was OK.”
Ross: And do you feel that oral sex might put you at risk for contracting HIV?

John: Well, I don’t think so, but you never know. I mean some people say it’s possible, but I don’t think so myself. I’m not really sure.

Ross: It sounds to me like you might be worrying about it. You’ve had quite a few tests. Are there other things that you feel you might have gotten HIV from?

John: No, all I ever do now is oral sex. I mean I had anal sex with my boyfriend but we always used condoms for that. But since we split up I haven’t done anal sex. I don’t have anal sex with guys I’m not in a relationship with because for me it’s too personal. I know you can get HIV a lot easier from that. And I’m not worrying about sucking guys off, which I do when I go out, but I’m not sure. I mean, have you ever had anyone who got it from oral sex?

Ross: The California Office of AIDS, which has collected data on about fifty thousand gay and bisexual men, tells us that oral sex is an extremely low risk activity. But that doesn’t mean it’s 100 percent safe or that it’s impossible to get HIV through oral sex. But I feel like maybe you’re uncomfortable with the idea that there’s any risk at all.

John: Well, getting AIDS would be a big deal. I know there are a lot of treatments now, but . . . I also know that some people say you should use condoms for oral sex, but I’ve never met anyone who wants to do that. I mean, it’s pretty bad, and I don’t want to do it either. Even if I did, I’d have trouble asking another guy to do it anyway.

Ross: Well, I’m wondering now if oral sex with other guys—without condoms—is important to you. Or how important it is.

John: Well, like I said, it’s the only kind of sex I have. . . .

Ross: And is sex important for you?

John: I feel like you’re saying it shouldn’t be important. Well, I don’t know if you’re saying that, but I know that a lot of people would say it’s a lot more important not to get AIDS. That’s your job, isn’t it? To tell me to not get AIDS, which I already know? I mean, most of society doesn’t even think I should be doing it at all.

Ross: I didn’t mean to suggest that sex shouldn’t be important to you or that it should be important. I’m trying to understand how you feel. You say that you do oral sex fairly often, that it’s the only kind of sex you have, but you also seem afraid of getting HIV from it. I feel like you want me to assure you that it’s completely OK, and if I could only tell you it was completely safe, you could feel better about it.
John: Well, it's important to me. And I don't think I deserve AIDS for it. But if I had to tell my family I was positive, I know they'd just kill me. I would never want to have to tell them that, especially my mother, because I know it would just be too much for her. I could never tell her.

Ross: Tell me if I'm wrong. If it were just you, I feel like you're telling me that you'd take a very small risk for the oral sex you're having, that it's important enough to you that you'd do that. Normally, we do take some risk for things we value. For the moment, I'm just thinking about how you feel.

John: Yeah, when you put it that way, then I'd say that I know I'm not going to stop having sex, that I don't want to do that. If there's a little bit of a risk, well, I'd say that I just have to take that chance, because I know you can't be completely safe and still have a life. I'm not having sex all the time, but having sex with guys is important to me.

Ross: I believe that a lot of people would support your sexual feelings—and that they would want no harm to come to you for expressing them. I also know that you have some other feelings here too, especially about your family and maybe about what society—at least some of it—think about gay sex. I know that those feelings may be important to you too and that they can affect how you feel about sex—that you worry some about it—even though sex is important to you and even though you seem to be having sex in a very reasonable way.

John, we have to stop in a few minutes, and I have a couple of ideas. One is that I can tell you about a few commonsense things that we think may lower the very low risk of getting HIV through oral sex. And the other thing I thought of is that we have groups of gay men about your age in San Francisco who get together to talk about all kinds of things—including sex and their families! I thought that you might find one of these groups fun and that it could help you think through some of your feelings that we haven't had time to talk about today. I can tell you who to call about a group if you think you might like to do that, even if you just want to see what it's like.

In this vignette, the counselor believes that John is well educated about the facts of HIV transmission, that his behavior probably falls in a very low range of risk, and that, with assistance, John is capable of clarifying his feelings and values. John is probably not engaging in activities that pose an unknown, unnecessary, or unintended risk. He does not seem to be using sex in unconscious,
compulsive, or destructive ways, and Ross feels that John needs some reassurance about his sexual feelings and behavior.

It is also apparent that John feels some conflict between his own sexual feelings and needs and his sense of others’ expectations of him: “Well, it’s important to me. And I don’t think I deserve AIDS for it.” The latter assertion, a feeling introduced by John himself, suggests that John might actually have some unstated or unconscious feeling that he does deserve AIDS for gay sex, that others are expecting him to get AIDS, or that gay sex might somehow inevitably lead to contracting HIV. Ross believes that such unstated or unconscious feelings might contribute to John taking more risk than he would otherwise take. Thus, more comfort with his sexuality (as well as insight about the prohibitive or punitive feelings and expectations of other people) might lower John’s risk of contracting HIV.

Although this issue seems too complex to address in the session, a peer group of gay men might help John clarify some of his feelings. Because John has been living in San Francisco such a short time, the counselor also believes that John may lack nonsexual connections with other gay men and adequate social support. John’s comment that he would “have trouble asking another guy to do it anyway” suggests that he might also benefit from talking about sex with other gay men in a nonsexual setting.

Roger: Taking Risks for Unsatisfying Sex

Roger is a thirty-nine-year-old gay man who has been living in San Francisco for eleven years and is not currently in a relationship. Roger tells his counselor, Ann, that he “probably does some things I shouldn’t do” and that he has not tested for HIV in four years. His response to his negative result is flat—“Well, that’s good”—and he seems anxious to leave the counseling session.

Ann: I’m wondering what we could talk about that would be useful for you.

Roger: Well, this was more your idea than mine. Apparently I’m negative, and I don’t know what else there is to say about it.

Ann: It was sort of my idea—the state of California is paying for me to spend some time with you. But maybe we could do something with the time that would be useful to you anyway. One thing I’m wondering about is why you tested at this particular time. You haven’t tested in several years.
Roger: No particular reason. Like I said, I’ve probably done a couple of things I shouldn’t have.

Ann: When you say you “shouldn’t have,” I’m not sure what you mean. Do you mean things you didn’t want to do but did anyway?

Roger: Yeah, things I could’ve gotten HIV from. I know all about safe sex, but I’ve had some unsafe sex. I’ve had anal sex without a condom—twice with a guy I know was positive. I don’t usually do that. And I’ve had anal sex with guys whose status I didn’t know, once or twice.

Ann: I’m wondering about the possibility that you wanted to do this, but that it also posed an HIV risk, which you didn’t want. I know you know that receptive anal sex without a condom is one of the easiest ways to get HIV. And I guess what I’m wondering about is whether you did what you did because it was important enough to you that you felt like it was worth the risk.

Roger: It seemed like it at the time.

Ann: But not later? Not now?

Roger: No, I don’t think so. I mean, it depends. I have a lot of sex when I have nothing else to do. I get restless. I usually go out on the weekends for sex, and, you know, it’s very easy to find. And mostly it’s—well, you don’t get much from it. I usually feel worse afterwards.

Ann: Could it help you feel better?

Roger: It could help me feel better, I guess, but it usually doesn’t. I guess if I’m down or feeling bad about myself, I have the idea that it will help me feel better.

Ann: And do you feel down a lot?

Roger: Yeah. I mean, I have this incredibly boring job, and I feel like I should be going somewhere with my life. And I don’t have that many friends anymore. Some of them have died and a lot of them have moved away.

Ann: So it sounds to me as if you are feeling pretty bad a lot of the time. And also that you’ve been using sex to try to feel better.

Roger: Yeah, that sounds right. Mostly I don’t go out anymore, but when I do, it seems to be for sex. The part I’m leaving out is—well, last year I was dating a guy for a while, and that really made a difference. It didn’t work out, but it made a big difference anyway.

Ann: Sex with different people can be very different. Some of it can be very important and some of it you can take it or leave it. But I have the idea that it’s been the sex that isn’t important to you that you’ve been taking the HIV risk for. Does that seem right to you?
Roger: Yeah, I’d say that’s right. It’s the anonymous sex. With Tim—the guy I was dating—I didn’t know my status, so we always used condoms. With guys I meet when I’m just out having sex, that’s when I’ve had unsafe sex.

Ann: Well, normally we take some risk for things we value. But it sounds like at least some of the risk you’ve been taking—that it wasn’t that you valued it but that you were feeling down and were trying to feel better. And we don’t take as good care of ourselves when we’re down, and it makes sense that this is when you would have unprotected sex and put yourself at the most risk. That’s the part that bothers me in what you’re telling me: that you take risk for sex that doesn’t mean much to you, and it’s not making you feel better anyway.

Roger: That’s right.

Ann: Roger, we’re going to have to stop in a few minutes, but I want to make a suggestion that might be helpful. Even if your feeling down were not motivating you to have unprotected sex that you might get HIV from, I’d be concerned about it just because it makes you feel bad.

Ann closed the session by briefly mentioning that many HIV-negative men are experiencing some feelings about loss and isolation because of the epidemic and that sometimes such feelings can lead to sexual behavior that they later regret. She also gave Roger information about available groups for HIV-negative men.

Clearly Roger is well educated about HIV transmission, but he is taking considerable risks and is disturbed by that behavior, even if he does not conceptualize his situation as being primarily about HIV risk. Ann begins to help Roger understand that there may be some connection between his “down” feelings and the unsatisfying behaviors that are also potentially exposing him to HIV. Because of Roger’s lack of satisfaction with much of his sexual activity, Ann feels that Roger may be using sex compulsively, perhaps in response to anxiety (his feeling “restless”), loneliness (friends have “died or moved away”), or depression (feeling “down”).

Ann uses information Roger provides to discuss this connection between his feelings and his experience of unsatisfying sex, but she does this while remaining within Roger’s framing of the problem, that he has done “a couple of things I shouldn’t have” and is not happy with his life. She helps Roger clarify the meanings
of that experience without affirming or denying Roger's self-judgment that he has done something "wrong." She suggests that Roger may, in part, be having unprotected sex for understandable reasons—wondering if Roger "felt like it was worth the risk."

Because of the complexity of the issue, Ann does not address the possibility that Roger may actually be ambivalent about getting HIV. But she is aware that Roger might have some feelings that being HIV-positive connects him to other gay men and gives his life focus and purpose. Ann does help Roger notice that he values different sex differently but that he is not expressing these values in the way he takes risk. By reflecting back Roger's own description of his experience, she is able to point out that Roger is taking the most risk for the sex he values least.

Although they present different issues, both of these counseling vignettes demonstrate a client-centered approach intended to help the client clarify his experience related to HIV risk. In both instances, the counselors work from within the client's own description of his experience. They help their clients clarify both the feelings as well as the implications of sexual behavior. Because each counselor recognizes the complexity of the client's experience and the need for the client to develop his own motivations for any desired change, both sessions are concerned with clarification rather than resolution.

The focus is not on risk assessment per se, and the counselor does not suggest specific behavior changes. The counselor recognizes and accepts that there are reasons each client behaves as he does. These reasons are often different from the rationale the client initially presented, but they are usually discoverable in the client's explication of his own experience. For example, although Roger says he has sex when he has "nothing else to do," he discovers later in the session that it may have more to do with "feeling down." The counselors in these vignettes also recognize that the client must clarify and mobilize his own motivations in order to remain free of HIV and that neither the counselor's desire that he do so nor the assertion of expected standards of behavior will be useful in accomplishing this. In fact, to ensure that the counselor-client inter-
action is not prejudiced by the expectations implied by a checklist of "bad," "unsafe," or disapproved behaviors, any formal collection of risk-assessment data is conducted at the end of the session.

**Impediments to Client-Centered Counseling**

A client-centered approach to HIV counseling offers the possibility of helping clients initiate a process that can help motivate substantial, enduring changes in behavior. But the public health context of most HIV test site counseling and the counselor's own experience, values, and feelings may hamper or obstruct a truly client-centered approach. For purposes of discussion, two kinds of potential impediments might be described as "organizational" and "transferential," respectively.

**Organizational Impediments**

The potential organizational impediments to client-centered HIV counseling flow largely from the purposes of traditional public health and the institutions that represent it. Public health is dedicated to the greater public good and has, traditionally, not substantially concerned itself with the issues and needs of individuals—particularly "carriers"—unless addressing those issues can be shown to most effectively protect the larger public. Thus HIV counseling and testing for gay men has appeared to concern itself largely with collecting epidemiological data, influencing risk behavior in the short term, and, for HIV-positive results, providing referral for medical and psychological treatment. Other elements of traditional public health—including mandatory reporting of infection and partner notification—might also have been implemented had it not been for political pressures from AIDS advocates concerned with the potential stigmatization of people with HIV disease. Partly because of the traditional assumptions of public health, it has generally been assumed that knowledge of HIV status would change individual behavior and reduce transmission. In fact, research on gay men living in a community-wide epidemic is far from providing conclusive support for this assumption. The equation between knowledge of infection and behavior change is probably less supportable in communities with 50 percent rates of
infection and the complex identifications with HIV that many gay men experience.18

Although many of the traditional elements of public health are probably incompatible with client-centered counseling, the collection of epidemiological data per se is not. The way data collection is performed, however, can easily impede a client-centered approach. The very idea of “risk behaviors” suggests that these behaviors are without other purpose or meaning in the individual’s life, and it is thus contrary to a client-centered approach. People engage in very little behavior that is, subjectively, about nothing more than undesired risk. If the counseling session begins with an inventory of risk behaviors around which the rest of the session is structured, a client-centered approach is not possible. The risk assessment will have already established the meanings—which is to say, the undesirability and meaninglessness—of the behaviors. The client-centered approach is about helping the individual clarify precisely those subjective meanings, meanings that motivate the client to engage in the behaviors despite the risk or because of the risk. This problem can be substantially eliminated by collecting epidemiological data unobtrusively in the course of the session and supplementing that data with other, still-needed information on completion of the session. Data collection can be nothing more than a perfunctory addendum to the client-centered session.

More serious organizational impediments to client-centered HIV counseling arise from the cognitive-behavioral assumptions of traditional public health and its apparently limited confidence in more psychological, less structured, and less directive approaches. It is little exaggeration to say that cognitive-behavioral models of human experience, as well as the structured behavior change models that have grown from them, assume that individuals lack conscious or unconscious motivations for seemingly “irrational” behaviors, are generally conscious of any motivations they do have, and will wish to change any behavior that is demonstrably irrational. Through such “behavioral reductionism,” cognitive-behavioral models dismiss important unconscious feelings or motivations, thereby defining many important human behaviors as dispensable. This dismissal is particularly noteworthy in the psychologically complex, almost entirely irrational realm of human sexuality.
In contrast, a client-centered approach assumes that a client who engages in complex, fundamentally irrational—and, perhaps, potentially self-injurious—behaviors may have motivations that are partly or wholly unconscious. Further, the approach recognizes that an individual’s feelings about the risk-benefit balance of any behavior may contradict the rationalistic assumption of risk elimination. A measure of the substantial, fundamental difference between cognitive-behavioral models and client-centered counseling is suggested by public health’s common adaptation of behavior change models for substance addiction to the “problem” of normal human sexual behavior. While addictive, long-term cocaine use may not be a natural human condition, the practice of penetrative sex without condoms most certainly is.

Transferential Impediments

Transferential impediments to client-centered counseling arise from any of the counselor’s beliefs, values, or feelings that interfere with his or her ability to work from within the client’s frame of experience. Transferential impediments may also be supported by organizational ones. Broadly speaking, public health does not pay for the subjective well-being of the individual. The public health context of most HIV counseling places the counselor in the position of “representing” the state, which is primarily concerned with protecting the health and welfare of the greater public, reducing the public expense for HIV infection, and helping stop individual behaviors that contradict those ends. Although a counselor’s personal motivations might partly or wholly include such public purposes, they are purposes that cannot be pursued in client-centered counseling. Thus the counselor may experience his or her responsibilities as divided between the state and the individual client and hence conflicted.

Whether or not this conflict exists, the counselor’s transference feelings may inhibit the neutrality basic to client-centered counseling. For example, HIV test site counseling for gay men must assume the acceptability—and human importance—of sexuality in general and homosexuality in particular, and must affirm the client’s values by assuming a harm-reduction, rather than a risk-elimination, approach. Client-centered counseling must constantly
affirm respect for the individual in acknowledging that only the client himself can take responsibility for his life. Counselors with strong feelings about the importance or unimportance of their own sexuality, and counselors who are anxious about or adverse to any risk must examine the ways in which such feelings can easily impede a truly client-centered approach. Likewise, counselors who wish to help gay men by “saving them from themselves” must remind themselves that client-centered approaches can be grounded only in authentic respect for the client, his values, and his efforts to create for himself a life that is rich and satisfying enough to be worth protecting from unknown, unnecessary, or unintended risk.

Notes
1. Prochaska, J. O., Velicer, W. F., DiClemente, C. C., and others. “Measuring Processes of Change: Applications to the Cessation of Smoking.” Journal of Consulting and Clinical Psychology, 1988, 56(4), 520–528. Prochaska and associates have also discussed stages of behavioral change in the context of other behaviors, including weight loss, HIV prevention, and drug addiction. Prochaska’s work is among the most frequently cited in describing structured behavioral change. His Stages of Behavior Change model is rooted in cognitive and behavioral psychological models and describes individuals as falling into one of five categories leading to change: precontemplative, contemplative, ready for action, action, and maintenance.
ated safety is essentially the practice of preventing HIV transmission through seroconcordant partner selection rather than by preventing HIV transmission between serodiscordant partners by behavioral means. Although some American educators argue against negotiated safety because gay men are thought to be less monogamous than heterosexuals, the real issue is whether sex outside the relationship, if any, is conducted “safely” to prevent HIV from being introduced into the relationship.

7. Virtually all the epidemiological literature on gay men that has tabulated data about condom use for oral sex has shown very low levels of use, typically less than 3 percent. For example, see Ostrow, D. G., Di Francisco, W. J., Chmiel, J. S., and others, “A Case-Control Study of HIV Type I Seroconversion and Risk-Related Behaviors in the Chicago MACS/CCS Cohort, 1984–1992.” American Journal of Epidemiology, 1995, 142(8), 875–883.


11. Although educators usually argue against “negotiated safety” (unprotected sex between partners of mutually known antibody status) because gay men are thought to be less monogamous than heterosexuals, the critical issue would be whether or not protected sex was practiced outside the relationship to prevent HIV from being introduced into the relationship. If protected sex would not serve this purpose, it would not prevent HIV from being transmitted within the relationship. Thus, the monogamy of a couple ought not to be the issue in discussing negotiated safety.


14. I am grateful to Susan Thompson and Edward Wolf, both working in counseling and testing for the UCSF AIDS Health Project, for their insights on the problems confronting counselors.


Chapter Two

HIV Test Counseling
Does It Change Behavior?

Susanne B. Montgomery
David G. Ostrow

HIV antibody counseling and testing has been one of the cornerstones of the national AIDS prevention strategy since testing first became available in 1985. It seems a reasonable assumption that knowledge of HIV serostatus in conjunction with individualized prevention counseling will lead to behavior change. For this reason, counseling and testing has been promoted as a simple solution to a difficult problem, and most experts agree that this seeming simplicity has led to unrealistic expectations about the powers of counseling and testing. But others see counseling and testing as an important and rare opportunity to reach people at high risk of HIV infection in the context of a personal interaction.

Counseling and testing has also been promoted as a means of guiding newly identified HIV-infected people who may be candidates for early medical intervention toward treatment. Medical intervention has become an increasingly significant option in light of new treatment regimens using protease inhibitors and combination antiviral therapy. Counseling and testing has also become a venue for secondary prevention, a forum for educating people with HIV disease about protecting their partners.

At a time when local governments are seeking to reduce spending on counseling and testing and some public health experts are advocating home testing with only rudimentary counseling, it is useful to consider the efficacy of current counseling and testing
approaches. Taking into account more than a decade of experience, this chapter describes the counseling and testing process and reviews the evidence concerning the efficacy of counseling and testing in terms of both behavioral and mental health consequences. It also discusses the role of private practice therapists in the counseling and testing process.

The Counseling and Testing Paradigm

The Centers for Disease Control and Prevention (CDC) now mandates that publicly funded antibody test sites provide client-centered counseling according to specific guidelines. In this context, the term counseling and testing refers to a three-part process: pre-test counseling (known in California as the risk assessment session), the blood draw procedure, and post-test counseling (known in California as the disclosure session), at which time the counselor discloses the test results. This process combines informed consent for testing and information about the medical aspects of the testing procedure with risk-reduction education, emotional support, and referral for follow-up regarding any problems that might be identified through counseling, such as substance abuse, spousal abuse, or psychiatric disorders.

Pre-Test Counseling

During pre-test counseling, providers lead clients through the decision-making process of the testing experience, ensuring that clients understand the physical process of the test and the emotional implications of testing and of the information they will learn from testing. Pre-test counseling offers a unique opportunity to provide focused education to people who identify themselves as being at risk for infection. The pre-test session is an ideal time to help clients assess personal risk, develop an individualized plan for behavior modification, address barriers to this plan, and develop responses to these barriers. Practitioners generally agree that behavior change messages are more likely to be effective during pre-test counseling than during post-test counseling, when clients are likely to be preoccupied with the imminence of their results or the results themselves.
Pre-test counseling also addresses the emotional charge related to the decision to test, including fears about being seropositive, potentially having to disclose that fact to friends and family, getting sick, and having to come out as gay or bisexual, as a drug user, or as someone who has had sex outside a primary relationship. Finally, during pre-test counseling, providers explain the testing procedure, the meaning and limitations of laboratory findings, and conditions under which primary care follow-up or retesting is recommended. The testing procedure itself is usually carried out by a nurse or phlebotomist, who draws the blood on the same day as the pre-test counseling. The sample is then sent to a diagnostic laboratory for analysis. See Exhibit 2.1 for an outline of the pre-test process.

Post-Test Counseling

Post-test counseling, which follows pre-test counseling any time from a few days to two weeks later (depending on the program structure, the volume of testing, and the process of confirmation of test results), focuses on disclosing test results, dealing with clients' emotional response to the results, and helping clients plan next steps to deal with the implications of the results. Much of this task depends on whether the client expected the result that he or she received, on the adequacy of his or her social support system, and on the strength of his or her personal coping mechanisms. In all cases, providers must be gentle and compassionate, allow clients sufficient time and opportunity to express their feelings, be open to the ambiguity and uncertainty that arise during the window period before which antibodies develop, and emphasize the behavioral consequences of both seropositive and seronegative results.

The greatest challenge for the counselor in the pre- and post-testing situation is to be empathic and supportive while at the same time confronting misinformation and denial. A counselor's ability to create an atmosphere that encourages communication and understanding may determine the adherence of the client to post-test recommendations, particularly the referral of the client for medical and mental health follow-up in the case of a positive test result. Exhibit 2.2 outlines the post-test session process.
Exhibit 2.1. Elements of Pre-Test Counseling.

Assessment of Client
Behavioral risk
Psychological needs
Adequacy of social support
Intentions to share results with others
Coping style
Clarification of values and health belief systems related to self and partners

Discussion of Reasons Individuals Fail to Return for Results
Procrastination
Denial/fatalism
Fear of inability to cope with positive test results
Fear of lack of confidentiality
Concern about laws regarding “knowing exposure” of others

Discussion of Behavior Modification
Development of a realistic personal plan for behavior modification based on risk behaviors
Agreement about feasibility of the behavior modification plan
Identification of anticipated reactions and possible barriers to suggested changes

Supportive Interventions for Waiting Period
Availability of counselor for questions and supportive counseling by telephone if needed to help client deal with, among other concerns, prenotification anxiety and suicidal ideation

The Demographics of Testing
Counseling and testing is carried out in a number of venues ranging from publicly funded anonymous and confidential test sites to doctor’s offices, hospitals, and blood banks. The most complete data regarding the demographics of testing come from public test sites, which are monitored by the CDC. The use of these sites increased markedly between 1989 and 1992 and then decreased slightly after that: from 1,014,973 tests in 1989 to 2,689,056 tests in 1992 and 2,399,529 tests in 1994. As of the end of 1995, the
Exhibit 2.2. Elements of Post-Test Counseling.

Assessment of Client
Behavioral risk
Psychological needs
Adequacy of social support
Coping style
Discussion of test results
Meaning and limitations of laboratory findings
Assurances that results are certain
Recommended follow-up procedures, including whether or not client should retest

Behavioral Assessment and Counseling
Emphasis of behavioral consequences: infection (for seronegatives) and reinfection (for seropositives)
Denial/fatalism
Importance of protecting others and notifying partners (for seropositives)
Introduction to behavior modification interventions as needed

Psychological Reactions to a Positive Result
Expression of feelings and reactions to result
Assessment of immediate reaction to test results, including possible psychogenic shock
Counseling or referral regarding potential adverse mental health or behavioral outcomes
Acknowledgment of legitimate fears and concerns, including past behavioral decisions, anger toward individuals who might have transmitted HIV, possibility of having infected loved ones, disclosure of results, fears of abandonment, employment and insurance coverage issues
Assessment of potential psychological or behavioral decompensation if denial mechanisms are disrupted
Referral to community supports and primary medical and psychosocial care
number started to rise again, to 2,491,434. Among these sites are dedicated HIV counseling and testing centers, which in 1995 accounted for 29.8 percent of all tests and 34.9 percent of all seropositive test results in 1995, and sexually transmitted disease (STD) clinics, which in the same year accounted for 26.7 percent of reported tests and 25.1 percent of all seropositive results. In 1995, family planning and prenatal-obstetric clinics accounted for 12.6 percent of tests (2.3 percent of seropositive results) and drug abuse treatment centers and prisons accounted for another 8.2 percent of tests (14.3 percent of seropositive results).

Among clients at publicly funded sites, both African American and Hispanic clients were overrepresented compared to their proportion in the national population: 48.7 percent of clients were White; 32.6 percent were African American; and 14.9 percent were Hispanic. Similarly, the proportion of seropositive tests in these populations was high: 20.7 percent of the seropositive tests were among Hispanics and 49.0 percent were among African Americans, compared to 27.7 percent among Whites. More than half of the tests at publicly funded sites in 1995 were of women, although more than two-thirds of seropositive tests were among men. Among both men and women, the twenty to twenty-nine age group accounted for the largest proportion of all antibody tests; the thirty to thirty-nine age group accounted for the largest proportion of seropositive tests. Also, although people with a history of male-to-male sex or injection drug use accounted for only 12.7 percent of all tests, they made up 48.6 percent of all seropositive tests. Finally, the proportion of tests reported that included post-test counseling rose from 38.9 percent in 1989 to 59.6 percent in 1995, with HIV counseling and testing centers reporting the highest rate of post-test counseling (82.7 percent).

Home Testing
It is important to acknowledge the potential movement away from formal testing, either at anonymous or confidential test sites, at STD or public health clinics, or in private medical offices. In May 1996, the U.S. Food and Drug Administration approved the HIV antibody home test, the first HIV testing system that is not entirely linked to the medical setting. The introduction of this technology
has been touted by some prevention advocates as a way to dramatically improve access to antibody testing\textsuperscript{10,11} and by others as a potentially dangerous undertaking. Detractors argue that home testing will lead to "missed opportunities" for behavioral counseling and leave individuals open to potential abuse by institutions—employers, insurance, border patrols—as well as by sexual partners.\textsuperscript{12}

Home testing kits are available through pharmacies or through mail order. (Johnson and Johnson, one of the home test manufacturers, discontinued its product after losing the rights to market it. The remaining manufacturer is Home Access.) To conduct the test, the individual pricks his or her finger to obtain a blood sample, which is placed on the designated areas of the test card and mailed to the manufacturer for analysis. Seven days later, the individual can call for the results. For seropositive individuals, testing company representatives give results over the telephone, providing counseling that consists of a review of treatment and prevention information and referrals to local medical practitioners and AIDS agencies. For seronegative individuals, counseling consists of information regarding prevention. However, seronegative clients have the choice of a tape-recorded message or a live counselor, and the majority choose the recording.\textsuperscript{13}

The important issues raised by home test kits include whether or not adequate pre- and post-test counseling can be provided; whether the kits are used by people who currently do not get tested at counseling and testing sites; whether the psychological and behavioral impact of receiving HIV antibody test results at home differs from the impact of receiving results face-to-face at testing sites; and whether linkage to early medical care and prevention interventions is adequate. Home testing advocates hold that the most crucial prevention tool in the counseling and testing process is the testing—that is, once a person knows his or her serostatus, he or she is more likely to implement prevention strategies. They also assert that the home testing population is different from the population of people who receive counseling and testing at established sites, and that those who would access home testing compose a large population of at-risk individuals who are failing to be tested because they are unwilling to use public and even private test sites.

Opponents of home testing counter that without face-to-face counseling and referral, individuals conducting their own HIV test
will experience adverse psychological reactions (such as depression and anxiety) to the testing process. In addition, opponents contend that the automated disclosure or brief counseling that accompanies seronegative results fails to take advantage of prevention counseling opportunities.

Rates of use of the home test kits are lower than were expected by manufacturers and prevention planners, mediating both beneficial or problematic consequences and, for the moment, making arguments about the pros and cons moot. However, new technologies that would permit home testing with immediate results are on the horizon and will undoubtedly raise similar and additional concerns. It will not be long before such instant tests will be available for testing of potential sexual and drug use partners in the moment. These will raise a variety of ethical and public policy issues, not the least of which will be whether consumers will have the right to interpret their own HIV antibody test results.

**Viral Load Testing**

Given recent advances in viral load testing and antiviral prophylaxis at very early stages of infection, many clinicians and public health officials suggest there is an even stronger need for HIV testing for those who have reason to worry about the possibility of infection. This potential influx of individuals requesting testing will likely also affect the counseling and testing paradigm.

As viral load testing of seropositive people becomes more widely available, it is likely to have profound prevention implications. Viral load testing and antibody testing will likely be used extensively by people who have a slip in protected behavior significant enough to frighten them into action (even despite the fact that the antibody window period is as long as twelve weeks following exposure). Such individuals may be the ripest for prevention counseling: they are likely to have had a recent and what they define as a clear instance of risky behavior and to have a clear memory of the situational and emotional factors related to the slip. This may be the best time to counsel about behavior change among people who are most likely to take sexual or drug use risks.
The Motivation to Test

The decision to get tested is a complex and difficult one composed of several stages. Testing requires confronting a multitude of difficult emotions: fear, anger, and guilt about past behavioral decisions; fear about the possibility of having infected loved ones; and concerns about potential loss of family and livelihood. For these reasons, understanding why people choose to get tested and the decision-making process that surrounds HIV antibody testing is important.

Although reasons for taking the test are varied, refusal tends to be higher among men than women, and higher among African Americans than among Whites. Several studies suggest that specific psychological and situational motivators drive the testing decision. For instance, individuals choosing not to be tested said that being afraid of the heightened anxiety and depression following a seropositive test result dissuaded them, whereas those who did test said that the belief that their results would help them cope with and reduce high-risk behaviors was a significant motivator. Additional potential barriers to testing include the misperception of risk of HIV infection, confidentiality and anonymity concerns, fear of stigmatization, and fear of rejection if seropositive. Among other reasons for electing to test was to be reassured that safer sex was working, that unsafe sex had not led to transmission, and that earlier test results were accurate.

Although some studies found seroprevalence among those who took the test to be twice as high as it was among those who did not, other studies found the opposite: people who refused antibody testing were approximately twice as likely to be seropositive as people who tested. Despite the methodological and substantive differences among these studies, they did uncover one consistent finding: there were significant discrepancies between subjective perceptions of risk and actual seroprevalence. The basis for misperception and the psychological reasons for refusing testing, however, may differ among subgroups. For example, an Australian study of 545 sexually active men who refused testing found that bisexual men acknowledged risk but procrastinated before being tested; heterosexual men denied risk; and gay men feared antibody-positive results and distrusted confidentiality practices.
It is important to understand not only why people get tested but also what motivates them to return for results once they have been tested. CDC data indicate that failing to return for results is not a rare event: only 74 percent of seropositive and 63 percent of seronegative individuals return; and freestanding HIV antibody counseling and test sites were more successful than STD clinics in getting individuals to do so.24 These data provoke us to ask what the mental health and behavioral consequences are of going through pre-test counseling and antibody testing without the closure provided by post-test counseling. Might behavior modification plans made during pre-test counseling be negated by the same psychological response—perhaps denial—that impels the clients to avoid post-test counseling? In order to increase a client’s likelihood of returning, it is of the utmost importance that pre-test counseling address unresolved fear and guilt, and provide help with the psychological implications of both seropositive and seronegative test results. This can only be done by assessing a person’s reasons for seeking testing and his or her emotional state, coping strategies, and social supports—including whether he or she intends to share test results with partners, family, or friends. This approach is likely not only to communicate concern about a client’s well-being but also to increase the chances that the client will return for test results.

**Testing and Behavior Change**

The efficacy of counseling and testing in bringing about behavior change has been the focus of controversy since the HIV antibody test was developed in 1985. This debate became especially vigorous when home-based testing was approved. Today, despite the market failure of home-based testing, the essential question remains: Does knowledge of serostatus bring about behavior change, and if so, is counseling a necessary component of any risk reduction that is associated with the testing process? Overall, the evidence for the behavioral impact of HIV testing remains mixed at best.25 Although it has been shown that voluntary counseling and testing can enhance safer sexual behavior in couples in which each partner has a different serostatus and each partner receives counseling,26 there is little evidence for behavior
change after counseling for heterosexuals if only one partner is tested,27 and some studies have even documented an increase in risky behavior in people who receive a seronegative result.38

It is important to note, however, that few studies control for the quality of the counseling process—a troubling fact, considering the findings of an external review of the CDC’s counseling, testing, referral, and partner notification program.29 This review found that pre-test counseling typically lasted between two and ten minutes and post-test counseling between ten and thirty minutes. It also revealed that counselors tended to de-emphasize the prevention message in favor of more technical jargon about the test. The review also found considerable variation in the content of the counseling, the intensity of sessions, and the training of counselors. Such variations in the extent and quality of HIV antibody test counseling may well taint any summary results about the efficacy of prevention counseling in the testing setting; we must remember this as we review the following summary of the data for particular subgroups—including gay and bisexual men, injection drug users, and women.

Behavior Change Among Gay and Bisexual Men

In 1987, the U.S. assistant secretary of health mandated that everyone undergoing HIV antibody testing be informed of their test results. Since that time, only a few controlled studies have been able to compare the behavior change of gay and bisexual men who were aware of their HIV antibody status to those who were unaware. Overall, according to a 1997 analysis of published longitudinal studies and cross-sectional studies, much of the observed risk reduction was independent of HIV counseling and testing and was consistent with overall behavior change in this population.30 The magnitude of behavior change in three of these studies was independent of knowledge of serostatus—hence counseling and testing—and also of actual serostatus.31,32,33 Furthermore, several of the studies present data suggesting that even if counseling and testing may have led to the observed behavior change, the magnitude of change was greater among seropositive men than among seronegative men.34,35,36

A few studies identified particular patterns of unsafe behavior following testing. A New York City study found increased receptive
anal intercourse among HIV-infected men. Several other studies found that some seronegative individuals infer from their test results that they are in some way naturally immune to HIV whether or not they reduce risk. Finally, a Chicago study found that men who were depressed, had weaker social supports, felt greater isolation, and had engaged in higher levels of denial and fatalistic coping were more likely to lapse from safer sex to unsafe sex after testing.

All of this evidence indicates that although much behavior change was observed, it is difficult to clearly link this change to counseling and testing. For those studies that attempted to isolate the effects of knowledge of serostatus itself, the evidence that successful behavior change is based merely on antibody counseling and testing is negative or weak at best.

Behavior Change Among Injection Drug Users

Overall, HIV risk reduction—that is, sexual and needle-sharing behavior change—has been less substantial among injection drug users than among gay and bisexual men. However, what little has been published on the relationship between counseling and testing and behavior change in this population suggests that the counseling and testing process motivates risk-reducing behavior, specifically safer needle-use behaviors, and smaller reductions in sexual risk behaviors, especially among injection drug users receiving drug treatment. Two small longitudinal studies comparing seronegative to seropositive injection drug users report both drug-related and sexual behavior changes among subjects who knew their serostatus, with more significant changes occurring in HIV-infected individuals. The single most important change was the reduced frequency and regularity of equipment sharing.

However, most published studies draw participants from methadone maintenance treatment programs; the results therefore have limited generalizability to injection drug users who are not in treatment. For example, although one study found that “in clinic” testing was widely accepted by injection drug users and that most clients in treatment (63 percent) elected to learn their serostatus, this number is bound to be lower among drug users not in treatment. Furthermore, in the only random prospective study—
comparing HIV education alone to HIV education plus counseling and testing—researchers found increases in condom use and needle hygiene among all participants, with no significant differences between groups.\textsuperscript{48}

Behavior Change Among Women

Although women use publicly funded counseling and testing sites slightly more than men,\textsuperscript{49} there has been little research on women and their behavioral responses to antibody testing.\textsuperscript{50} What has been published focuses mainly on serostatus and reproductive decision making. Given the high probability of perinatal transmission in the absence of any prophylactic antiviral treatment, additional counseling is recommended for high-risk or seropositive pregnant women. This counseling should include, among other topics, discussing rates of transmission, the option of terminating the pregnancy, and treatment with zidovudine (ZDV), which has been shown to reduce perinatal transmission.\textsuperscript{51} There is considerable and ongoing research to determine both the optimal and least costly forms of antiviral treatment to prevent perinatal HIV transmission.

A recent review article suggests that findings with respect to counseling and testing of women are inconsistent.\textsuperscript{52} Half of the studies found serostatus to be unrelated to pregnancy decisions, whereas the other half found that seropositive women were significantly less likely than seronegative women to become pregnant. There were similarly inconsistent findings regarding birth control, condom use, and pregnancy termination (although overall, seropositive women were slightly more likely than seronegative women to terminate pregnancy). In summary, the majority of the data show that knowledge of serostatus does not have an important influence on pregnancy decisions among seropositive women, although increasing publicity about the efficacy of perinatal prophylaxis will undoubtedly motivate increasing numbers of pregnant women to seek testing. Whatever decision a seropositive woman makes regarding pregnancy, she will have an increased need for ongoing support and follow-up to help her navigate a medical care system that is not well informed about the HIV-related issues women face.
Studies of women who are not pregnant but who are at high risk of HIV infection demonstrate a clearer relationship between risk, serostatus, and counseling and testing. A longitudinal study of a representative sample of women of childbearing age who received counseling and testing in Africa found that seropositive women were more likely to negotiate their partner’s use of condoms than were seronegative women. Moreover, seropositive women whose partners were also tested were more likely to negotiate their partner’s use of condoms than those whose partners were not tested, yielding a lower rate of new infections.

A study of sex workers found that women who underwent both counseling and testing and a skills-based intervention reported a significant increase in condom use during vaginal intercourse with their customers. Although women who received counseling and testing alone changed their condom use behaviors during vaginal sex, they reported a significant decrease in condom use during oral sex with their customers, indicating the need for both clarification of oral sex guidelines for counselors and skills-building regarding the process of negotiating condom use for oral sex. This and other studies with similar findings suggest that more intensive counseling and testing interventions may be necessary to lead to behavior change.

Behavior Change in Other Subpopulations

Although research has found higher HIV seroprevalence rates among clients at STD clinics than in the general population, there has been little formal research into the issue of counseling and testing in these settings. It appears, however, that heterosexuals who are at high risk of infection but who do not fall into other risk categories have not been accessing HIV antibody counseling and testing. For example, half of the respondents of an STD clinic population who identified themselves at very high risk for HIV infection said that they had never been referred for counseling and testing. Similarly, one U.S. study found that 36 percent of individuals newly diagnosed with AIDS were first tested for HIV antibody only two months prior to their diagnosis, and 51 percent only within one year of diagnosis. Testing so late in the course of HIV disease represents a missed opportunity for early intervention;
58 percent of those studied had finally tested because of symptomatic illness.80

Most research shows that knowledge of serostatus in STD clinic populations is effective in reducing risk among at least the infected subpopulation.89 Studies comparing seropositive to seronegative individuals found that counseling and testing for seropositive individuals was associated with reductions in sexual risk behaviors. However, there was no such effect for seronegative individuals; in some cases, knowing their serostatus led to increases in unprotected behaviors. For example, a study of people who underwent counseling and testing at a large, urban STD clinic found at one-year follow-up that there was a 29 percent decrease in gonorrhea rates among people who tested seropositive, but a 106 percent increase in gonorrhea rates among those who tested seronegative.69 These startling results suggest a disinhibiting effect or false belief in immunity, which seems to be validated by a general population study in which a significant number of seronegative people knowingly engaged in unsafe sex after receiving their test results.64

The body of research on heterosexual couples in which partners have different serostatuses (serodiscordant couples) has provided the strongest support for the effects of counseling and testing. Several longitudinal studies have found high levels of consistent condom use and abstinence among serodiscordant couples when compared to concordant couples.62,63

Adolescents are another important group to consider, as many currently infected individuals were infected during late adolescence—a time for experimentation. However, there is little published research because of the special legal issues regarding research with minors. One of the few published studies looked at college students.64 The study found that students who received education plus counseling and testing increased their communication with sexual partners about HIV infection as compared to students who received either the educational intervention alone or no intervention at all. However, the study showed no reduction in risk behaviors.

Another study, conducted on seropositive youth in an urban clinic, found that the majority of males—but none of the females—said that they had increased safer sex behaviors, that they had been consistent in using safer sex only in ongoing relationships, and that
the ceasing of drug use increased safer sex behaviors more than knowledge of serostatus did. Finally, in a study exploring HIV risk in homeless youth, counseling and testing was, in fact, associated with higher levels of behavioral risk. For the most part, it seemed that youth used serial testing as a tool for monitoring their serostatus. In sum, the evidence for a risk-reducing effect of counseling and testing for adolescents is not encouraging. It may well be that the perceived need to experiment at this point of development supersedes rational decisions about HIV risk and protective behaviors (see Chapter Four).

Resolving Ambiguous Research Literature

In agreement with the key literature review on the subject, it is clear that although there is a mixed pattern of counseling and testing efficacy, the process nevertheless seems to motivate behavior change (including seeking early or prophylactic treatment) across a variety of different populations. The most unequivocal evidence for this comes from studies of heterosexual serodiscordant couples. The evidence in other populations, such as men who have sex with men, is harder to link to the counseling and testing process because of the tremendous overall risk reduction that has occurred in these populations during the past fifteen years. This does not mean that counseling and testing is not effective in this or the other populations, nor can the widespread availability of counseling and testing be dismissed as a contributing factor in these behavior change trends. It is notable that seropositive individuals are clearly more likely than their seronegative counterparts to have reduced their risk behavior practices as a result of counseling and testing. Furthermore, the literature on injection drug users indicates a pattern of successful behavior modification, although because most of the data were obtained from treatment populations, the generalizability of these findings is limited.

There are many possible reasons for the lack of consistency in the data. Primary among these is the unrealistic assumption that any short-term, brief intervention such as counseling and testing will bring about sustained behavior change in sexuality. As important, the counseling and testing protocols studied in the literature vary tremendously in both quality and quantity, a fact confirmed
by the external review of the CDC’s counseling and testing programs. Among the variations in protocol were factors as fundamental as counselor training, the use of lay people as counselors (some of whom were poorly trained), and the time spent on each of the many tasks of the counseling session.

**Responding to Programmatic Weaknesses**

Rather than conclude that counseling and testing is in and of itself ineffective, it would seem wise to develop approaches that respond to the limitations identified in the literature. For instance, there seems to be a “dose-response” relationship between HIV antibody counseling and testing and behavior change. The combination of testing plus single sessions of pre- and post-test counseling alone is unlikely to help an individual sustain behavior change. However, several sessions of individual, couples, or group counseling, ideally in conjunction with a variety of skills-based interventions, may reduce risk. Unfortunately, although an intensive counseling and testing process promises to be the most successful approach, scarce resources make it difficult to implement.

Given this scarcity, it is useful to identify those who are most likely to benefit from or need intensive counseling and intervention—for example, individuals who participate in activities that put them at risk of infection but who have not yet thought about testing. The studies reviewed in this chapter show that many of those who defer testing are indeed more likely to be HIV-infected. The reasons for deciding not to get tested may include individuals’ failure to recognize risk, their fears of the results coupled with the sense of being unable to respond, and their concerns about breaches in confidentiality and the resulting stigmatization. Improved outreach can identify and attract those clients at highest risk. Protection and promotion of test site confidentiality can allay fears of discrimination. Client-friendly sites, as defined by the particular community a site serves, can enable counselors to capitalize on the teachable moments provided by the counseling and testing experience.

Another population that might be targeted is of those at highest risk for adverse mental health outcomes in the usual counseling and testing process. In addition to its prevention role,
counseling and testing may provide support to people facing the testing process. To aid in the identification of such clients, pre-test counseling should include mental health screening in addition to a multidimensional assessment for both sexual and drug-related risk behaviors. This is especially important considering that a significant proportion of clients do not return for their results. In this area, a psychotherapist can play a role in the counseling and testing process. Most lay counselors are not well trained in the assessment of an individual’s coping and social support resources, nor do they have the time to adequately undertake such an assessment in most counseling and testing settings. By adopting a supporting and consultative role to the counseling and testing staff, psychotherapists can help counselors develop the skills they will need to assess a client’s need for further counseling either on-site or through referral to an outside resource. Such assessment and referral is cost-effective and can be accomplished easily using a few short, standard questions.

Recommendations

Given that a significant number of people at high risk of being HIV-infected are likely to continue to resist antibody counseling and testing, what practical recommendations emerge from this review? In the first place, all health care providers need to be well informed regarding the basic implications of HIV antibody testing and test results. This includes being knowledgeable about reporting and contact-tracing requirements, local laws regarding confidentiality of test results, and the basics of early intervention with potent antiviral combinations. Furthermore, health care providers need to be versed in the essentials of post-test counseling, as they may well be put into a situation where they have to provide counseling services and, at the least, be knowledgeable about appropriate HIV-related referrals for their clients.

Test program planners and antibody test counselors need to understand the psychological and behavioral implications of both positive and negative test results and ensure there are appropriate resources at hand during the counseling of clients with a variety of backgrounds. Primary health care providers need to recognize that they may be the most influential in helping their clients decide to
take the antibody test and that they must be able to perform adequate HIV risk assessment and discuss the importance of the testing option. Because it is likely that testing will increasingly take place in medical offices, primary health care providers and office staff must be able to perform pre- and post-test counseling, which requires among other things a familiarity with behavior change approaches.

Finally, in light of at-home and rapid testing procedures, greater numbers of clients will be turning to primary medical and mental health caregivers for assistance in coping with the psychological, behavioral, and medical results of antibody testing. And once clients have been motivated to seek testing, they must be able to access not only high-quality counseling and testing but also the most up-to-date counseling, treatment, and support services for both seropositive and seronegative people. In following these recommendations, HIV counseling and testing can achieve its intended goals and be a crucial entry point for everyone in need of HIV prevention and support.

Improvements in five areas can facilitate prevention goals in the HIV counseling and testing setting:

- Using the test as an entry to longer-term and more intensive interventions rather than as an end in itself
- Actively linking clients to other HIV-related prevention resources
- Developing and enforcing minimal standards for the quantity and quality of a counseling interaction
- Ensuring that counselors are well trained in terms of behavior change approaches, resource development and referral, the whole range of HIV-related issues, and most important, counseling skills
- Targeting future research on defining ways to counsel people with negative test results who have participated in risky behaviors, so that these results do not reinforce risky behaviors

Test counseling remains for many people the only, and sometimes the most comprehensive, HIV-related prevention intervention to which they will be exposed. To the extent that awareness and education are crucial precursors to action, it would seem that
simply talking about risk and risk reduction becomes an important preventive step. But the counseling and testing encounter is an opportunity to go even further, perhaps the only one for most of us: a chance to go beyond education, to help people think through the issues involved in instituting and maintaining safer behaviors. If we are serious about HIV prevention, how can we pass up this opportunity?

Notes
8. Ibid.


38. Schechter, Craib, Willoughby, and others, “Patterns of Sexual Behavior and Condom Use.”


40. Beltran, E., Ostrow, D. G., and Joseph, J. G. “Predictors of Sexual Behavior Among Men Requesting Their HIV-1 Antibody Status: The

42. Wolitski, MacGowan, Higgins, and Jorgensen, "Effects of HIV Counseling and Testing on Risk-Related Practices."


49. Centers for Disease Control and Prevention, HIV Counseling and Testing in Publicly Funded Sites.


60. Otten, Zaidi, Wroten, and others, “Changes in Sexually Transmitted Disease Rates.”


63. Allen, Tice, Van de Perre, and others, “Effect of Serocounseling with Counselling.”


68. Corby, Barchi, Wolitski, and others, “Effects of Condom Skills Training.”
76. Ostrow, Di Francisco, and Beltran, “Performance of Pre-Screening.”
Chapter Three

Behavior Change Theory and HIV Prevention

David Silven

A few years ago, at a conference for health educators on the topic of preventing continued unsafe sex among gay and bisexual men, a participant suggested that theory-based principles of behavior change be used as guides for developing interventions. Other participants responded with skepticism: they believed instead that focusing on theory might impede tangible progress and that theory should remain in academic settings.

What use, if any, does theory have in this critical area? To address this question, this chapter summarizes the research on high-risk sexual behavior change and presents an overview of four basic behavior change theories—the Health Belief Model, Social Cognitive Theory, Stages of Behavior Change, and Marlatt’s Relapse Prevention Model. To help us appreciate the utility of these theories in understanding and responding to risk behaviors, I propose to integrate the theories and apply the resulting model to the prevention challenge faced by gay and bisexual men. My primary emphasis, particularly in the case examples in the final section, is on interventions provided to individuals or small groups rather than on mass media strategies aimed at large audiences.

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Behavior Change Theories

A number of research studies have attempted to identify factors associated with sexual risk reduction among gay men. The findings are not always consistent across studies, a result that we can at least partially attribute to variations in the research methods used. The studies identify a variety of factors, including the level of substance use preceding sex;1-6 degree of social isolation;7 existence of peer norms supportive of risk-reduction changes;8-11 perceptions of personal susceptibility to HIV infection;12,13,14 level of reinforcement value, or gratification, associated with high-risk behaviors;15-18 attribution of probability of becoming infected to external factors such as chance or luck versus internal factors such as effort and ability;19 and self-efficacy, that is, the belief in one's own ability to reduce risk.20,21,22

A separate body of research has examined small-group, primarily single-session, interventions to reduce high-risk sexual behavior among gay and bisexual men and other target populations. Some of the single-session interventions involve lecture and discussion of sexual risks and preventive behaviors, with limited modeling of condom use or negotiating safer sex, but these interventions include no guided practice of risk-reduction skills.23-24,39 Others combine lecture and discussion with skills training, including role-playing, for handling high-risk situations.25-27,39 One describes the use of a self-instructional guide and introduces a problem-solving strategy for coping with high-risk situations.29

Multiple-session interventions reported in the literature range from four to twelve sessions.30-35 Most of these interventions combine lecture, discussion, guidance in identifying barriers to risk reduction and methods for dealing with those barriers, and modeling and role-playing of risk-reduction behaviors. Modeling is usually accompanied by reinforcement of successes and help in thinking about and resolving difficulties.

One or more of the four behavior change theories discussed in the sections that follow address each of the factors that the research literature associates with sexual risk reduction among gay men. The interventions reported in the literature also encompass many of the recommendations derived from these theories.
The Health Belief Model

The Health Belief Model grew out of research in the 1950s and 1960s by a group of social psychologists at the U.S. Public Health Service—Godfrey Hochbaum, Stephen Kegeles, Howard Leventhal, and Irwin Rosenstock—examining the widespread failure of people to take preventive measures against health threats.\textsuperscript{34,35,36} Such measures included annual physical checkups and screening tests for tuberculosis and dental disease. The model postulates that individuals will take preventive health-related actions when they

- Perceive that they are personally susceptible to a disease that would have at least moderately severe negative consequences
- Perceive that taking a preventive action would be beneficial in reducing the threat of the disease and that the benefits of that action sufficiently outweigh costs such as the inconvenience and effort required, embarrassment, and financial expense
- Perceive a stimulus or “cue to action,” either internal, such as perception of an uncomfortable bodily state, or external, such as mass media campaigns, newspaper articles, or personal knowledge of someone affected by the disease

The perception of threat and the occurrence of a cue to action that raises the individual’s awareness of feelings of threat are what lead to the decision to act. The direction that the action takes is influenced by the individual’s beliefs regarding the relative availability and effectiveness of alternatives for reducing the threat. These factors, in turn, are influenced by social norms. Demographic variables, such as age, ethnicity, and social class, influence an individual’s beliefs regarding the seriousness of the disease, his or her perceived susceptibility to it, and the benefits and costs of preventive action.

Social Cognitive Theory

Albert Bandura’s Social Cognitive Theory—formerly called Social Learning Theory—holds that in order to take a particular course of action, individuals must not only possess the required skills to execute the action but also believe that the action will lead to a
desired outcome and that they are personally capable of performing the action. This belief in personal capability, known as self-efficacy, is a pivotal concept.

Given that an individual possesses adequate skills and incentives to execute the desired behavior, the theory considers self-efficacy to be the primary determinant of the extent to which individuals will initiate and maintain desired behavior changes. The degree of self-efficacy influences how much effort a person will invest when taking an action, and how long he or she will persevere in the face of difficulties or disappointing results. Unlike more generalized concepts such as self-esteem or self-confidence, self-efficacy refers to the individual’s beliefs about his or her ability to perform a specific desired behavior.

A person develops self-efficacy with respect to a particular behavior or action by accumulating feedback from four primary sources: personal experiences of successfully performing the behavior, vicarious experience through observing and imitating others perform the behavior ("modeling"), verbal persuasion by others who convey to the individual that he or she is capable of performing the behavior, and the individual’s own physiological states.

Of these four sources, successful performance, also referred to as "mastery" experiences, is considered the most potent in raising the level of self-efficacy. Proficiency with new behaviors requires extensive practice. Ideally, practice occurs with the help of considerable external guidance, encouragement, and feedback. In order for the individual to attain a maximum level of self-efficacy, practice is structured so that he or she approaches progressively more challenging situations, followed by the gradual removal of external aids and increased opportunities for self-guided practice. Repeated failures, particularly if they occur early in the course of trying out the new behavior, can have devastating effects on self-efficacy. This problem can be minimized by starting with realistic, achievable subgoals and working gradually toward the ultimate behavioral goal. Failures and difficulties are not to be completely avoided, however; they constitute an important ingredient in the learning process. People build a strong and resilient sense of self-efficacy by overcoming setbacks through perseverance.

The second source of self-efficacy feedback—learning by modeling—is the most common way by which humans acquire new
behaviors. People judge their capabilities in comparison to others whom they regard as similar to themselves. Greater degrees of similarity increase the model's personal relevance for the observer and the model's impact on the observer's judgment of his or her own self-efficacy. For example, a person who is afraid of a particular situation benefits more from seeing models overcome their own fears and the difficulties associated with the process in that situation than from observing fearless models who overcome obstacles seemingly without effort. Using multiple models with diverse characteristics increases the probability of identification with one or more models.

The third source—verbal persuasion—provides suggestions and encouragement that can lead an individual to believe that he or she is capable of performing a desired behavior. Self-efficacy expectations induced this way, however, are likely to be substantially weaker than those arising from personal mastery experiences, because persuasion does not provide a direct experience of capability. The impact of verbal persuasion on self-efficacy varies according to the perceived credibility of the persuaders.

Finally, individuals rely partly on their state of physiological arousal as the fourth source of information for judging their ability to perform desired behaviors. Because high arousal usually interferes with performance, individuals are more likely to expect success when they feel relatively free of internal agitation or tension. People can strengthen their self-efficacy by acquiring skills for reducing uncomfortable physiological reactions, such as tension and agitation, and by learning to interpret these reactions as normal rather than as signs of inefficacy.

Stages of Behavior Change Theory

In the early 1980s, James Prochaska and Carlo DiClemente outlined several fundamental stages through which individuals typically progress when making behavior changes: precontemplation, contemplation, action, and maintenance of change. More recently, Prochaska and DiClemente have added a fifth stage, between contemplation and action, called preparation.
ing a problem. They are either naively uninformed about the consequences of their behaviors, or they actively resist being informed about their problems. Precontemplators avoid changing their thinking and behavior and tend to be defensive.

Contemplators are seriously thinking about changing their behavior. They tend to be highly responsive to feedback and education as sources of information. Along with this increased openness to information about their problem behaviors, contemplators report feeling and thinking more about themselves in relationship to their problem behaviors. This increased self-evaluation can lead contemplators to become upset enough with themselves and their behaviors to make commitments to change. The contemplation stage ends at the point that a person makes a commitment to change.

In the preparation stage, individuals intend to take action in the very near future to change their behaviors. Typically, they have taken action in the recent past that has fallen short of the level of change they desired, and they are deciding how and when to proceed more effectively. The action stage involves carrying out the decision to change. Finally, the maintenance stage has to do with the stability of changes over time. People in this stage work to prevent relapse and to build on the achievements made during the action stage.

Progression through the stages is cyclical rather than linear. That is, people do not generally progress from one stage to the next; rather, they often revert to an earlier stage, which is then repeated.

Different processes of change tend to be associated with the different stages of change. For example, in the preparation stage, people tend to use counterconditioning, substituting alternatives such as relaxation or positive self-statements for the problem behaviors, and stimulus control, avoiding situations or stimuli that evoke the problem behaviors. In the action stage, individuals add three other goals: self-liberation, which focuses on their beliefs in their own capacity to change; relationship building, which garners support from others; and reinforcement management, which incorporates rewards for behavior changes. In the maintenance stage—still an active rather than a static process—people continue to rely on counterconditioning and stimulus control.
Marlatt's Relapse Prevention Model

In the mid-1980s, Alan Marlatt and his colleagues developed a cognitive-behavioral model for understanding relapse based on Social Learning (Social Cognitive) Theory.46-48 Because it specifically addresses relapse rather than behavior change in general, the model focuses on coping responses in "high-risk situations." These are situations that pose a threat to the individual's sense of control and that increase the risk of relapse. Marlatt identifies three types of high-risk situations associated with the majority of relapse episodes: negative emotional states such as frustration, anger, anxiety, depression, or boredom; interpersonal conflict that is ongoing or relatively recent; and social pressure to engage in the taboo behavior, including the indirect pressure resulting from being in the presence of others engaging in the behavior.

If the individual effectively copes with a high-risk situation, his or her self-efficacy in dealing with such situations increases. This, in turn, increases the likelihood of effective coping in the future. If the person does not carry out a successful coping response—either because he or she lacked the required coping skills, was inhibited by fear or anxiety, or failed to recognize the risk in time to respond effectively—his or her sense of self-efficacy will be diminished. This will often be accompanied by feelings of helplessness and a tendency to passively give in to the situation. In order to cope with uncomfortable feelings associated with decreased self-efficacy, the individual may be tempted to engage in the avoided behavior, leading to an initial "lapse" or "slip." This risk is increased by the lure of the immediate gratification anticipated from engaging in the prohibited behavior.

In Marlatt's model, lapses are considered important and expected components of the behavior change process. The model views the maintenance stage, which follows the implementation of the changed behavior, as a period of "unlearning" old habits and learning new ones through a process of trial and error. Lapses in high-risk situations are beneficial to the extent that they provide corrective information about coping.

Whether a single lapse is followed by a total relapse—that is, a complete return to baseline levels of the former habit or behavior—is largely determined by how the individual reacts to the lapse.
Marlatt calls this the "abstinence violation effect." If the individual attributes the slip to the fact that the situation was a particularly difficult one or regards it as a sign that he or she needs more practice, the lapse is unlikely to lead to a relapse. On the other hand, if the person attributes it to personal weakness or failure, there is an increased risk of relapse.

Another aspect of the abstinence violation effect is the experience of cognitive dissonance resulting from the disparity between the individual's self-perception as an abstainer and the occurrence of the prohibited behavior. The dissonance creates conflict or guilt and motivates efforts to eliminate these unpleasant feelings. In an attempt to produce positive feelings to replace the unpleasant ones, the individual may engage further in the prohibited behavior. Alternately, the individual may change his or her self-image and begin thinking of himself or herself as a non abstainer. In either of these cases, the stage is set for relapse.

Several additional cognitive factors may increase the probability of relapse. Denial allows an individual to remain ostensibly unaware of potential negative consequences of lapses. Through the "reactance effect," some individuals may perceive a commitment to abstinence as a threat to their personal freedom and choice, leading them to relapse in an attempt to free themselves from this oppression. In addition, many individuals who relapse can be seen as making a series of decisions or choices that place them in a chain of events eventually leading to an extremely tempting high-risk situation. Once in that situation, they may regard themselves as overwhelmed by the external circumstances and therefore unable to avoid a relapse.

Finally, rationalization acts to justify prohibited behavior. A common rationalization is that indulging in the behavior provides balance for the demands of everyday life. Recent research has explored rationalization in the context of self-justification. Australian psychologist Ron Gold interviewed 296 gay men who had unprotected anal intercourse and found that 20 percent of them used self-justifications—for example, believing that unprotected anal intercourse is "OK" as long as the insertive partner withdraws before ejaculation; fearing that the use of condoms will "spoil" the sexual encounter; feeling "fed up" with having to worry about AIDS; refusing to think about AIDS; and adopting the nihilistic notion
embodied in such statements as “After all the risks I’ve taken, I’m probably already infected, so I’ve got nothing to lose.” Additional rationalizations included a sense of boredom, the desire for excitement, and the desire to replace feelings of sadness with “something to make me feel good.”

The success of new combination antiviral treatments for people with HIV disease has begun to influence the justifications some people use for engaging in unsafe behaviors. A San Francisco study of fifty-five high-risk, seronegative gay men (men who had tested HIV antibody negative at least once before and who admitted to unprotected anal insertive or receptive intercourse in the previous twelve months) included questions regarding the effects of the new treatment success on decision making. Of twenty-two men responding to a separate questionnaire, 18 percent reported that at the time of a recent high-risk sexual encounter, they had the thought, “If I am exposed to HIV, I can take the new drugs (protease inhibitors, the “cocktail”) that will prevent me from becoming infected.”

The study also included general data on how the new treatment success affected attitudes toward prevention (although it was not explicit that these were justifications considered in the moment of relapse). Of the 55 men, 26 percent said that they were “less concerned about becoming HIV infected” because of the new treatments; 15 percent said they were more willing to take a chance of getting infected when having sex, and 15 percent stated they had already done so.

**An Integrated Model**

This section integrates concepts from the four behavior change theories previously discussed into a model specific to high-risk sexual behavior. The model draws from the four behavior change theories to address a wide range of reasons why gay and bisexual men might continue to have unsafe sex and to suggest strategies for how to intervene. Among these reasons are the lack of accurate information, inadequate skills, insufficient belief in the capacity to change behavior, the absence of external “cues to action” and perceived social norms, and the lack of internal readiness to change. It may be useful to compare this integrated model to other mod-
els that have been proposed to explain HIV-related changes in sexual risk behavior.40-58

Lack of Accurate Information
Some individuals may lack information regarding the degree of risk of their behaviors, the efficacy of preventive measures, the degree of sacrifice and the actual steps involved in carrying out preventive measures, the process of behavior change, or any combination of these factors.

Degree of Risk
Many situations demonstrate a person's lack of information about the degree to which behaviors constitute real risks to well-being. Young seronegative men may think that only older men get AIDS and that the risk is somehow significantly less or negligible for them. Men who have remained uninfected despite repeated incidents of unsafe sex may also believe that the risk is low or negligible for them. People who have not been subjected to media or personal discussions about AIDS and unsafe sex may not recognize their susceptibility to, or the gravity of, HIV infection.

Some men with HIV disease may continue to have unsafe sex with other seropositive men because they question the legitimacy of warnings against the dangers of "reinfection" by HIV. Many seropositive men may be unaware of the serious risk to their immune systems of other diseases that can be contracted through unsafe sex. Some men are unaware that some behaviors—for example, being the insertive partner during anal intercourse—involve potentially serious risks of being infected.

According to the Health Belief Model, all of these individuals may lack the perception of personal susceptibility needed to motivate effective preventive action. Social Cognitive Theory suggests that they may also lack adequate incentives for engaging in preventive behaviors.

Efficacy
A person's lack of information about the degree to which available preventive measures actually succeed in reducing the risk can lead to high-risk behavior. Many men doubt the effectiveness of condoms
in preventing HIV transmission. They may have heard stories about condoms breaking or about men becoming infected presumably without having engaged in unsafe sex or other high-risk activities. As the Health Belief Model and Social Cognitive Theory assert, the belief in the efficacy of particular actions in achieving desired outcomes is a key motivating factor underlying effective implementation of those actions.

**Sacrifice**

For men who have had limited enjoyable experiences with condoms or with safer sex activities that do not require condoms—for example, frottage and mutual masturbation—the notion of safer sex may connote extreme sacrifice and loss of a key source of pleasure in life. According to the Health Belief Model, these men may perceive that the costs of preventive action outweigh the benefits, thus reducing the likelihood of their taking such action. This may be particularly true if they have doubts about the efficacy of safer sex behaviors or if they do not recognize their degree of susceptibility to HIV infection.

**The Process of Behavior Change**

Men who make attempts to use condoms or to focus on safer sex activities other than anal intercourse may prematurely stop trying if they do not understand that acquiring new behaviors normally requires practice and learning from mistakes, which entails making slips. Without this understanding, they are more likely to give up when they encounter difficulties or when they fail to perform according to their own expectations. Social Cognitive Theory and Marlatt's model both address the role of trial and error in learning and sustaining new behaviors.

**Inadequate Skills**

People may lack skills in using condoms, negotiating safer sex, engaging in safer sex, managing distress, dealing with high-risk situations and with slips, and disengaging from risk-associated chains of events. As Social Cognitive Theory asserts, inadequate skills will sabotage the development of self-efficacy even among those who are motivated to change their behavior and who are reasonably confident about being able to do so.
Using Condoms
Many men may be unaware of important details of condom use. These include the correct way to unroll, apply, or remove the condom, the importance of water-based versus oil-based lubricants, and the differences among brands of condoms in terms of size, texture, and taste. Others may have adequate information about use and type, but may lack sufficient practice in a variety of situations for building solid and effective skills. For example, attending one or two “safer sex” workshops where the presenter demonstrates condom use on models, even if accompanied by guided practice, is likely to be insufficient unless there is follow-up practice.

Negotiating Safer Sex
Many men lack experience talking frankly with partners about what they will and will not do during sex. As with other skills, developing comfort and efficacy in negotiating safer sex requires guided practice through trial-and-error learning.

Engaging in Safer Sex
Even though they may be aware of the range of safer sex activities that exist, many men have not had sufficient opportunities to develop their abilities and the comfort to engage in these activities in ways that are truly pleasurable to them. This lack of opportunities may strengthen any doubts they may have about the benefits versus the costs of safer sex. According to the Health Belief Model precept that action is related to a perceived cost-benefit ratio, such doubts may predict a decreased likelihood of sexual behavior change.

Managing Distress
Some people experience high levels of anxiety or tension when they contemplate or attempt using condoms, experimenting with new types of safer sex, or negotiating safer sex with a partner, and they react by feeling overwhelmed or defeated. If they lack skills in managing their distress, they may tend at least temporarily to forego further efforts to change.

Dealing with High-Risk Situations
For some men, high-risk situations may include being intoxicated while having sex or while attempting to negotiate safer sex; having sex following a period of prolonged sexual abstinence; having sex
in settings they associate with high-risk sex, such as parks or sex clubs; or having sex with a partner who is exceptionally attractive to them. Because these men lack experience effectively responding to such high-risk situations, these circumstances continue to trigger unsafe sex. Marlatt’s model points out that failure to respond effectively in high-risk situations reduces self-efficacy, resulting in increased distress, which in turn increases the potential for a lapse in behavior to occur.

**Dealing with Slips**

Even if men have heard that slips are a natural part of the behavior change process, the perceived societal pressure to avoid unsafe sex 100 percent of the time may make a single slip feel like a terrible failure. This can lead some men to give up trying. In accordance with Marlatt’s model, men who have had insufficient experience “recovering” from unsafe sex slips are at increased risk of repeating their slips.

**Disengaging from Risky Chains of Events**

As Marlatt’s model points out, we can view high-risk situations as the final link on a chain of events—a chain that can be broken. For example, an individual may typically end up going to bars to drink and look for sex on weekend evenings when he has nothing to do and is sitting at home feeling bored or frustrated about his work. Alternatives would require interrupting the pattern by identifying enjoyable interests or activities that do not involve drinking, seeking help for a possible drinking problem, or making weekend plans in advance with friends.

**Insufficient Belief in Capability to Change**

Whether or not they possess necessary information and skills, individuals may lack a sense of self-efficacy: they may question their ability to carry out changes in behavior. For instance, an individual may feel that he cannot effectively use condoms, especially when his partner seems to want to avoid using them. Or, fearing that his partner will lose interest in him, he may feel incapable of saying that he wants to limit the couple’s sexual activities to safer
sex. According to Social Cognitive Theory, low self-efficacy can arise from insufficient experience with mastering a behavior, inadequate exposure to credible models, or agitation that gets interpreted as inadequacy.

**Absence of External “Cues” and Perceived Social Norms**

The Health Belief Model emphasizes the importance of “cues to action” in motivating prevention behaviors. In the absence of sufficient environmental cues, a person may not develop an awareness of the need to act without delay. Many men in large urban areas may have stopped attending to the safer sex media messages that captured their attention during the early years of the epidemic. In some cases, long-standing media messages may no longer be compelling; new messages as well as new methods of disseminating the messages may be required.

The Stages of Behavioral Change Theory recognizes the importance of being able to rely on the support of helping relationships in order to sustain momentum after making a commitment to action. Relatively isolated gay and bisexual men without supportive peer networks to reinforce positive behavior changes are therefore likely to have difficulty maintaining changes over time.

For gay and bisexual men living in places without a strong and visible gay community, safer sex messages in the media may be scarce or weak, and peer norms reinforcing the need for safer sex may be rare or absent. For gay and bisexual youth, peer norms may not consistently and strongly reinforce safer sex and may, in some cases, convey approval of continued unsafe sex.

Furthermore, some individuals may perceive strong safer sex social norms in one context (for example, at home with a new sex partner) but not in another context (for example, in a public sex environment such as a sex club). Gold cites recent research suggesting that for a number of gay men, the stronger their link to the gay community—and, presumably, the greater their exposure to peer norms promoting safer sex—the more likely they are to engage in unsafe sex. The reasons for this unexpected finding are unclear, but it suggests that in addition to peer norms, one’s degree of motivation to comply with peer norms influences behavior.
Lack of Internal Readiness to Change

The Stages of Behavior Change Theory implies that many people, at various times in their lives, may be psychologically unready to commit to change. This may be true even for those who have been exposed to considerable information about risk and who recognize the consequences of postponing change. For this reason, attempts to even enter into a dialogue about changing behavior are likely to fail.

Others may be contemplating changing their behaviors but may be resistant to pressure to act immediately. They may need more time to accumulate information and fully evaluate risks and alternative courses of action. Many who are feeling the effects of loss and grief may lack the motivation to invest effort in changing behavior for the sake of long-term goals. As psychologist Walt Odets has described, people who have experienced multiple losses and grief may come to feel hopeless about the future. As a consequence, they may regard the idea of surviving the AIDS epidemic as neither favorable or desirable and may view becoming infected as a way to avoid such a fate. Another possible explanation for such a lack of motivation to change is Marlatt’s notion that people may rationalize their continuing engagement in high-risk behaviors as a way of balancing the burdens and demands of everyday life.

Guidelines for Intervention

A central implication of this overview of behavior change theories is the need to identify the obstacles to unsafe sex before implementing prevention interventions. Providing a homogeneous intervention to a heterogeneous target population will likely help some, alienate others, and discourage the many who fail to respond because their particular needs are not addressed.

Among any particular pool of gay and bisexual men recruited to participate in a risk-reduction intervention—for example, counseling, a safer sex workshop, or a support group—there will be a broad mix of types. Some men will be motivated to change but lack essential information about risks or about alternative behaviors. Others will have adequate information but lack skills or confidence to implement low-risk behaviors. Still others may be well informed
and have the necessary skills and confidence but lack the internal motivation to commit to change or a supportive peer network that provides models and norms reinforcing sustained behavior changes. Each of these subgroups requires specific types of help. By carefully screening clients prior to implementing interventions, counselors can ensure that individuals receive appropriate support.

For those who lack basic information, interventions should include the necessary education in areas where participants are deficient. Ideally, this education will be provided by credible presenters with whom the participants can easily identify. Those with information deficits are also likely to be deficient in one or more skills related to risk reduction. Modeling of risk-reduction behaviors, again preferably by people who share many characteristics with the participants—including some degree of anxiety—will enhance skill acquisition. Structured practice over time, which incorporates opportunities for coping with failures, will build resiliency. Counselors can enhance such an intervention by providing or promoting a peer support network that encourages and reinforces low-risk behaviors.

Individuals lacking the internal motivation to change their sexual behavior require different approaches. Those who are not even considering change are unlikely to have sustained interest in interventions clearly designed to promote sexual behavior change. They may be more amenable to participating in less specific interventions, such as counseling aimed at dealing with painful emotions or other areas of personal concern, or social activities that will put them into contact with peers who may eventually influence them to consider changes. Those who are contemplating or preparing for change would likely benefit from opportunities to talk about their decision-making process and considerations and to observe others at the same stage, opportunities that would promote modeling of decision making and exchange of information about how best to proceed. For those who lack a supportive peer network that establishes and reinforces norms encouraging low-risk sexual behavior, interventions should mobilize the formation of such a network rather than simply transmit information or teach skills.

Theory is often easier said than done, and applying several theories at once can daunt the most committed counselor. Case examples offer the opportunity to test out and practice theoretical
approaches. The following two cases deal with two central aspects of HIV prevention: acknowledging risk and interrupting a pattern of unsafe behavior.

Jimmy: Acknowledging Risk

Jimmy is a twenty-two-year-old seronegative man who finally agrees to join an eight-session HIV-related support group after having been urged to do so for several months by a close friend, Tom. Most of Jimmy's friends are sexually active with multiple partners, and using condoms with anal sex is the exception rather than the rule. Jimmy, like his friends, finds anal sex without condoms to be much easier and more pleasurable, and he frequently has unprotected anal intercourse. He does not seem to be particularly worried about this behavior and feels that Tom's concerns are overblown.

Jimmy is understandably resistant to participating in the group but, encouraged upon learning that others in the group also have unsafe sex and question the need to change behavior, he decides to continue coming to the meetings. Jimmy reaches a turning point in the second session of the group, when one of the other group members discloses that he became infected with HIV at age nineteen, having had unprotected anal intercourse only a few times. Others in the group report knowing men around Jimmy's same age who have become infected. Jimmy is motivated by these incidents to ask a few HIV-knowledgeable acquaintances about the frequency of young men becoming infected, and the information he gathers is consistent with the reports of the members of the group.

By the fifth session of the group, Jimmy still expresses skepticism about changing his behavior but has actively begun to solicit information about HIV infection and unsafe sex from other group members. Although he has always disliked condoms, after the group spends almost an entire session practicing placing condoms on dildos and giving each other encouragement, Jimmy feels confident enough to commit to using condoms with a supportive sexual partner who understands that he is "learning."

When he returns to the group the following week, Jimmy reports that he still needs practice with condoms and intends to continue experimenting with them. Group members laugh as they share stories about the mishaps and embarrassments they experienced when trying out condoms. Jimmy also reports that despite feeling more comfortable using condoms, he is having trouble insisting on condoms with partners who want to have unprotected anal sex.
Other group members give understanding nods. The facilitator guides the group through a number of role-plays. In each role-play, group members set up the scene to depict a situation in which it would be especially difficult for them to negotiate safer sex. Whenever a participant in a role-play feels “stuck,” the action is temporarily stopped, and other group members are invited to give suggestions or to enter the role-play and try out their approach.

At the final session of the group, Jimmy reports that he failed to insist on safer sex during his most recent sexual encounter. He notes, however, that he realizes how he could have handled the situation differently and intends to use this information to help him in such situations in the future. The group members exchange phone numbers, and Jimmy looks forward to keeping in touch with those in the group whom he regards as new friends.

The group was helpful to Jimmy in a number of ways. It provided him with needed information about risk and personal susceptibility, as prescribed by the Health Belief Model, and about how to carry out lower-risk behaviors. In witnessing other group members in similar circumstances trying to change, he came to appreciate that developing new behaviors takes time and practice (an important component of Social Cognitive Theory) and that setbacks can be opportunities for learning rather than signs of failure (a crucial understanding in terms of Social Cognitive Theory and Marlatt’s model). Jimmy received guided practice in new behaviors during the group meetings, and encouragement from the group members to continue practicing outside the meetings. As he began taking action to change, he used the support of his peers in the group and the reinforcement provided by their encouragement to persist in his efforts to change, conforming to the Stages of Behavior Change Theory. Finally, by allowing him the time he needed to accumulate information, evaluate his risks and alternative courses of action, and arrive at a commitment to change on his own, the group respected the Stages of Behavior Change—that change is a process rather than an instantaneous event.

_Michael: Interrupting the Pattern of Unsafe Sex_

Michael is a forty-year-old seronegative man who seeks safer sex counseling at a local AIDS organization because he has concerns about occasional slips into unsafe sex. He has often felt emotionally drained and depressed since his
lover's death eighteen months ago. Michael says he generally feels optimistic about being able to go on with his life, but sometimes he gets the urge to escape, and he lets go of his inhibitions and has anal sex without protection.

Michael weeps during his first counseling session as he describes missing his lover and the other friends who have died. He explains that he has rarely used condoms and that he never used them with his lover. Two things are readily apparent to the counselor: Michael is suffering grief and perhaps depression associated with the death of his lover and friends, and he has not had much experience using condoms.

Michael accepts the counselor's referral to a therapist with expertise in the area of grief and loss, and he later joins a ten-week grief support group facilitated by the therapist. He agrees with the safer sex counselor that he may need more practice using condoms, and they use time in one of the early sessions practicing putting condoms on a dildo.

During the following month, Michael hesitatingly admits to the counselor that he slipped the week before and had unprotected anal intercourse. He feels devastated by the slip, expressing doubts that he can ever change. When Michael mentions that he has several friends who have stopped having unprotected anal intercourse, the counselor suggests that he ask a few of them about the process they went through trying to change. Michael discovers that a good friend had several slips during the first months of his efforts to change.

Michael subsequently reveals that, despite earlier denials, he does have concerns about the amount of alcohol he drinks. He admits that when he has unsafe sex, it is usually when he is intoxicated. In response to the gentle but persistent efforts of both his therapist and the counselor, Michael eventually makes a commitment to stop drinking. Over the course of the following month, he slips twice, and both times counseling helps Michael identify what led to the slip and how he might handle things differently in the future.

During this period, his counselor also realizes that Michael is afraid to initiate safer sex with the men he typically meets in bars. He and his counselor discuss alternative ways to meet men, and Michael decides to consider joining a gay club as a way to meet friends and potential sexual partners.

Individual counseling provided Michael with an opportunity to begin to release painful feelings of grief in a setting where he
felt heard and respected. The resulting rapport is likely what motivated him in large part to accept the counselor’s suggestions to seek therapy and to acknowledge his alcohol problem. By refraining from pressuring Michael to commit to complete abstinence from unsafe sex, the counselor allowed Michael to proceed at his own pace through the Stages of Behavior Change: contemplation, preparation, and action.

Similarly, support and encouragement to get help for his alcohol problem allowed Michael to interrupt one chain of events—drinking followed by sex—that repeatedly led to unsafe behavior. Guided practice in using condoms, along with encouragement to explore additional avenues of sexual activity, helped increase his sense of self-efficacy to avoid unsafe sex and to enjoy alternatives. Support in viewing his slips as natural elements of the behavior change process decreased his self-criticism and pessimism and increased his confidence in his ability to keep trying, a result predicted by both Social Cognitive Theory and Marlatt’s model. Perhaps equally important, counseling enabled Michael to expand his social contacts, reducing his isolation and increasing his exposure to new peer norms that could reinforce his behavior changes.

Behavior theory points to the wide variety of reasons that can account for a person’s failure to avoid high-risk sexual behavior. Before intervening, counselors should first attempt to identify the obstacles to change that are specific to each individual. Simply providing general information, persuasion, and a limited amount of practice with generic behaviors (such as using condoms) may fail to address these specific obstacles.

Behavior change theories emphasize several factors in motivating behavior change. These include awareness of the need for and the benefits of change, practice in the skills for implementing new behaviors in a variety of settings, and confidence in the capacity to engage in and maintain new behaviors in light of changing circumstances and setbacks or failures. Being aware of this complexity of factors should help practitioners more precisely identify problems and select suitable interventions.
Notes


16. Kelly, St. Lawrence, and Brasfield, “Predictors of Vulnerability.”

17. McKusick, Coates, Morin, and others, “Longitudinal Predictors of Reductions.”

18. Stall, Ekstrand, Pollack, and others, “Relapse from Safer Sex.”

19. Kelly, St. Lawrence, and Brasfield, “Predictors of Vulnerability.”

20. McKusick, Coates, Morin, and others, “Longitudinal Predictors of Reductions.”

21. Centers for Disease Control, “Patterns of Sexual Behavior Change.”

22. Aspinwall, Kemeny, Taylor, and others, “Psychosocial Predictors.”


Chapter Four

A Developmental Perspective on Behavior Change

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Why do people behave the way they do? One way to answer this question is to study the continuing process of human development: of how a person changes and how he or she stays the same over time. Behavior change must include a developmental component, because the ability to understand HIV risk-reduction messages and to change sexual and drug-using behaviors is determined by levels of cognitive, psychological, and moral development.

Development is a lifelong process, and a developmental perspective can be useful in designing HIV prevention approaches for people in all age groups. However, development is most apparent during adolescence and youth, and understanding development is particularly important for educators and counselors seeking to understand the motivations of younger people. Too often, HIV-related behavior change approaches are based more on what is known about AIDS than on what is known about a target population. Communicating with adolescents and young adults involves more than just simplifying a message that seems to work for adults: it requires an understanding of development.

This chapter, which focuses on younger people but is applicable to all age groups, defines theories of cognitive, psychological, and moral development, identifies the major proponents of these theories, and discusses how these theories relate to HIV preven-
tion and prevention counseling. Psychological development addresses how issues such as personal identity and intimacy develop over time. In particular, two of Erik Erikson's eight developmental "crises" are central to behavior change. A cognitive developmental approach, exemplified by the works of Jean Piaget and of Roger Bibace and Mary Walsh, "focuses not on what people know, but rather on how they understand." Finally, theories of moral development, as reflected in the work of Lawrence Kohlberg and Carol Gilligan, describe how a person’s perspectives on what is "right" and "wrong" change on the basis of age, experience, and perhaps even gender, and how these changes affect behavior.

Although these developmental perspectives are central to understanding behavior change, individual, group, and cultural differences make it difficult to define absolute developmental stages and draw firm conclusions about behavior. Even a basic concept such as adolescence is defined variously by different cultures, and this is reflected in research. For example, Laurence Steinberg defines adolescence in terms of three subperiods ranging from ages ten to nineteen. Other researchers consider adolescence as one homogeneous period running from age eleven to eighteen. There are many pieces to the developmental puzzle, which in the solving turns out to be a Rubik's cube, with an almost infinite number of combinations. Nonetheless, because a person's understanding of HIV disease is based on his or her development, an awareness of developmental tendencies is critical to effective HIV prevention.

**Psychological Development: Identity and Intimacy**

Although there are several perspectives on adolescent and young adult development, Erik Erikson's theory (one of the earliest) serves as a good introduction to the basic issues of psychological development. Erikson identified eight "crises" that an individual may confront throughout life and concluded that healthy development is achieved if a person successfully resolves these crises; unsuccessful resolution produces psychological distress. This section will focus on the two crises that Erikson identified as being relevant to adolescence and young adulthood.
Identity Versus Role Confusion: Who Am I?

For Erikson, a major aspect of adolescent development is the resolution of a crisis he defines as "identity versus role confusion." During this time, a typical adolescent works to answer the question, Who am I? He or she develops a sense of self by testing a variety of roles—including sexual ones—and integrating these different roles to form a single identity. If HIV prevention programs try to discourage role testing because, for example, such testing is considered "risky," will adolescents be able to develop coherent identities? Identity is not achieved by having people tell you who you are; it is discovered by finding out who you are.

As identity develops, so do the elements of trust and self-understanding, creating the potential for relationships that are based on mutual caring and need fulfillment. If these two elements do not develop, relationships may involve "using" others and not "caring" about them. In particular, trust, identity, and self-understanding have powerful implications for the counseling experience, insofar as the client can understand his or her relationship with the counselor as well as with others in his or her life. Erikson's perspective was exclusively heterosexual, hence his belief that identity formation was primarily an activity of adolescence and early adulthood. For gay men and lesbians, however, identity formation is likely to be achieved somewhat later, perhaps in the mid- to late twenties or even later. Prevention messages targeted specifically toward gay men and lesbians will be effective only for those who have achieved a gay or lesbian identity; such messages are likely to be virtually irrelevant to those who are still struggling to define sexual identity. This insight has two important implications for efforts at prevention: messages aimed at "gay teens" may not reach many young men who are having sex with men but who do not perceive themselves as "gay"; and gay adults may continue in "adolescent" identity development beyond adolescence.

In response, in the same way that mass marketing targets specific messages to specific segments of a consumer audience, client-centered counseling approaches, which already acknowledge the individuality of each client, are best served by a deeper understanding of a client's psychological development. This understanding enables the counselor to respond in ways that are not only
consistent with a client’s values and beliefs but also developmentally comprehensible to that client. Further, client-centered counseling approaches must acknowledge and address issues of social class and educational level, as differences in these areas may affect the expression of sexual identity.  

Likewise, substance use during adolescence may complicate and delay psychological development. For example, in a longitudinal study of adolescent drug use from the mid-1970s to the present, Peter Bentler found that “heavy drug use as a teenager, in turn, further interferes with the mastery of critical developmental tasks, such as formation of a prosocial behavior identity [behavior based on helping and sharing done to benefit other people without an expected reward], gaining interpersonal and educational skills, and learning to take on family and work role responsibilities. Thus, drug users may develop a pseudomaturity that does not adequately prepare them for the real difficulties of adult life.”

Intimacy Versus Isolation: How Close Can I Get?

The word intimacy is often used as a euphemism for sexual intercourse. Psychologically, intimacy relates to personal disclosure: the ability to reveal parts of the self that are normally hidden from others. Although sexual intimacy and psychological intimacy often go together, the distinction between the two is important, and confusing sexual intimacy with psychological intimacy has important implications for prevention.

Erikson defined the crisis of intimacy versus isolation as one of early adulthood. Young adults need and want intimacy, a deep personal commitment to another. The inability to achieve such intimacy may produce isolation and self-centeredness. Moreover, the capacity for intimacy is based on a sense of identity (usually acquired in adolescence), which can serve as a source for evaluating the correctness or incorrectness of personal choices. Without a strong identity, one is unable to be intimate. Trust and intimacy are central not only to self-definition but also to successful interpersonal and counseling relationships.

Erikson limited intimacy to heterosexual relationships that produced children, having excluded other lifestyles—homosexual, celibate, single, childless—from his analysis of “healthy” development.
Despite these omissions, his understanding of identity formation and intimacy development have important implications for HIV prevention. For example, will irrational fear of HIV cause adolescents to test fewer roles, take fewer risks, and thus make it more difficult for them to discover their identity? Distrust of others, when combined with a lack of self-definition, may make intimacy difficult or impossible. Although safer sex messages that focus on sexual abstinence may keep adolescents physically healthy, such messages may have a negative impact on the healthy development of identity, trust, intimacy, and sexuality. An abstinence-based approach also fails to take into account the importance of touch as a human experience, and the physical, psychological, and social implications for people who are not able to touch, or be touched, for years at a time. Fear and distrust engendered in all these ways may be hard to overcome later in life.

Erikson also identifies a crisis of middle adulthood: "generativity" (being productive in a meaningful way; caring for children; guiding the next generation) versus "stagnation" (feeling empty and without purpose). From the standpoint of HIV prevention, a middle-aged adult in the generativity phase should be concerned with the health of young people, whereas an adult in the stagnation phase may feel no particular responsibility to the next generation. Although Erikson's approach gives some insight into the connections among generations, it does not address how this crisis could be used to guide HIV prevention efforts for adults. For example, a "stagnating" middle-aged adult—who is likely to be self-absorbed, self-indulgent, and bored—will probably focus on his or her own gratification and fail to take responsibility for actions toward sexual partners. Shifting from stagnation to generativity requires a belief in the future and the ability to care about others. Generativity and responsibility go hand in hand.

**Cognitive Development:**

**Concrete Versus Abstract Thinking**

Whereas psychological development focuses primarily on a person's relationship to the self, cognitive development determines a person's relationship to the outside world. Thinking changes with age; that is, thought processes evolve over time. Jean Piaget's work
demonstrated, for instance, that young people go from a period of concrete thinking to one of more abstract thinking. The central difference between these two periods is the degree to which a person is able to conceive of a reality beyond the immediate. Concrete thinkers focus on the here and now, on using logic to solve only immediate problems, and on things they can perceive. For example, concrete thinking may emphasize "things" such as consumer goods that allow a young person to compare himself or herself to others. Abstract thinkers are able to imagine—to think in terms of possibilities and the consequences of their behavior. Their comparisons with others are likely to be based more on values and ways of thinking than on immediate experiences or tangible objects. These distinctions are crucial to HIV prevention, and, in applying Piaget’s theories, Roger Bibace and Mary Walsh conclude that people cannot even understand the concept of prevention, much less implement behavior change, until they reach a certain level of cognitive maturity.

What Do People Understand?

In order to understand how young people conceive of illness and, more recently, of AIDS, Bibace and Walsh have expanded on Piaget’s approach. In their early work, Bibace and Walsh identified three stages—preoperational, concrete operational, and formal operational—that put conceptions of illness into the context of cognitive development (see Table 4.1).\(^8,9\) They found that some people progressed through these developmental stages and others did not: hence, some adults may apply concrete as well as abstract approaches to thinking. A summary of their findings offers insights into how people at different ages may understand important health concepts—in particular, what causes illness.

In more recent work, Bibace and Walsh examined how children at the preoperational (ages five to seven), concrete operational (ages eight to ten), and formal operational (ages eleven to thirteen) stages think about HIV infection. The five- to seven-year-olds understand AIDS in terms of “association.” That is, they explain AIDS as an association with an event, or person, or object. For example, having heard that a person with AIDS “throws up,” a child concludes that the “throwing up” causes AIDS. This reflects
Table 4.1. Bibace and Walsh's Stages of Cognitive Development.

<table>
<thead>
<tr>
<th>Period</th>
<th>Age</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preoperational</td>
<td>2-6</td>
<td>Phenomenism: illness comes from external source (example: God causes colds)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contagion: illness comes from objects or people (example: other people cause colds)</td>
</tr>
<tr>
<td>Concrete operational</td>
<td>7-12</td>
<td>Contamination: illness due to external and harmful source (example: colds come from not wearing a hat)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Internalization: illness is in the body but is caused by outside source (example: colds come from breathing germs)</td>
</tr>
<tr>
<td>Formal operational</td>
<td>12+</td>
<td>Physiological reasoning: external cause for internal illness (example: a virus causes colds)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psychophysiological reasoning: physical explanation for illness (example: virus causes cold; stress lowers resistance)</td>
</tr>
</tbody>
</table>


“magical thinking” and suggests that prevention efforts for people at this stage of development need to address vague fears about being magically victimized by AIDS.11

Older children, ages eight to ten, who are more likely to be concrete thinkers, attribute HIV infection to a specific sequential experience that is bad for the body. Bibace and Walsh cite the child who concludes that “you get AIDS from falling into a puddle that someone with AIDS fell into before and they had a cut. And if you have a cut, it goes in yours and you get AIDS all over you.” At this stage, children may describe AIDS in terms of internal body symptoms, but these descriptions are not very specific.

The oldest children, ages eleven to thirteen, understand HIV infection as an interactive process. “You get AIDS from a virus that gets into your bloodstream. It causes your immune system to stop fighting germs. Then, when another germ gets into your system,
like pneumonia, the immune system can’t fight it and you get very sick and may even die from the pneumonia.”

Such developmental factors have been identified by other researchers as well. One study found that even though elementary school children may know the facts about AIDS, they do not necessarily understand those facts. It also found that although about 25 percent mentioned drugs as a cause of AIDS, when pressed for specific examples, some listed cigarettes, alcohol, cocaine, and marijuana. Another study found that 19 percent of the high school students surveyed believed that HIV infection could be spread by sex between two uninfected people!

Clearly, comprehension of the symptoms of HIV disease seems to follow a characteristic developmental progression. Children know and understand more about colds than they do about AIDS, probably because they have more experience with colds than they do with HIV disease. However, with increased education, it is possible to improve a child’s understanding of HIV disease so that it matches his or her level of understanding of the common cold—but this can happen only if school-based HIV education programs are more closely linked to the developmental level of the child.

David Schonfeld adds to Bibace and Walsh’s formulation by connecting children’s explanations of illness to the concept of “immanent justice”—a belief that justice comes from inanimate objects and that misbehaviors will be punished. If a child perceives illness as punishment, then he or she will likely feel guilt and shame for being sick.

Although these analyses deal primarily with the conception of illness by children, adult thinking may reside at any of these three levels. For example, for some adults, AIDS is due to immanent justice—not to HIV infection. Bibace and Walsh recount the story of a police officer who was afraid to handcuff a prostitute for fear that he might get AIDS from touching her, an example of “contamination,” which reflects a form of concrete operational thinking. They concluded that the police officer’s cognitive development did not allow him to understand the concept of prevention. Such magical thinking occurs even among college students who are well informed of the “facts about AIDS.” One study found that a majority of students believed that eating with silverware previously used by
someone with AIDS would be a risky experience—even if the silverware had been washed and even if the person with AIDS had used the silverware a year earlier. An obvious implication of this finding is that a one-size-fits-all approach to HIV prevention is unlikely to fit everyone equally well.

An adjunct to Bibace and Walsh’s work, a survey of fifth, seventh, and tenth graders, identified two general concerns about AIDS: the disease effects and the social effects. Disease effects included the lethality of AIDS, the magnitude of the disease, personal vulnerability to AIDS, helplessness if you have the disease, and uncertainty about whether someone has AIDS or not. Social effects included compassion for and victimization of those who have AIDS, phobias about people with AIDS, restrictions on sexual behavior because of fear of AIDS, ignorance about AIDS, and irresponsible behavior by people who do not take precautions. Although students at all ages were upset about the disease effects of AIDS, older adolescents tended to be more upset by its social aspects. In addition, whereas fifth graders were more concerned about the lethality of AIDS, tenth graders were more concerned about being helpless in the face of AIDS.

Even without specific education, children and adolescents are likely to form intuitive theories about AIDS, often based on their experiences with other diseases, such as the common cold. If colds can be transmitted through sneezing, why not AIDS? Two studies have shown that school-based HIV education can change the intuitive theories held by some children, suggesting that young people’s level of understanding may not be as fixed as was earlier thought. This body of work suggests that young people may not progress steadily through several stages of cognitive development but may formulate and reformulate their own theories regarding HIV disease. Again, these developmental researchers argue that school-based prevention should be linked to the different kinds of intuitive theories that students apply.

Research also points to a relationship between psychological development and the decision to use drugs. A study of eighth-grade adolescents exploring this decision process found that for those students who decided to use drugs, the major factor in their decision was “personal choice.” They viewed drug use as a personal issue and, significantly, did not consider the perceived harm
of drugs and the social sanctions against drugs. In part, this attitude may reflect a thinking style that emphasizes certain aspects of concrete thinking, such as a focus on the present, magical thinking, egocentrism, and a complete lack of awareness that other factors might be valid. Because these decisions are not influenced by perceptions of harm, prevention programs that highlight the hazards of drug use may be largely irrelevant for these youth. In response, program developers must adopt psychologically sophisticated prevention approaches that incorporate magical thinking and egocentrism in order to reach this hard-to-teach population—in short, to fight fire with fire.

**Moral Development: Considering Convention**

For many people, morality comes from religion—not from psychology. Although religious morality has influenced the content of many HIV prevention programs, the science of moral development has had a negligible impact on program planning, implementation, and evaluation. Moral development should play a role in prevention planning; that it does not is based more on a lack of familiarity with developmental principles than on data showing it to be ineffective.

Many people would like to believe that a person’s morality remains the same throughout life; however, psychological research clearly shows that moral thinking and behavior change over time, consistent with what is known about other cognitive and psychological phenomena. From a psychological perspective, “Morality does not consist of any specific behaviors but of a special perspective of the agent.” This definition suggests a very different approach from those that would categorically (and simplistically) list “moral” and “immoral” behaviors and argue that HIV prevention should be based on specific “right” and “wrong” behaviors. Unfortunately, such moralistic arguments are likely to fail in preventing transmission because they are based more often on the beliefs of their proponents than on those of target populations, especially adolescents and young adults.

Although the idea of moral development is a valuable perspective from which to examine behaviors that include some aspect of moral thinking (for example, alcohol and drug use, sexual
behaviors, and aggression), it has not been widely applied to prevention and behavior change. The standard methodology for studying moral development involves fables or stories that comprise a moral dilemma. Researchers ask participants to resolve the moral dilemma and explain why they chose the solution that they did. This methodology is applicable to AIDS prevention, which has many issues that could be described as dilemmas with no clear-cut right or wrong answers. Within this qualitative context, researchers could better determine “why” safe or unsafe decisions are made, and understand the thinking strategies that are used by people of different ages, sexual orientations, genders, and ethnicities.

Two theorists have propelled the field of moral development: Lawrence Kohlberg and Carol Gilligan. Understanding their constructs may help us to develop effective HIV prevention interventions.

**Kohlberg: Laws Versus Values**

Lawrence Kohlberg identified six stages of moral development organized sequentially through three levels. Although other researchers have developed age-appropriate guidelines applying Kohlberg’s theories, it must be emphasized that some people never develop beyond a particular stage. Thus, in terms of moral development—even more than for psychological and cognitive development—age per se is no guarantee that a person has progressed to a higher level of moral thinking.

**Level I: Preconventional Moral Reasoning (Primarily Ages Four to Ten)**

Preconventional moral reasoning is based on external control by others. Behaviors are chosen to avoid punishment or gain rewards. This stage of moral development reflects the “concrete” thinking processes of young people: pain is bad, reward is good. A person at this level of moral thinking will probably change behaviors only if there are tangible consequences, either good or bad, of their behaviors.

In Stage 1, people ignore the motivations for a behavior and focus only on its concrete aspects (for example, how big a lie was told) or the consequences of the behavior (for example, how much property damage was done and how much it will cost to rec-
tify). In Stage 2, individuals conform to rules out of self-interest and consideration of what others can do for them.

**Level II: Conventional Moral Thinking**  
_(Primarily Ages Ten to Thirteen)_

Conventional moral thinking reflects law and social conventions. Here a person seeks approval and avoids disapproval, dishonor, or guilt by obeying laws and social expectations. People internalize the standards set by others and are capable of deciding—on the basis of these internalized values—whether their own actions are good or bad.

In Stage 3, people want to please and help others. In response to specific situations, they evaluate actions based on motivations behind the act, a thinking strategy they could not accomplish in Stage 1, and can take into account mitigating circumstances. In Stage 4, they try to meet their responsibilities, be respectful to authority, and maintain the social order. Behaviors that violate a rule and harm others are always wrong regardless of the motivation for the behavior or the circumstances surrounding it.

Conventional adolescents will act on the basis of law (either secular or religious) and social expectations. Conventional morality means "doing what you are told," especially if those instructions come from authority figures, such as parents, clergy, teachers, political leaders, or peer leaders. Young people at this level might be more likely to change their behaviors if they would gain public approval for their behaviors from relevant authority figures and role models.

**Level III: Postconventional Morality (Not Before Age Thirteen; Often Not Until Young Adulthood; Sometimes Never)**

Postconventional morality represents the attainment of true morality, the ability to acknowledge conflicts between two incompatible standards and decide between them. At this point, behavioral control becomes more internalized, in terms of both standards and reasoning about right and wrong.

In Stage 5, people think more rationally and abstractly, and value majority rule as well as society's welfare. Obedience to the law is viewed as good for society. In Stage 6, the most highly developed stage, people do what they believe is right, regardless of legal
standards or authoritarian demands. People in this stage have internalized standards based on abstract principles, and they must live according to their own ethical standards, or experience anxiety about being dishonest.

Because it depends on life experience to evolve, Level III may not develop until a person's twenties or even later. As experiences change, so do perceptions of right and wrong. Thus, the abstract morality of an adult is likely to be different from the concrete morality of an early adolescent. Efforts to produce behavior change among individuals with a postconventional moral perspective are likely to be ineffective if they rely on messages that emphasize simplistic right-or-wrong messages (conventional morality) or the immediate consequences of one's actions (preconventional morality).

Kohlberg assumed that people progressed through their developmental stages in a relatively orderly way, and that once a particular stage was reached, all moral decisions would be consistent with that stage. Further he assumed that behavior would always be consistent with moral reasoning. Neither of these beliefs is entirely true. Some people progress through these stages in a disorderly manner; some use reasoning from one stage to resolve one type of problem and reasoning from another stage to resolve another type of problem; and some may regress to an earlier stage under stress, for example, upon learning that they are seropositive. Kohlberg also based his analysis on research with male subjects, and commentators have questioned the generalizability of his results to women. Despite these complications, Kohlberg offers a compelling understanding of moral development in adolescence and young adulthood, one that can be helpful in developing effective behavior change strategies that are based on a reasonable theoretical foundation.

Gilligan: Moral Development Among Women and Men

Carol Gilligan pioneered the theory that female morality differs from male morality. She defines male morality, which she says is what Kohlberg describes, as being based on concepts of justice and fairness, whereas female morality is based more on concepts of caring and social responsibility. According to Gilligan and Jane Attanucci, a justice orientation—that is, an external community
standard—focuses on problems of inequality and oppression, with a goal of reciprocal treatment and equal respect: fairness and justice. Conversely, they define a care orientation—that is, an internal personal standard—as focusing on problems of detachment and abandonment, with a goal of attending and responding to need. Gilligan and Attanucci found that although men and women applied both orientations in their moral decision making, women were much more likely to use a care orientation and men were more likely to use a justice orientation. For example, the maintenance of interpersonal relationships is a central value for women and affects their moral reasoning, decision making, and behaviors.

Gilligan identified three levels of moral development in women:

- Individual survival, in which a woman concentrates on what is best for her
- Personal value based on self-sacrifice, in which a woman sees herself as responsible for others and subordinates her needs to theirs
- Nonviolence, in which a woman's moral judgments are based on not hurting anyone, including herself

From a health promotion standpoint, it makes sense for a woman to protect herself from HIV infection by insisting that her partner use a condom. From a developmental perspective, however, enforced condom use might threaten the stability of her relationship. A man may refuse to wear a condom and may threaten to end the relationship unless his female partner agrees to unprotected sex. Depending on her stage of moral development, the woman will base her decision on the importance of maintaining her health (individual survival) or maintaining the relationship (self-sacrifice).

Applying Moral Development to HIV Prevention

Both Kohlberg and Gilligan have studied a relatively small number of subjects, and it seems premature to conclude that differences between men and women are consistent and enduring.
Their findings are also limited by their lack of focus on people of color and on the effects of chronic alcohol or drug use on moral development. Despite these limitations, the crucial lessons of these theories are that moral development is individual and that there is no lifetime standard for moral decision making.

**Adolescent Development and HIV Prevention**

Psychological, cognitive, and moral development affect a person's response to prevention messages and counseling, and the failure of many prevention approaches may be due to an ignorance or disregard of developmental principles. Equally significant, prevention programs that do not take development into account may advocate responses that work against psychological health and that may lead to increased HIV-related risk. These conditions are likely to be true for people of all ages but are most obvious and easiest to chart among adolescents.

Risk reduction may be difficult to accomplish during adolescence, given the many developmental changes that occur during this time and the limited number of objectives that can be addressed in even the most complete prevention program. Because adolescents (especially younger ones) do not think like adults, risk-reduction programs for adults will be less effective for older adolescents; even strategies developed for older adolescents may be less effective for younger adolescents. There are four areas in which development is crucial to adolescent prevention: risk taking, peer influence, the significance of touch, and the concept of perfection.

**Is Some Risk Taking Necessary?**

As mentioned earlier, some risk-taking behavior is a normal part of psychological development. Although abstinence from drugs and sex is often a desired goal, the total elimination of risk-taking behaviors during adolescence may have at least some negative consequences for some teenagers.

In a study of 101 sixteen-year-olds who had been followed since preschool, researchers found that those adolescents who had engaged in some drug experimentation (primarily with marijuana) were the best adjusted; frequent drug users were characterized by
interpersonal alienation, poor impulse control, and emotional distress. Surprisingly, the study found that adolescents who had never experimented with any drug (the abstainers) were relatively anxious, emotionally constricted, and lacking in social skills. Although these teens were chemically healthy, they were not psychologically healthy. The authors concluded that some drug experimentation, in and of itself, does not seem to be psychologically destructive. This conclusion may also apply to sexual experimentation, and it challenges the wisdom of defining abstinence as the only acceptable goal of prevention programs.

Peers Versus Friends

Many prevention programs focus on "peer pressure" as an influence on alcohol, drug, and sexual behaviors. However, peers are also friends, and educators must be careful not to advocate eliminating friendships when they try to reduce peer influences. Although peer pressure can be negative, the absence of peers can be dangerous, and the most psychologically unhealthy person may be the one who has no friends. Friendship involves identity, trust, and intimacy, all of which can be supported or discouraged by the quality of a given prevention program.

The Need for Touch

One possible outcome of an abstinence-based approach to adolescent sexuality is that some adolescents could go for years without touching or being touched. The long-term effects of touch deprivation are not yet known, but it is known that human beings need touch and that "safer sex" recommendations may be helpful in meeting that need.

In his treatise on touch, Ashley Montagu linked the lack of touching in infancy to later problems in physical, psychological, and emotional development. As children move into adolescence, they are touched less often by their parents, and they seek to fulfill the need for touch through contact with friends. As they move through adolescence, sexual activity may be a primary method for touching and being touched and may be an important element of psychological and emotional development. Risk-reduction programs
based on scare tactics—for example, those that cause people to fear sexuality—may interfere with this progression and produce young adults who are physically healthy but psychologically isolated. In the long run, such isolation may produce a variety of psychological problems.

**Perfection Versus Development**

Approaching perfection is difficult and, for some, even undesirable. Although abstinence has been recommended for many years, those who recommend it often seem to be unaware of how hard it is to achieve the behavioral perfection that is the essence of abstinence. Abstinence is a common treatment goal for alcoholism, drug dependency, and cigarette smoking, yet its attainment is based on expected relapse. Simplistic recommendations for sexual abstinence that do not take into account relapse and relapse prevention will not achieve long-term success. At the very least, prevention planners should be aware of the work in relapse prevention so as to include that strategy as part of the program.

Priests take a religious vow of abstinence—perhaps the strongest and most public statement that can be made about not having sex. Even so, researchers estimate that between one-third and one-half of all Catholic priests have engaged in some form of sexual behavior, either heterosexual or homosexual.\(^4\) Abstinence apparently works better in theory than in practice. Why should young people be expected to achieve a degree of abstinence that cannot be achieved by priests? Might the need for touch throughout the life span be related to relapse from abstinence? What role does touch play in intimacy? In self-disclosure? In identity? Although these concerns are not resolved by current research and theory, clearly they will not be answered by denying the questions.

**Prevention Counseling**

For some people, the counseling relationship itself can be part of a viable prevention strategy. Depending on whether the client is thinking about engaging in risky behaviors, engaging in risky behaviors, or trying to resist relapsing back into risky behaviors, the counseling experience may be a forum for primary, secondary, or tertiary prevention.
Clients can learn that caring for someone else—one’s sexual partners, for example—can be a way of helping another to help oneself. Care becomes a strategy for mutual prevention. However, if people “use” other people (instead of caring about them), they jeopardize the likelihood of others being there for them when they need help. Or the person may be there if needed but, as Gilligan might frame it, only on an external level, based on community standards and expectations, rather than on an internal level, based on mutual caring and respect.

In counseling, clients may tend to judge their behaviors. Clients who apply concrete thinking (keeping in mind that concrete thinking often is the only thinking that occurs in times of crisis) may evaluate risky behavior by saying, “I did terrible things,” “I shouldn’t have done that,” or “I’m a flawed person.” As counseling progresses, therapists can help clients shift to more abstract levels of thinking, as suggested by the statements, “What’s happening now in my life?” “How can I be emotionally intimate?” or “How can I take back my family?” Indeed, these three elements—current life occurrences, intimacy, and family—are key components of the counseling process itself.

A major limitation of concrete thinking is that it leads to judgment, which prevents psychological growth. After making a judgment, such as “I am a terrible person,” a client is left with nowhere to go. As his or her thinking becomes more complex, the client is able to take greater emotional risks, recognize personal strengths, and accept himself or herself. Two case vignettes exemplify a developmental approach to prevention counseling.

**Clem: An Obligation to Self and Others**

Clem is a twenty-one-year-old White, gay male, an undergraduate at a major university in the United States. He was referred for counseling with Laura Harris, Ph.D., because of unrelenting anxiety and rage. Responding to increasing distress, Clem immersed himself in several dependent relationships with lovers who did not share his wish for long-term commitment or who were frightened by his neediness.

Clem was raised in a moderately large town. When he realized that he needed to explore his gay identity, he left home for the “big city” and college. Lacking connection and support, he quickly became homesick and desperately plunged into the relationships that were now troubling him. In order to
maintain these relationships, he allowed himself to engage in unprotected anal intercourse. Although Clem did not want to become HIV-infected, he was willing to risk his own health to maintain a particular relationship, fearing that if he refused unsafe sex or insisted on safer sex his partner would reject him, ending the relationship. At this time in Clem’s life, a relationship was more important than his health, and knowledge of his health risks did not lead him to behavior change.

Clem had left his hometown to avoid hurting his parents—putting their position and “good name” in jeopardy—by coming out. Clem conceived of this move as an act of “goodness.” It was better to leave than to risk hurting his family or friends—and, as a result, being abandoned by them. Realizing this in therapy, Clem began to reconsider his decision to “spare” his parents in terms not only of caring for others but also of caring for himself.

At the beginning of therapy, Clem exhibited conventional moral thinking (Level II in Kohlberg’s schema). He was dependent on his parents for approval and psychological support; protecting this support required protecting their reputation, even if it meant physically separating himself from them. As Gilligan notes, “Once obligation extends to include the self as well as others, the disparity between selfishness and responsibility dissolves.”

While working on a more mutually supportive relationship with his parents, Clem developed the skill to identify and protect his own needs and values and to make decisions based on his own well-being. His dependency on his family was a positive, motivating feature. That is, Clem realized that he could take care of his parents so that they would take care of him.

Clem was able to see the value of others and himself. Valuing his relationships meant valuing himself as well. In this way, Clem became receptive to HIV prevention and was able to integrate an appreciation of safer sex and its role in protecting him into his life.

Jeremy: Accepting Ambiguity

Jeremy is a twenty-four-year-old Asian American graduate student in philosophy at a university in the Midwest. He was born in Korea, adopted at sixteen months old, and raised by a hard-working White couple living in a large midwestern city. Jeremy was always wary and distant in his interactions with his family and peers. He said that he was not good at acknowledging and expressing feelings and described himself as having always been uncertain about his
sexuality. During adolescence, Jeremy experimented a lot in his sexual relationships with a variety of partners (both men and women) and usually in the context of drinking alcohol.

In his second year of graduate school, Jeremy learned that he was HIV-infected. He was shocked, and he relied even more on alcohol to maintain denial about his condition. This led to further isolation in his social life, increasing distrust of others, and academic failure. Jeremy was thrown into a state of angry crisis, and this led to more and often random sexual encounters.

Jeremy came into therapy through a crisis visit after he repeatedly failed to meet the academic goals set by his adviser. His depressive feelings and behavioral remedies—drinking and compulsive sex—commanded too much of his time and energy. In therapy, Jeremy’s counselor, Warren Simpson, M.S.W., worked to emphasize the critical nature of Jeremy’s situation and used the crisis to maintain the break in Jeremy’s denial that had brought him into therapy. Simpson acknowledged Jeremy’s painful rage and supported Jeremy’s need for relief from it. Simpson also asserted repeatedly the consequences and dangers of pursuing risky behaviors, despite Jeremy’s efforts to avoid these topics, and focused discussion on practical behavior and attitudinal changes that Jeremy could make to respond to the crisis. Surprised by the attention Simpson paid to his feelings, Jeremy began to acknowledge the hurt he felt and the support Simpson provided.

Through this process, Jeremy came to believe intellectually that there were some reasons why it might be useful to more actively protect his health and safety. The crisis of his HIV diagnosis aroused the rudimentary self-protection anticipated by Kohlberg’s Level I preconventional moral reasoning. Simpson’s constant reinforcement led, as might have been predicted by Erikson, to Jeremy’s attention to the consequences of his behavior.

As Jeremy progressed in therapy, Simpson suggested he join a support group for people with HIV, and after some consideration, Jeremy did so. Jeremy later reported that he had begun to enjoy these interactions. As other group members shared their stories and expressed genuine warmth, Jeremy began to reciprocate, at first because of the social reward (as suggested by Kohlberg’s Level II conventional thinking), but later because of his success at internalizing their positive feedback. In doing so, he came to be more certain about his being gay, and increasingly less random in his sexual expression.

A close call with a major opportunistic infection served as a final turning point, at which time Jeremy found others concerned about him
without expecting a specific “payback,” which would suggest development in conventional moral reasoning and identity formation. He began to reflect on the varied nature of individuals. It was at this time that Simpson encouraged Jeremy to consider the ambiguity and gray areas in morality and human interaction in order to interrupt his customary all-or-nothing thinking.

Through this process, Jeremy’s concrete view of the world began to give way to more flexible observations and experiences. Jeremy gradually began to see that his indiscriminate and noncommittal, risky and self-destructive behaviors were misguided quests for absolute unambiguous comfort from outside sources rather than from himself.

The Failure to Apply Theory to Prevention

Calling a program a “prevention intervention” does not make it one. One of the surprising findings from studying drug abuse prevention programs is that some interventions have actually led to an increase in use of at least a few drugs.\(^{30,37}\)

When queried about the questionable efficacy of one such program—Drug Abuse Resistance Education (DARE)—one corporate sponsor said that it would continue to fund the intervention because it was popular with young people and that the sponsor would support another program only if it were as “popular” as DARE. To ensure effective prevention, providers must consider issues of ethics and the use of knowledge. Despite unimpressive outcome evaluations, DARE has been used widely throughout the United States.\(^{30,39}\) Conversely, other substance abuse prevention programs that have been shown to work significantly better than DARE have not been implemented. Can the same phenomenon happen with HIV prevention?

Psychologists Jeff Stone and Elliot Aronson have applied the psychological principle of cognitive dissonance to encourage young adults to use condoms.\(^{49}\) Most people like to think that they have a consistent set of values and behaviors. Confronting their own inconsistencies makes them uncomfortable, and uncomfortable feelings (cognitive dissonance) can lead to behavior change. Working with college students, Stone and Aronson provoked cognitive dissonance by first having students publicly advocate the importance of safer sex and then making the students conscious of
their past failures to use condoms. The researchers expected the students to be motivated to purchase condoms to relieve the dissonance. They did.

Unfortunately, Aronson has been unable to infuse the concept into local prevention programs.41 He notes that we are all social psychologists, with our own intuitive theories about how to get other people to change their behaviors, and that sex education has paid insufficient attention to the psychological complexity of behavior change. For example, many people—including some mental health professionals—believe that homosexuality is simply a freely chosen behavior that can be easily “cured” with the right kind of therapy. This intuitive theory, which may be strongly held, may be unchangeable, even when contradictory scientific evidence is presented.

Does enthusiasm for a program lead administrators and parents to believe that their children are being helped by interventions that are popular but ineffective? Are administrators willing even to ask tough questions about prevention programs if there is strong financial and social support for them? Who really benefits from a corporation’s support—the students, the administrators, the community, the corporation? Would corporate dollars be better spent on a less visible but more effective program?

The book Ethical Implications of Primary Prevention addresses ethical aspects that often are overlooked in prevention programs.42 In their efforts to help, prevention planners are sometimes unaware of the harm they may do. One type of harm may be done when a prevention program is inappropriate for its target audience. Researchers, evaluators, and policymakers may think of prevention programs simply in terms of being effective or being less effective. But do we consider the ethical implications of “less effective” programs?

Using Knowledge

Far too often, HIV-related and psychological research is not applied in developing HIV prevention. Although many have called for conceptually based interventions, most interventions have been founded not on sound psychological principles and developmental perspectives but more often on an informal combination of logic
and practical experience: what the prevention planner thinks will work, hopes will work, or wants to work.\textsuperscript{45}

This failure to apply existing theory is not unique to HIV prevention. Thomas Backer defines knowledge utilization as "research, scholarly, and programmatic intervention activities aimed at increasing the use of knowledge to solve human problems."\textsuperscript{44} But using knowledge is difficult, as difficult for the person who finds out that he or she is seropositive as it is for the person planning an HIV prevention program. Although a complete analysis of this problem is beyond the scope of this chapter, Backer identified six strategies that can help organizations use knowledge in a more effective manner. Briefly, the strategies are the following:

- \textit{Interpersonal contact}. For an innovative technique to be used in a new setting, there should be direct contact between staff members from the adopting organization with those who know about the innovation.
- \textit{Planning and foresight}. A plan must be developed for how the innovation will be adopted in the new setting.
- \textit{Outside consultation on change}. Outside consultants can help design the change in a more efficient way and offer an objective perspective on what should be done.
- \textit{Information transformation}. What's known about an innovation needs to be translated into a language that can be understood by potential users. Key issues covered in such a discussion should be, Does it work? and How can I replicate it in my organization?
- \textit{Individual and organizational champions}. The likelihood that an innovative technique will be adopted is greater if influential staff members and organizational leaders are enthusiastic about it.
- \textit{Potential user involvement}. Everyone who will be affected by the organizational change should be part of the planning process. This will broaden the range of ideas for adopting the program and increase user ownership while decreasing user resistance.

Incorporating developmental issues into HIV prevention and counseling requires far more than merely reading this chapter or even this book. Providers should use Backer’s six steps as a way of
mustering the growing base of HIV-related theoretical and practical knowledge.

The goal of prevention should not be to eliminate all risky behaviors from life; instead it should be to help people learn about inappropriate and appropriate risks. There is life after adolescence, and individuals who have grown up in a risk-free environment may not be able to cope with the challenges of adulthood—the workplace, parenthood, and relationships—without having had some risk-taking experience. To facilitate later psychological development, it may be more helpful to know how to take risks in a “safer” way than simply to “say no” to all potential risks.

Behavior change is difficult—and even more difficult if behavior change strategies fail to consider psychological development. How can human sexual behavior be understood without understanding identity and intimacy? How can client counseling or HIV prevention be effective without understanding cognitive or moral development? Far too often, interventions use a one-size-fits-all approach, severely limiting an intervention’s efficacy.

In fact, HIV prevention needs to come in many shapes and sizes: mass media, school-based HIV education programs, and individual and couples counseling. Almost twenty years into the epidemic, most program planners have a reasonable understanding of the “facts about AIDS,” but many are often totally unaware of key developmental issues. Without that awareness, prevention programs will have minimal success—when they really need to have maximum success.

Notes
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30. Sigelman, Estrada, Derenowski, and others, "Intuitive Theories."


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Chapter Five

Prevention and Culture

Working Downhill to Change HIV Risk Behavior

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Noel A. Day

The behaviors that place people at risk of HIV infection are rarely apparent on a conscious level; rather they are rooted in basic instincts, reinforced by pleasurable sensations, and layered with cultural values. Unfortunately, the HIV prevention field has tended to view culturally embedded roles and attitudes only as obstacles to change.\(^1\) Many cultural beliefs do present challenges to encouraging safer sex and drug use, yet the success of HIV interventions often depends on the capacity of counselors to use rather than to mitigate the power of culture.

The effects of culture on individuals are often so strong that they seem to be inborn. Harnessing such a tremendous force to influence human behavior is a strategy that counselors can use to become more efficient, effective agents of change.

Herb Shepherd, a pioneer in the field of organizational change, used to say he had the choice of “working uphill or downhill” when he was trying to modify an organization: like Sisyphus, he could roll the boulder of institutional beliefs and norms uphill, grunting, sweating with the effort only to be frustrated as it rolled back downhill, or he could take advantage of the momentum of these same values. To work downhill, he would analyze an organization’s culture and identify consistent strategic interventions based on the
inherent values of that organization, in this way speeding the group toward its goals.

Similarly, counselors trying to help their clients reduce their HIV risk behaviors can lose considerable time and effort working against their clients' seemingly counterproductive cultural values about sex, drugs, health, and death. This chapter presents a model for working downhill, enabling counselors to uncover the meaning each client gives to significant HIV-related issues and to work in concert with these meanings to change life-threatening behaviors.

Culture, Values, and Behavior Change

When most people use the word culture, they think about foods, clothing, art, or music. In fact, culture is much more than these symbols—it is the force that shapes a person's core, that tells each of us how to be, how to survive. A successful culture is not static: these ways of being and the rules that surround them have evolved over time to meet needs specific to particular environments and circumstances, new conditions, or the assimilation of other groups and their precepts.

A culture is a group's design for living, which defines the perception and interpretation of the group's experience of being human: the inherent quality of human beings (good, evil, or both), the relation of humans to nature (harmony, subjugation, or mastery), the rules of human relationships (individualistic, collateral, or lineal), the temporal focus (past, present, or future), and the basic purpose and direction of human activity (doing, being, becoming).\(^5\) Shared meanings and values develop not only within ethnic groups but also within affinity groups—those based, for example, on social class, gender, and sexual orientation. Spoken and written language are only two of the many ways to communicate effectively. Behavior is culture made manifest, giving visible form and expression to beliefs, values, and attitudes of both client and counselor.\(^6\) Movement, art, spatial sensibility, color, and audio tone are among the other explicit languages of culture.

Perhaps because the stakes in HIV prevention counseling are high, many clinicians avoid interventions with clients whose cultures seem at face value different from their own and, in this way, avoid interactions that risk failure. The diversity of the populations
at risk for HIV infection requires different sources and deeper levels of inquiry, but one of the best models for working downhill with cultural values lies in the fundamental premise of client-focused work: the client is at the center of the interaction, and the therapist as facilitator of change collaborates with the client, listening for the meanings and metaphors that can establish and promote the intervention plan the therapist and client have developed together.

If it is hard, in many cultures, to talk about risk behaviors, it is even harder to change them. Counseling interventions are dependent not only on appropriate and precise language but also on rules of courtesy, sequencing, familiarity, assertiveness and candor, phrasing, grammar, and medium. Each aspect involves an exchange of expectations determined by a combination of personal experience and cultural messages. Clear communication of these expectations and the correct interpretation of cultural meanings in turn develop the rapport necessary for uncovering and harnessing the attitudinal norms that are central to behavior. They also instill trust, a prerequisite to accepting and incorporating protective health measures into everyday life.69 Violating cultural expectations, on the other hand, may compromise the therapist-client relationship and hazard negative judgments of being rude, dangerous, uneducated, untrustworthy, or incompetent.

HIV counselors are pilots in cross-cultural communication, seeking the modes, form, pace, and meanings that will best promote healthy behaviors. They rely on clients’ guidance as well as their own careful study to make the correct interpretations and use of their cross-cultural tools. Some people have argued that such efforts are a burden to already stretched resources. But the initial energy and motivation required to reconsider the limitations of prevention activities are more than offset by the eventual downhill momentum gained in efficient communication and by the ultimate success of prevention interventions.

The Challenge to Counselors

The pervasiveness and intransigence of cultural lessons can keep counselors from putting clients at the core of risk-reduction counseling. Culture is like your skin; you’re not aware of it until it itches. Most people have no consciousness of the ways in which culture
influences their every perception and expectation. Some uphill interventions, in fact, deny cultural differences for the sake of a global "people are people" approach that professes the benefits of an impartial, culture-free intervention. But as Vicente Navarro notes, "Culture-free service delivery is nonexistent—the counselor's objectivity is tempered by the subjectivity of his or her own norms and values." Working downhill toward the client does not demand negation of the counselor's cultural contribution to the interaction. Rather it presents an opportunity to enhance the counselor's knowledge of self and of what he or she brings to the interaction.

Counselors who want to increase their understanding of the meanings of HIV disease in other cultures will find little help in the literature. In the scant qualitative work published, African Americans, American Indians, Latinos, as well as people of Asian and Pacific Island descent have been considered inherently "hard to reach," a term that serves simply to distance populations with whom professionals are unfamiliar. The descriptions of numerous cultural barriers provide neither solutions nor more positive cultural elements with which counselors can build prevention strategies. Appropriate interventions for many groups have been hindered more by this marginalization than by the cultural attributes that researchers ascribe to the groups. It is true, for instance, that access to men of color is sometimes limited by their high rates of institutionalization and mortality in the United States, but a more frequent impediment is the inability of institutions charged with targeting prevention efforts to distinguish among the heterogeneity of experience, class, and language within racial groups.

Paradoxically, there is evidence in the literature of both stereotyping—"Latino men are macho"—and invisibility. Again men of color provide an example: despite reports that the characteristics of homosexuality are different in different cultures, most researchers generalize about the attitudes and behaviors of all gay and bisexual men from samples consisting largely of men of European descent. In this way, useful cultural variables are ignored or treated as exceptions in the creation of normative scales.

The narrowness of information in the literature points even more to the need for counselors to listen consciously for cultural lessons communicated continually in their own lives. The success of
cross-cultural work relies, in particular, on the counselor’s sharp, active assessment of professional and personal relationships that may provide insights into how to affect safer sex and drug behaviors.

The Cultural Context of HIV Counseling Models

Counseling requires the use of self as a tool for the change of others. HIV disease further challenges counselors in a downhill mode to examine their own feelings about the existential, metaphorical, and practical aspects of such issues as disability, death, homosexuality, race, age, gender, class, and ethnicity. In the counseling relationship, the parties involved may not share beliefs about these issues or about fundamental concepts in counseling, medicine, and even the science of HIV. Until we assess our own belief systems, we can neither understand the gaps between ourselves and our audience nor appreciate the tenacity of cultural norms and values.

Cultural concepts central to mainstream American beliefs determine both the substance and the structure of HIV prevention interventions and affect the counselor-client relationship in the context of power and powerlessness. The most influential behavior change models in the HIV counseling arena reflect Anglocentric, pedagogical notions. Indeed, the idea of changing cultural attitudes—a central HIV education method—reflects a largely doomed strategy tantamount to cultural hegemony and is the epitome of working uphill.

In terms of the substance of prevention approaches, these principles value individual responsibility and control, assume that the medical system is trustworthy, and propose that client-based issues like low self-efficacy or denial are the primary obstacles to behavior change. In terms of the structure of prevention strategies, the models suggest that single interventions are appropriate and that information—the more the better—should be presented in a didactic form with knowledge passing in one direction, from presenter to audience. The issue of power and powerlessness affects both the substance and the structure of interactions, plays a particularly important role in HIV prevention models and in the counseling relationship, and is central to the reality of living outside the mainstream.
Substance: Uncommon Ground

Among the ideas that relate to HIV disease and vary most from culture to culture are the role of the individual, definitions of sex, the motivation to take the HIV antibody test, and perceptions about the medical system. Although most HIV prevention strategies value taking active, measurable control of one’s health, other worldviews are fatalistic or reliant on outside forces; for example, some cultures see prayer as a practical, dynamic intervention, not a passive strategy. Many HIV prevention interventions focus on individual responsibility, although many ethnic cultures in the United States are oriented toward collective behavior in which the target of a prevention activity may be the entire family. Some groups attribute illness to an imbalance in life or in the environment rather than to a pathogenic agent like HIV. Reticence to talk about HIV disease may be wrongly interpreted by a counselor as homophobia or denial rather than, possibly, the desire to ward off bad omens, the shame of the death of children before a parent (an attitude in many Asian cultures), or the need to maintain the expected boundaries around private versus public behavior.\textsuperscript{17,18,19} The existence of such distinct perceptions highlights the importance of seeking life-saving strategies within the context of a client’s worldview and the utility of taking time to define meanings within this worldview that will suggest authentic motivations for risk reduction.

Although guidelines for safer sex attempt to standardize definitions, individual conceptions of what is and is not “sex” can affect behavior change counseling. Similarly, in a number of ethnic groups, men who have sex with men as well as with women do not envision their same-sex behaviors as linked to a sexual identity. In uphill interventions, this attitude is sometimes misread as a rejection of self and targeted as an obstacle to behavior change. In fact, it may instead represent a separation of behavior, role, and sense of self that has long been common in many cultures throughout the world.\textsuperscript{39}

Fundamental differences both in biological beliefs and in perceptions of medicine may influence decisions to undergo antibody counseling and testing. For instance, people from some Asian cultures believe blood tests upset the balance of yin and yang in the body or diminish \textit{chi}, the vital life force. People from some dis-
advantaged groups have learned that it is appropriate, even essential, to distrust the health care system. Modesta Orque and colleagues note that “Blacks [for example] entering health care programs automatically exhibit more ‘paranoid responses’ than other patients,” based on their past experiences or on their perceptions of the health care system as unsafe.31

Such distrust reflects a body of historical fact. American medicine is replete with well-documented evidence of an impersonal and self-serving medical system, a history that taints the current beliefs of whole groups of people regarding the causation and prevention of illness. Examples include the use of clinical diagnoses of rebellious slave behavior to justify beatings, the forced sterilization of many African Americans, the performance of lobotomies to “cure” homosexuality, the release of viruses into the New York subway to study their viral paths and life spans, and the Tuskegee Institute’s experimentation on Black men and their partners, which left them untreated for syphilis for forty years. Considering this legacy, it is easy to understand the pervasiveness of conspiracy theories in the dialogue on HIV among African Americans, who have so often been viewed as expendable in these “research” efforts.22,23,24 Studies have found that many African Americans—including college-educated and churchgoing men and women—hardly radical or marginalized groups—distrust information they have heard about both the source and impact of HIV, instead viewing the epidemic and even standard prevention measures such as condom use as part of a larger genocidal plot against African Americans.26 White counselors might be surprised by the number of their Black colleagues who share some of this same skepticism about the source or the implications of the disease.26

Counselors can choose either to dismiss such responses as dysfunctional or to explore the meaning of such beliefs, acknowledging the credibility of such suspicions and joining with clients to discover what each sees as the implications of such a history for HIV prevention. Typically the substance of HIV education negates alternative theories regarding, for example, disease etiology; these approaches are therefore destined to alienate a significant part of their intended audience. Despite the goodwill of providers, clients may view theories about the origins of HIV as a kind of provocation or intellectual imperialism. Counselors should reconsider the
purpose of presenting information that does not directly assist behavioral negotiation. It is unclear, for example, what purpose communicating the theory that HIV originated in Africa serves, except to offend African Americans and deflect their attention away from the more critical prevention messages.

In the counseling interchange, offering information about the virology and etiology of HIV similarly may help providers feel grounded in their cultural assumptions, but the time spent on disseminating this information might be better spent building empathy and rapport. There is already so much to be done to maintain the most basic elements of an HIV intervention, it makes sense to allow individuals their particular understanding of illness as long as these ideas do not impede the movement of counselor and client toward an agreement on safer behaviors.

Structure: One Size Fits All?

Terry Tafoya and Doug Wirth, psychologists experienced in HIV-related cross-cultural training, point out limitations in the Anglo-Saxon belief in rationalism and the power of knowledge, a belief that is at the foundation of HIV prevention education: “It is a common American cultural belief and communication strategy that if enough information is presented, an audience or client will automatically reach the same conclusion as the presenter or practitioner.” Laurence Green calls the same belief the “empty vessel fallacy.” He suggests that this fallacy leads “health educators to behave as if all they have to do to ensure the success of their programs is to pour health information into the empty minds of an eagerly awaiting target population. As an extension, technologies are sought that will transmit the most information to the most people by and large regardless of their differing beliefs, attitudes, values, and perceptions.”

Green identifies two other shortcomings in health education practice born of mainstream American values. One he calls the “fallacy of the more, the better.” This notion, consistent with the value placed in our society on accumulation, assumes “that positive outcomes will increase proportionately with more time, more television coverage, more media equipment, more personnel, or more contacts.” The second he calls the “fallacy of the inherent
superiority or inferiority of some methods.” By that he means that many practitioners advocate particular methods regardless of whether those methods are appropriate for the particular population they are serving—truly a one-size-fits-all assumption. In this vein, Tafoya and Wirth caution, “Techniques and effectiveness will always vary along a bell-shaped curve with any given population as long as one uses only one approach, intervention or curriculum.”

**Counselor-Client Power Relationships**

For traditionally oppressed groups such as ethnic minorities, “A strong determinant of world views is very much related to racism and the subordinate position assigned to them in society.” Therefore, interventions that work downhill with individuals from any historically oppressed group should begin by assessing both real and learned powerlessness, the source of many cultural adaptations and survival mechanisms that seem to oppose HIV prevention strategies.

This assessment also should acknowledge the distinct effects of class, generation, and other elements that bestow privilege or diminish social status. Many beliefs and behaviors attributed to ethnic culture are, in fact, values of a drug-using lifestyle or what Elaine Pinderhughes calls “the victim system,” a set of shared norms and survival strategies developed in response to being the objects of abuse within a society. An African American woman who is only able to discuss immediate issues and dismisses prevention as “I'll deal with it when it comes up” is not expressing a value inherent to her ethnic culture; she is expressing a victim-system belief, focusing on her limited power in the here and now while leaving tomorrow to fate or chance.

In such instances, HIV counseling might well borrow from twelve-step programs, which turn tomorrow into a series of “todays.” This approach can permit people who have adapted to their absence of control to limit their expectations to momentary gains. In doing so, it offers them small doses of experience in the power of behavior change—in the present and one day at a time. This kind of intervention is difficult for many HIV counselors because it requires resisting provider-culture values about planning and future orientation. Instead, the strategy accepts the client's in-the-moment
values, remembering that these may nonetheless lead to behavior change.

Providers too often stereotypically assume powerlessness among whole populations. For example, presumed absence of power among low-income, immigrant women of color is cited by many HIV counselors as a reason to avoid prevention efforts with these populations. Describing these women as passive, obedient, and "traditional," and emphasizing the potential physical danger for women in taking the initiative in sex, this theory suggests that the unequal distribution of power in these cultures is the primary obstacle to protective behavior. Although there is sometimes truth in these concerns, misreading the power balance in relationships may be just as damaging to HIV prevention efforts as failing to acknowledge power interplay at all. In some cases, counseling a woman to be sexually assertive may be working uphill against her values if she is, in fact, acculturated to be submissive to her partner in such decision making. For instance, a culture that seems to support a passive role for women may also possess dynamics that can foster HIV protection through matriarchal components that enable certain women to speak with authority or exert dominance in certain contexts.

Even a minimal effort to uncover the innate cultural features that define and support HIV protective measures ultimately eases the HIV prevention task. For example, clients who have been subjected to war, political repression, torture, domestic abuse, or other traumas may experience residual power imbalances, which may play out in their risk behaviors; these imbalances need to be made explicit in order for prevention interventions to be effective.

Finally, HIV prevention messages are themselves delivered and heard within a power framework, because

the helping relationship is in itself a power relationship in which the dynamics of power and lack of power are operating. ... The cross-racial and cross-ethnic helping encounter compounds the consequences of this power differential. For the client, intervention by a member of a group he or she regards as the oppressor may reinforce the powerlessness felt in a moment of need. Intervention by a worker whom the client sees as inferior may also reinforce the client's sense of helplessness. Power issues related to differences in
ethnicity, class, sex, age, and other social markers may exaggerate the power inherent in the helping role in a way that causes the worker to misperceive the client. With an awareness of the influence of power in complementary relationships, [the counselor] is better prepared to guard against occurrences that may result in destructive use of the worker’s power or the client’s lack of power.  

Clients tolerate a great deal to come to providers: they give up personal information, time, and transportation costs; they sustain the potential dissonance regarding information presented in the session; and they endure the demands counselors make on them based on organizational rules or bureaucracy. At the same time, they risk shame, stigma, and judgment. It is a sacrifice counselors too often take for granted because they hold all the cards. Consider HIV prevention, a topic that is already likely to be culturally charged in this power context, and it is clear why the onus is on counselors to adapt.

For counselors to employ the power in the client’s culture to reach prevention goals, his or her empathy and acceptance of the social context are critical. An awareness of this context can help counselors gain a true picture of clients’ capabilities and endowments and identify both the sense of powerlessness clients may feel in relationships and the sources of power on which they rely for health promotion.

The Power of Culture and Working Downhill

Barbara Solomon defines the attributes of the nonracist counselor quite simply: “the ability to perceive in any behavior—one’s or another’s or one’s own—alternative ways to explain that behavior, particularly those [behaviors] which the self might most strongly reject as false.” Counselors establish cross-cultural credentials with clients not by showing off bits of knowledge about the traditional behaviors or beliefs of a group but by regularly demonstrating an openness to learning about the forces that affect clients and influence their HIV-related risk or protective behaviors. Francesca Farr concurs: “The minority patient will respect and appreciate your acknowledgment of cultural differences. . . . It is not how much one knows about the culture that determines the success of the clinical
encounter, but the clinician’s overt recognition that the patient’s culture is important and as deep and rich as anyone’s culture.”

To seek alternative explanations and, thereby, more effective prevention strategies, counselors can learn to wonder before they speak—to question the meaning of a client’s behaviors in the context of the function of these behaviors. Thus, working downhill in HIV prevention counseling consists of four steps:

1. Find ways to acknowledge regularly to oneself and to the client that each human being comes with both cultural and personal histories and that both of these are integral to a sense of self and a shared worldview. These histories are especially important when dealing with elements, such as sexual activity, that are essential to one’s identity, well-being, and social role.

2. Rather than limiting communication to the verbal mode favored in psychotherapy, incorporate a full range of sensory information and expressive resources to uncover the style and medium that makes prevention approaches most accessible, understandable, and acceptable to the client.

3. Don’t be afraid to modify prevention messages, modes, and materials on the spot in the counseling session as new information emerges that may make culturally biased prevention concepts clearer to clients with different worldviews.

4. Account for the cultural dynamics on both sides of the therapeutic engagement, exploring not only the client’s barriers to change but also the meanings of power, sex, drugs, and other HIV-related issues to the counselor.

This last point is crucial and often minimized: counselors must be aware of their own values and beliefs if they are to consider the effect their behaviors might have on the cross-cultural message. This requirement parallels the general responsibility of therapists to sort through motivations, emotional determinants, and countertransference through the processes of supervision and consultation.

To this end, it may be useful for providers to consider every client interaction to be cross-cultural and to wonder out loud and without interpretation when they encounter behaviors that seem inappropriate or incomprehensible. For example: “I don’t know what it means, but I’ve noticed you haven’t made eye contact with
me during the discussion of condoms. [Pause to leave room for client if he or she wishes to respond.] I mention this because I want to be as useful as I can in helping you to decide what to do. I always want to know if there something I might be doing differently to help you feel supported, so you can ask or do what you need.”

This is not a script; an interchange like this one will involve the counselor’s perception in the moment, risk taking, the forestalling of behavioral interpretation, and most important, the willingness to accept whatever the client communicates.

It is essential to go through an explicit process of uncovering expectations and determining with the client the parameters of an appropriate exchange. Overlooking this process will open the door to blaming the client and his or her culture for failing to fulfill a contract that was never made apparent. If this process is undertaken honestly, the counselor will realize that he or she too expects to get something from these contacts: the recognition of his or her words with a nod or a question, a greeting and farewell, even a thank you. To maximize the momentum of these interactions requires counselors to be aware of their own expectations of each intervention—for example, “I want her to make a verbal commitment to me to use condoms and take several home to try.” Some counselors will want to give or get more, and others less, so they must continually grapple with their own met and unmet expectations.

Another principle, almost self-evident yet rarely heeded, is to spend time learning something about the cultural worldviews and HIV-related behavioral taboos of clients. The ability to engage in a humble and honest acknowledgment of difference is not part of therapeutic training. In fact, such discussion is traditionally discouraged in American culture in favor of the concept of a cultural melting pot, a concept that labels difference as bad and sameness as unifying. This exploration requires a major expansion of social and professional circles, contact with a range of consultants, and the development of referral and support networks before cross-cultural contacts occur.

Credibility is critical to working downhill and to the therapeutic relationship. A study by Jacquelyn Flaskerud found that effectiveness and trust depend on the client perceiving the counselor as credible. This too may seem obvious, but mainstream American providers often assume that credibility accompanies degrees
or job titles. Although such achievement may indeed be critical to credibility with some clients, many groups confer status only in terms of the quality of each interaction or a person's reputation for delivering something of value to others in the group. Thus a counselor may gain credibility and respect only in response to his or her prior success as a healer, as someone able to offer tangible aid well beyond the abstractions of HIV prevention. Counselors need to attend carefully to the measures of credibility clients use and to how they as providers can meet these expectations. Beyond the usual medical, sexual, and drug-use histories, effective counselors learn by observation, inquiry, and study of a client's cultural identity, which counselors integrate to different degrees into the assessment and resolution of a "problem." Cultural identity includes aspects of "Old World," American mainstream, and victim-system worldviews.

The LEARN Model

LEARN is one of the structural models useful in acknowledging a client's culture and developing insights into how she or he conceptualizes a problem or concern.4 The acronym LEARN stands for

Listen with sympathy and understanding to the client's perceptions of the problem—an active process of soliciting in many ways the information necessary to understand what a person feels he or she needs.

Explain your view of the problem, which may or may not be different from the client's but is expressed in terms that relate to previously learned information.

Acknowledge and discuss the differences and similarities between these two views—as you heard them.

Recommend a response.

Negotiate agreement about what both client and counselor will do and about who else should be involved in the process.

Psychologists representing diverse ethnic cultures endorse LEARN, but some of them caution that it is not a shield against ethnocentrism. Tafoya and Wirth recognize the validity of the
LEARN model, but suggest that all too often focus is taken away from the client through the practitioner’s failure to effectively manage the five components. For instance, the client’s perception of events is glossed over or ignored in the Explain state as the practitioner focuses on preparing to Recommend a response. This failure to Acknowledge leads directly to an inability to Negotiate, and demonstrates “a lack of understanding of the critical importance and attention that must be given to process when working with culturally-diverse clients.”

This process represents the route by which both provider and client can integrate cultural perspectives into the clinical response.

The components of LEARN should lead to HIV counseling strategies and tactics that work downhill with culture rather than uphill against it. The caption from an AIDS education poster targeting one element of the gay male subculture epitomizes the absolute synchrony of the message with this subculture’s values and behaviors, and serves as a model for working downhill: “If you’re dominant, demand a condom. If you’re submissive, beg for one.”

When human beings lived in small, isolated, homogenous settlements, they tended to be culturally similar and to behave in the same ways. However, as the human experience became more complex, the number of reference groups with which people could identify increased, and people identified not only as male or female but also as a member of a particular racial or ethnic group, age group, social class, religious denomination, nationality, region, and profession or occupation. The cultural mandates of each of these reference groups overlay each other like a series of lenses through which to view the world. For this reason, counselors must guard against stereotyping and assuming that all members of a cultural group can, and should, be approached using exactly the same methods. Stereotypes serve only to separate counselors from their clients and to limit the view of who needs prevention counseling and services and how to reach them.

Cultural awareness requires the time and interest to go beyond stereotypes to uncover the realities and the meanings behind a client’s behaviors, the prevention approaches the therapist wishes
to implement, and the therapist's own behaviors. Dangers lurk
in this work: the downhill momentum can carry the therapist be-
yond the evidence at hand. It can also obscure the principle that
each person is a unique individual with combinations of emotional
and social risk factors specific to him or her, and that these differ-
ences require personalized interventions recognizing the distinct
skills, resources, and limitations each client brings to the counsel-
ing experience.

In the face of so many differences in interpersonal rules and
the charged content of AIDS risk, it is easy to feel paralyzed by the
potential mistakes that may seem to lurk in the HIV counseling re-
lationship. To paraphrase a wise clinical supervisor, however, "Our
patients are willing to forgive mistakes of the head. Mistakes of the
heart are more difficult. Our job is to know as much as we can and
to know the difference between our mistakes."

When therapists view clients as full participants in the HIV in-
tervention, they worry less about the inevitable cultural mistakes,
because in these moments, the message that the counselor com-
municates most clearly is that both client and counselor are en-
gaged in a learning experience that aims toward the shared goal
of ensuring the client's health. In acknowledging and exploring
cultural mistakes openly without devaluing the skills they bring to
the intervention, counselors further communicate the message
that everyone makes errors, a message easily applied to HIV-related
behavior change. Further, a counselor's sensitive response to cross-
ing cultures can model for clients how to handle the anxiety and
awkwardness of attempting new behaviors. For counselors working
with HIV disease, the experience of taking risks to reach across to
clients who are culturally different offers lessons applicable to all
clients and a perspective that makes them more effective coun-
selors to everyone they serve.

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Chapter Six

Substance Use
Case Management,
Harm Reduction,
and HIV Prevention

Miriam Garfinkel

Substance use—through needle sharing and sexual contact with seropositive injection drug users—still accounts for one-third of cases of HIV disease in the United States. But there have been notably successful efforts to reduce transmission among substance users, a group of people perceived to be unreachable. The most effective interventions have applied harm reduction, an approach to protect against transmission in the absence of abstinence. Guided by two key principles—self-efficacy and incremental change—harm reduction has manifested primarily in the form of drug treatment, especially methadone maintenance; needle exchange; and instruction regarding cleaning needles.

One particularly successful means of implementing harm-reduction principles has been clinical case management. Holistic in nature, this approach emphasizes as a therapeutic tool the relationship between client and case manager, at the same time acknowledging the importance of providing linkage to practical resources and other service providers. This type of case management integrates substance use and HIV prevention interventions, incorporating aspects of psychodynamic theory and harm-reduction theory to create a comprehensive model of care and change.
This chapter details the clinical case management approach and asserts its advantages in the context of HIV prevention for substance users. It also proposes a case management model—based on harm-reduction strategies—to protect injection drug users and their sexual partners.

**Harm-Reduction Theory**

Harm reduction was adopted in the United States in response to the HIV epidemic. It assumes that a using addict can make positive changes in his or her life despite continued drug use and melds ideas from behavior change theory with understandings of dependency and addiction. Harm reductionists posit the obvious but often overlooked axiom that people use substances—just as they engage in risky sexual behaviors—for a reason. Substance use is adaptive, a way to cope with real circumstances, past or present, such as poverty, racism, and abuse. Change must begin with understanding and accepting an individual in relationship to a behavior, helping him or her identify the harm that results from that behavior, and working with him or her to make small, incremental changes in the behavior to decrease that harm.

The *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association (*DSM-IV*) defines substance abuse and dependency as follows:

- A cluster of cognitive, behavioral, and physiological symptoms indicating that the individual continues use of the substance despite significant substance-related problems.
- A maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to the repeated use of substances.²

In contrast, harm-reduction theory conceptualizes drug use along a spectrum from casual use to controlled use to chaotic use, rather than in more general terms of dependency or addiction. A “casual” user is the equivalent of a recreational user, someone who truly uses a drug on a social basis with no signs of physical or physiological addiction. “Controlled” users may be dependent, physically or psychologically, but are able to use in a way that does not
create adverse consequences in their lives. A “chaotic” user is an individual who is physically or psychologically dependent and continues to use despite adverse consequences in his or her life.

Harm-reduction theory values the role abstinence may play in the lives of some users, acknowledging that whereas some users have the ability to move from chaotic use to controlled or casual use, some chaotic users may need to achieve abstinence in order to stop the damage in their lives. Other users may also benefit optimally from abstinence, but given the opportunity—through respectful, clinical engagement and the experience of improved quality of life—many active users have the ability to mitigate both HIV- and substance-related harm without achieving abstinence.

The Harm Reduction Coalition in Oakland, California, defines harm reduction in the following way: “A set of strategies and tactics that encourage users to reduce the harm done to themselves and communities by their licit and illicit substance use. In allowing users access to the tools with which to become healthier, we recognize the competency of their efforts to protect themselves, their loved ones and their communities. . . . You don’t remove a person’s primary coping mechanisms until others are in place. It starts wherever a person is at, and moves at the pace of the individual. . . . The operating principle is any positive change.”

Although some harm-reduction interventions, such as needle exchange and methadone maintenance, have received a great deal of attention, effective harm reduction is dependent on creativity and innovation in program development to meet individual needs. This perspective easily fits within the theoretical foundations of clinical case management.

**Clinical Case Management**

Although the concept of clinical case management preceded the formulation of harm reduction, it mirrors the key concepts in harm reduction: self-efficacy and incremental change. According to Robert Surber, clinical case management establishes and uses the relationship between the case manager and the client to achieve change in the client, within the client’s environment, and in the relationship between the client and the environment.4 The case manager–client connection becomes a vehicle through which
clients can better understand themselves, their interpersonal relationships, and their life goals. Surber describes this type of case management as, "as much a way of thinking about care as it is providing specific interventions. . . . What is therapeutic is what is helpful." Successful interventions are defined by their ability to help clients improve the quality of their lives.

A clinical case management intervention is one in which the ongoing case manager–client relationship is a key component in creating small, positive changes. When developed in the 1960s through work with chronic psychiatric populations, such a change might have been an improvement in medication compliance. In working with active users, change may comprise increasing compliance with medical appointments by limiting drug use on the day of the appointment, or reducing HIV-related risk by increasing intermittent use of clean needles or condoms. Preliminary results of a research project comparing HIV-infected substance users receiving clinical case management with those receiving usual care showed a greater than 50 percent reduction in positive urinalysis results after six months in case management.9 Linkage is a central function of case managers. Linkage includes a set of interventions ranging from referral to actually taking clients to appointments or helping them negotiate bureaucracies. These interventions are designed to facilitate access to resources. Case managers provide a combination of links to practical resources—housing, food, medical care—and to peer and social service support. In addition, case managers help with skills-building and may provide individualized counseling. The result of this menu of options is the opportunity for a comprehensive, individualized, client-centered treatment approach. Client participation is always voluntary, and goals are defined through a collaboration between case manager and client. Ideal results are outcomes that are meaningful on a practical as well as intrapsychic level. In other words, clients build a sense of self-efficacy and self-esteem through participation in developing and then realizing a concrete plan for change.

Case managers often come from the communities they are serving, as the importance of peer intervention has been proven over and over again in interventions with active users.7 Because clinical case management, unlike other types of peer relationships,
relies on a psychodynamic understanding of the interactions between the case manager and the client, it is essential that case managers have formal education in the foundations of psychodynamic theory or on-the-job supervision and training in this perspective. Understanding of such issues as transference and countertransference and maintaining boundaries are important for case managers to apply in their work with clients.

**Working with Addiction**

There are many theories of why people become addicted to substances. Substance use has been blamed on moral weakness, bad habits, a gene, a disease, and unresolved familial issues. In studying either active or abstinent users, it can be difficult to weed out etiology from the ravages of the addiction itself. It is not uncommon for retrospective histories to show evidence of preexisting character disorders, affective disorders, or thought disorders. In addition, the alluring power of the substances themselves cannot be dismissed.

Although people may have a variety of these psychiatric symptoms, some substance users become addicted partly by chance: they are young and impulsive, and they want to “fit in”; they fall into drug use because of peer pressure; and the power of the experience itself starts to take over. The sweet honor roll student becomes anxious, suspicious of others because he or she is hiding something; and as the person gives more and more attention to drugs, guilt takes over, grades slip, fear of getting “caught” leads to lying, and the road forks toward a very different life.

Regardless of his or her level of functioning prior to beginning use, once a user becomes dependent or addicted, or chaotic in his or her use, the addiction itself becomes a primary disorder with its own set of behavioral and psychological characteristics. Addicts generally have difficulties with self-esteem, are sensitive to the actions and thoughts of their peers, may present a somewhat grandiose external self (in order to manage a fragmented internal self), and can have difficulty “holding” or managing their emotions.

From a treatment perspective—and to apply a self psychological construct—the presence of an idealized, usable “selfobject” over a significant period of time is essential if the client is to man-
age internal change. Selfobjects, in this instance, are other people who provide the mirroring necessary for the development and internalization of healthy self-esteem and self-ambition. This suggests why community and peer interventions have proven to be essential components of both addiction treatment and HIV prevention. The centrality of self-esteem also poses a powerful argument for the addition of a therapeutic relationship within a client-centered framework in order to optimize harm-reduction or case management interventions. From the case manager's vantage point within this ongoing therapeutic relationship, it is also easier to sort out a client's coexisting psychiatric disorders, which may benefit from evaluation and treatment.

Maintaining a psychodynamic framework can be particularly challenging, as case managers have the freedom to work with clients outside of traditional social service provision sites such as agency offices, which furnish natural boundaries and role expectations. An essential tool to reach substance-using populations and develop trust with them, case management in San Francisco has included outreach in hospital emergency rooms, methadone maintenance clinics, and housing shelters, as well as on street corners where drug dealing and prostitution occur. Delivering services in these settings has several advantages. It helps case managers find clients and develop trust. In settings where there are other service providers, it allows case managers the opportunity to link with these providers. Linking with providers enables case managers to become “translators” between client and provider or service system, facilitating mutual understanding and the effective use of the system. Finally, by being present in these settings, case managers are able to foster connections among clients, facilitating natural peer support and creating formal peer support groups of users interested in making similar changes.

**Barriers to HIV-Related Case Management**

Drug users pose significant challenges to HIV prevention work, and much has been written about effective approaches to reach them. There are many potential barriers to this work. First, for many drug users, involvement in illegal activity to support addiction leads them to be suspicious of “outsiders,” including outreach
workers or social service personnel not well known to them. Second, African American and Latino users, who are disproportionately represented among injection drug and crack users, are more likely to distrust larger systems because of their experiences with institutional racism and classism. Third, drug users are reliant on community norms that may not support safer practices. Lastly, more pressing needs take precedence over HIV prevention; these can include maintaining an addiction and dealing with economic and social concerns, housing, food, and more acute medical problems.

Despite the challenges of overcoming these barriers, it is notable that education is not the predominant prevention difficulty when reaching out to this population. Injection drug users have, to a large degree, been successfully educated about safer needle-sharing practices. As has been shown time and again in many populations, however, education alone does not facilitate behavior change. Despite their knowledge about the dangers of HIV and the ways to protect themselves from these dangers, users continue to participate in unsafe drug-using behaviors. The reasons for this disparity are often connected to economics or interpersonal difficulties, circumstances that can supersede information.

The integration of case management focused on reducing both HIV and substance-using risk is a sensible one. Case managers can address some of these issues through linkage to needle exchange or skills-building programs. In addition, there is evidence that injection drug users are not as educated about safer sexual practices—in particular for those who are heterosexually identified—as they are about needle-cleaning practices. Case managers, through the fostering of ongoing, trusting relationships with active users, have the opportunity to create a venue for talking about sexual practices. The goal of this approach might be developing common understandings of HIV-related risks and implementing client-centered interventions designed to help lower these risks.

**HIV Prevention Efforts:**
**The Current Scene with Substance Users**

A review of current prevention efforts can help illuminate which have been successful and which have not, informing decisions about applying comprehensive clinical case management as a nec-
ecessary component of care. These efforts can be divided into those aimed at users seeking treatment and those aimed at active users.

**Working with Users Seeking Treatment**

Substance use treatment remains the most effective way to prevent HIV transmission as a direct result of substance use. At the very least, it secures a “captivating” audience. At best, treatment provides an arena for reevaluation of and recommitment to an individual’s life and well-being. Treatment can encompass a variety of approaches, including methadone maintenance, residential treatment, outpatient programs, and detoxification units.

**Methadone Maintenance Treatment**

For decades, methadone maintenance has been an effective and somewhat controversial method to decrease heroin use. Early on in the epidemic, methadone maintenance clinics, with their daily access to known injection drug users, became obvious venues for prevention messages. Since that time, methadone maintenance sites have delivered not only HIV prevention messages but also HIV-related counseling and medical care. The development of ongoing relationships with mental health or medical providers opens the potential for HIV prevention through work on self-esteem, increased health, and skills-building.

The obvious drawback of this type of treatment is that it reaches a small population of substance users: heroin addicts who wish to use methadone to manage, or detoxify from, their addiction. Case managers, working in conjunction with methadone maintenance clinic staff, have the ability to access a wide array of substance users in a variety of settings beyond methadone maintenance treatment programs, reinforcing prevention messages and facilitating linkage to services outside the clinic.

**Residential Drug Treatment**

Residential treatment settings, or “therapeutic communities,” offer ongoing behavioral and peer reinforcement for drug and alcohol users that can have long-lasting effects. They also have high attrition rates and can have waiting lists that are prohibitive for the user seeking treatment. In other words, they can work very well, but only for a small number of people.
In an environment where the examination of an individual's drug use and life issues is continually reinforced, it is logical to introduce HIV prevention efforts—although historically this integration has been challenging. Staff and program administrators, in their enthusiasm to help clients manage addiction, have feared losing that focus by introducing other issues, such as HIV prevention. In addition, staff are often recovering addicts, and it can be difficult for them to address HIV-related risk with clients if they have not explored these issues themselves. Funding streams have historically mirrored this compartmentalization of issues. It was not until 1997 that the Centers for Disease Control and Prevention allocated funds to ensure that treatment program staff understand HIV-related issues and have the skills necessary to work with clients regarding HIV risk behaviors and prevention.

As residential treatment programs move toward integrating prevention interventions, they will increasingly provide linkage resources for case management. In addition, case managers can work with clients who are on waiting lists for residential treatment, laying a groundwork of harm-reduction messages, both HIV and drug related, that residential settings will reinforce after a client enters the program.

**Outpatient Treatment Programs**

Outpatient treatment programs, settings that require attendance ranging from weekly to daily, have become popular as lower-cost interventions. In San Francisco, outpatient programs target a variety of types of substance use as well as specific populations such as African Americans, Asian Americans, Latinos, gay men, lesbians, and sex workers. Such a focus is an attraction for users and a strength for the program, building on the importance of community and peer reinforcement of norms.

Outpatient programs employ both group and individual counseling and education related to substance use. This combination offers a rich source of HIV prevention opportunities. A San Francisco study, in which researchers compared two HIV interventions with substance users seeking treatment, suggests how some of these approaches might be shaped. The first intervention was a psychoeducational group focused on information; the second was a series of individual sessions combining education and skills-
building in preparation for the high-risk situations that clients would most likely encounter. The group approach resulted in increases in HIV-related knowledge and self-efficacy that were retained three months later; the individual approach, augmenting education with skills-building related to real-life situations, resulted in even more frequent safer needle-sharing and sexual practices.

As with residential treatment, the HIV prevention opportunity in outpatient settings has been fettered for several reasons. Outpatient treatment staff may have difficulty knowing how to talk with clients about HIV risk and how to help clients explore such issues as deciding to take an HIV test, if they themselves have not explored these issues in their personal lives or received training in how to do so. Again, lack of prevention funding has historically reinforced the lack of service integration. Finally, because outpatient treatment is aimed at users who remain functional in their communities and daily lives, the most chaotic clients attend only sporadically and may have difficulty benefiting from the ongoing reinforcement necessary for successful change.

Clinical case managers have the ability to duplicate the best prevention efforts outpatient treatment offers. Case management is predicated on the idea of integrated service delivery, using the relationship with the case manager to address substance use as well as HIV prevention concerns. Case managers are educated and trained in providing comprehensive care, ensuring a focus on all aspects of harm-related activity in a client’s life. These providers can work with clients in their own environments and facilitate engagement with the most chaotic of users. With the development of an ongoing relationship, case managers can educate clients about HIV prevention issues and work with them to problem-solve in risky situations. As is true with linkage to residential treatment, case managers can work with clients who are waiting to enter outpatient treatment, laying the groundwork for a comprehensive approach to treatment.

**Detoxification Units**

Detoxification units, inpatient settings for those in acute withdrawal, respond to drug-related physical or emotional crises, usually among individuals who have not considered seeking drug treatment. To the outside observer, a detoxification program may
seem like a revolving door as clients enter on short notice, stay three to seven days, and leave once the crisis seems resolved.

A detox unit, however, can become an important point of contact for the disenfranchised, chaotic substance user and can therefore provide an important HIV prevention opportunity to clients at highest risk—a route to counseling and testing and linkage to other HIV-related services. Case managers can facilitate linkage within detox units, begin to establish relationships with users in the program, and continue that relationship once the client is discharged.

**Reaching Out to Active Users**

Successful prevention can and must take place outside of formal drug treatment settings if rates of infection are to be reduced among active users—those clients who are by definition the most likely to put themselves at risk. Current prevention efforts with this population have had some success and provide important lessons for a clinical case management model. Among the most notable out-of-treatment efforts are information dissemination, interventions performed by community health outreach workers, client contact in social service venues, and needle exchange programs.

**Information Dissemination**

Although education does not equal prevention, education is an essential component of risk reduction. Despite assumptions to the contrary, active users can learn to reduce risk. But it is even more useful to help these individuals understand how they can apply knowledge to real-life situations.

Prevention efforts in the early years of the epidemic were focused almost exclusively on education about needle sharing and cleaning—messages disseminated primarily through posters and leaflets, billboards and bus placards. Later, these messages became more comprehensive, including information about the dangers of sharing works—cotton and water—as well as needles. By the 1990s, surveys showed that injection drug users were relatively well educated about the likelihood of HIV transmission through the sharing of injection equipment. Far fewer were aware of HIV-related sexual risk.

In a 1991 study of injection drug users in Cleveland, 91 percent of respondents knew that HIV is not eliminated by cleaning nee-
dles with water alone. In contrast, only 46 percent knew that latex condoms provided better protection than other types of condoms. A 1992 Puerto Rican study found that although injection drug users knew about the HIV risk inherent in needle sharing, they knew less about the dangers of sharing works and having unprotected sex. The study found that users had little skill in negotiating situations that would challenge their abilities to use this knowledge—for example, dealing with pressure from partners to have unsafe sex.

Case managers can use the information clients have absorbed through HIV education campaigns as a springboard to deepen and broaden levels of understanding, ensuring that drug users are familiar with all the aspects of HIV-related risk. In addition, case managers can use their relationship to help clients increase their abilities to negotiate difficult situations—in other words, to apply their knowledge.

**Community Health Outreach Workers**

Community involvement and peer support are significant components of effective risk-reduction interventions, and the most successful efforts are performed by peers who are former or current users themselves. In the 1990s, HIV and substance abuse treatment providers have increasingly emphasized the efforts of community health outreach workers (CHOWs) in order to forge the connection between service providers and users within the community. CHOWs, generally most effective if they are members of the communities they serve, deliver prevention messages to drug users wherever they may be. CHOWs have the ability to spend days, weeks, or months in communities or neighborhoods building relationships and trust with drug users, relationships that reinforce and legitimize their prevention messages.

Outreach workers can also provide information and referral and, more recently, street-based HIV antibody counseling and testing through the use of oral testing methods. Antibody testing is difficult to sell to people living precarious lives one day at a time, who have no desire to discover they have a “fatal” disease. Studies have shown that even participants in paid studies have a difficult time returning for their disclosure session to receive test results. CHOWs can provide drug-using clients the ongoing support necessary for them to learn their serostatus. This is crucial both for
prevention efforts and for care for seropositive clients, who can benefit from early antiviral intervention with combination therapy.

Some of the most important functions of outreach workers are similar to those of case managers, though more limited in scope. CHOWs work with clients in their communities, focus on building relationships and trust, and provide information and referral. Case managers are able to take these functions several steps further through their ability to function in a broader array of settings, link their clients to resources, and apply a psychodynamic understanding of the relationship to further behavior change and self-understanding.

**Client Contact in Social Service Venues**

HIV prevention is most effective if the social and medical services to which drug users have access are integrated, ensuring that everywhere active users go, HIV prevention messages are introduced and reinforced. Most disenfranchised drug users come into regular contact with various social and health service delivery providers, for example, public health clinics, emergency rooms, and public assistance offices. Although these settings increasingly offer a forum for HIV prevention messages through written materials and structured client education programs, they themselves may frustrate prevention efforts by treating drug users in negative ways within such institutions. These perceptions may discourage clients from accessing services, or they may sabotage the provider-client alliance necessary to undertake the difficult conversations that accompany effective HIV prevention counseling. Case managers, through their ability to be physically present in these settings, can both reinforce prevention messages and act as “translators” between other providers and their clients, helping to interpret communications and facilitate relationships.

**Needle Exchange Programs**

Real-life concerns often take precedence over hypothetical HIV risk, and people are better able to make changes when their basic needs are met. Recent studies have shown that most needle users have no desire to share needles. Needle sharing usually occurs because of socioeconomic factors, such as the scarcity of new needles, rather than because of “subcultural norms” such as the ritual of using or the need for intimacy.
In study after study, needle exchange programs have demonstrated their role in preventing the spread of HIV disease. Needle exchange programs are generally mobile, with an emphasis on easy access by drug users; sites move to different neighborhoods on different nights of the week. Users bring in their “dirty” needles and are allowed to swap, one-for-one, for clean ones. The programs make establishing consistency and trust a top priority, laying the groundwork for other types of interventions.

Needle exchange programs are extremely popular among addicts themselves. In San Francisco, where the injection drug using population is estimated to be somewhere between twelve thousand and fifteen thousand, the needle exchange program distributes more than one million needles a year. Needle exchange programs directly prevent HIV transmission by deterring needle sharing and by providing an opportunity for further HIV education regarding safer needle sharing practices and sexual activity. In recognition of their access to users who may otherwise remain invisible to traditional service systems, San Francisco needle exchanges have begun to provide medical care and HIV counseling and testing.

Needle exchange is effective for some of the same reasons that clinical case management is: easy access, an emphasis on practical resources, the development of trusting relationships as foundations for dissemination of information and behavior change, and respectful engagement. Case managers have the opportunity to deepen these relationships.

Despite treatment advances, as we approach the end of the second decade of the epidemic we remain far from a cure for HIV. The virus continues to spread, people continue to die, and communities continue to be ravaged. In this atmosphere, it is difficult to acknowledge the prevention successes.

Over the years, prevention efforts have grown. Both success and failure have led to greater understandings of how people change behaviors. Interventions have increasingly emphasized skills-building and the influence of community norms. There has been a greater integration of HIV prevention efforts both within services for specific communities and in the general population. Divisions within social and medical service provision systems, which
arose to address HIV-related needs in the 1980s, have begun to dissolve, and the goal is shifting toward providing quality HIV treatment and prevention in the contexts of all medical and social service settings.

From this ground have grown harm-reduction strategies and HIV prevention clinical case management services. These two treatment approaches combine to form a holistic and comprehensive model with achievable objectives—an ideal approach for working with populations of substance users, who are at the highest risk for HIV infection but are the least likely to be reached.

Notes
5. Ibid., p. 3.

13. Ibid.


19. Ibid.


22. Finlinson, Guberti, Robles, and others, “What We Want to Know About HIV/AIDS.”


Part Two

Transformation and Psychotherapy
Helping Clients Live with HIV

It is a cliché—and a sentimental one at that—that HIV transforms the lives of people whom it touches. But like all clichés, this one carries a grain of truth, perhaps even a nugget: HIV is an agent of change. The cliché of transformation developed early on in the epidemic, around the time that “AIDS victims” became “people living with HIV.” Both of these concepts—transformation and living with AIDS—suggest that the powerful experience of HIV is one that leads not necessarily to death or only toward death but also toward some deeper understanding of life.

That is what psychotherapy is all about. It is a tool not to negate the horror of AIDS but to find some way of living with it, to change perspective in response to altered circumstances. At a time of hope, it is exciting to consider a future when we might treat HIV as a chronic, manageable disease—something that can be combated, requiring adaptation but perhaps little effort of self-discovery and understanding in order to come to terms with its effects.

But despite recent advances in treatment, that day seems distant. As long as there is illness and disability, loss and grief, fear and isolation, confusion and uncertainty; and as long as there is also recovery and rejuvenation—new beginnings and new challenges—we
will continue to rely on the empathic and transcendent power of counseling to help people adjust to unpredictable and sometimes unthinkable circumstances. Part Two provides insights into this process.
Chapter Seven

HIV Disease as an Agent of Transformation

A Survey of Therapeutic Approaches

Israel Katz

James W. Dilley

Since the early days of the epidemic, many of us—both seropositive and seronegative—have been challenged by the experience of living and working with HIV. In most cases, challenge has wrought change—some good, some bad, but nonetheless some transformation in the way we live, interact with others, and perceive ourselves.

If, in this way, HIV is a catalyst for transformation, psychotherapy is one of the most effective crucibles for safely engaging in such change. On a practical level, psychotherapy can improve self-esteem, provide emotional support, and teach coping skills—all central tasks for people coping with HIV disease. On a more fundamental level, psychotherapy can help people come to terms with basic existential issues: mortality, disability, spirituality, interpersonal relationships and intimacy, and change itself, whether adjusting to a threat to life or, at a time of exciting treatment advances, to renewed life. Sometimes an HIV diagnosis brings a person into therapy; other times it is one of many issues, coexisting with maladaptive behavioral patterns that preceded HIV disease and with dysfunctional views of the self and of relationships.

Up to now, no one psychotherapeutic approach has proven more effective than any other; and most therapists, regardless of their theoretical approach, can treat the person with HIV disease
with only some modifications to their basic techniques and an awareness of the HIV-specific concerns that emerge. The literature on psychotherapy for people with HIV disease has grown as knowledge about the psychological, biological, social, and cultural aspects of the epidemic has increased. Given the prevalence of HIV disease in the United States, therapists are increasingly likely to encounter one or more clients who are facing these challenges. This chapter begins to explore the psychological issues HIV disease raises and the psychotherapeutic techniques available to respond to these issues. Following this introduction, it presents four case studies as a survey of both clinical themes and theoretical approaches.

A Complex Psychological Circumstance

HIV disease is clearly a complicated medical condition, but it is also, perhaps more than any other illness, a complex social, cultural, and psychological circumstance. The literature bears this out. Many authors have written about the psychological challenges of living and coping with HIV, and an articulate and in-depth account of psychotherapeutic issues that arise for people with HIV disease has recently been published. Among these issues are rejection by others, social isolation and ostracism, initiating or maintaining intimate relationships, loss of cognitive functioning, shortened life span and “unfinished business,” grief and loss, potential job loss, and financial security and health costs.

Jeffrey Weiss discusses the use of a psychodynamic approach with seropositive gay men, and notes the common themes of loss, uncertainty, the evolution of HIV as self-identity, and the search for meaning. Peter De Roche explores issues of stigmatization and homophobia, the metaphorical meanings of contagion, helplessness and loss of control, fears of abandonment, fear of death, and the loneliness that many of his clients with HIV disease experience while in psychotherapy.

Several studies point to similarities between the psychological reactions of people with HIV disease and people with cancer. These studies found that structured group interventions that provided emotional support helped reduce depression and anxiety, and taught clients better ways of coping with their illness. Clinicians should also be aware of special issues that come up in the
course of treating diverse populations affected by HIV disease. Most of the research literature pertains to White gay men, but there is a growing literature on psychotherapies for women, lesbians, people of color, the chronically mentally ill, and pediatric and geriatric populations.

Psychological adjustment to HIV disease may require making peace with the life a person has lived and to work through the stages described by Elisabeth Kübler-Ross in dealing with a terminal illness: denial, anger, bargaining, depression, and acceptance. Bereavement, multiple loss, and survivor guilt are particularly pertinent issues for people with AIDS.\(^5\)

The Therapist's Stance

Therapists working with seropositive clients must be aware of these concerns and be able to shift treatment approaches as determined by their clients' needs. They must also be familiar with the medical consequences of HIV disease and be willing to adapt to the physical and psychological needs of their clients as these unfold. In the context of this unpredictability, strict adherence to a theoretical model may limit the efficacy of therapy.

Therapists must maintain a flexible therapeutic frame that allows clients to work through problems and enables therapists to maintain an empathic and supportive stance. Fees as well as the timing, frequency, and location of the sessions may have to bend. For example, home and hospital visits, or shortened or postponed visits, may become necessary in response to physical or cognitive changes.

In this context, therapists will have to be especially cognizant of the client-therapist boundary and of countertransference, including all of the therapist's emotions and thoughts related to the client during and between sessions. Therapists working with seropositive clients need to be aware of their own reactions to death, physical deterioration, the loss of cognitive abilities, helplessness, hopelessness, the stigma of HIV disease, fears of contagion, and a variety of other issues. Awareness of these issues and a therapist's reactions will help him or her to monitor thoughts and feelings during psychotherapy and promote the optimal therapeutic environment. (See also Chapter Sixteen, "Present in the Balance of Time."
The work of Eugene Farber and others examines helplessness in mental health professionals who treat people with HIV disease. He recommends solutions to combat this sense of helplessness, including reminders of the overwhelming biopsychosocial influences on a client’s functioning that place limits on how much the therapist can be expected to do, the maintenance of realistic and balanced professional expectations, and the exploration of death anxiety and crises of meaning for the therapist.

Psychotherapeutic Approaches

Clinicians will find that HIV-related psychotherapy—even insight-oriented approaches—will often have to be combined with more practical support, reassurance, empathy, help in coping with decisions, problem solving, and other factors related to the client’s daily functioning. It is also common for individual therapy to be combined with couples therapy, group therapy, emotional support groups, and other modalities based on the client’s needs and goals in therapy. As a result, the therapist often works collaboratively with social workers, psychologists, psychiatrists, physicians, and other clinicians in the multidisciplinary care of the client. The four case studies following this introduction illustrate common issues that arise in the treatment of people with HIV disease. They advocate different approaches to treatment and are based on different theoretical models, yet all provide support, help increase self-esteem, and help clients cope with HIV disease. The four approaches are described in the sections that follow.

Interpersonal Psychotherapy

Kathleen F. Clougherty and John C. Markowitz apply an interpersonal psychotherapeutic approach to the case of Albert, a seropositive, gay, Jewish man with major depression. Therapy occurred over the course of sixteen fifty-minute sessions, during which time the therapist emphasized the connection between the client’s mood and his social environment, and therapy explored the client’s interpersonal patterns as manifested in his relationships. Central to this approach is the “interpersonal formulation,” which links the client’s depression to one of four interpersonal
problem areas: grief, role dispute (disagreements with significant others), role transition (for example, diagnosis with HIV disease, and demotion or promotion at work), or interpersonal deficits (long-standing difficulties in maintaining relationships). In contrast to the therapist’s role in a more conventional psychodynamic approach, the interpersonal therapist is active, offering the client suggestions about what to do, refraining from exploring the client’s transference, and encouraging a problem-solving approach in the here and now—with a focus on one of the four interpersonal problem areas. The interpersonal approach does not encourage an exploration of the past as currently reflected in the present and focuses less on intrapsychic factors than on interpersonal relationships.

Self Psychology
Sharone Abramowitz applies self psychology to the treatment of a White heterosexual couple, Anthony and Helen, both of whom are in their thirties. Anthony has recently seroconverted; Helen remains HIV-negative. The couple enters therapy to deal with Anthony’s low libido and Helen’s frustration with the infrequency of their sexual relations.

The self psychological approach, based on the writings of Heinz Kohut and his followers, views the self as the center. In self psychology, symptoms and defenses are seen as attempts to attain cohesion of a threatened and fragmented self, and the approach emphasizes understanding the client’s subjective experience rather than the interpretation of unconscious conflicts. The theory suggests that the failures of parents and significant others to mirror the child’s healthy and age-appropriate needs to idealize others and to experience grandiosity lead to an arrested stage of self-development. The therapist can counteract this by providing “empathic attunement” and interpretation of the inevitable ruptures in the cohesion of the self that result when narcissistic injuries occur.

Self psychology emphasizes the environment and its capacity for mirroring the infant or the infant’s capacity for mirroring the environment, deemphasizing a view of the infant as being born with conflicts among drives or instincts. The purpose of psychotherapy is to understand and empathize with the client’s subjective
experience and to help the client explain this experience in terms of his or her self's attempt to recruit from the environment what it needs to feel whole. Self psychology considers transference and past relationships, and the therapist maintains therapeutic distance while empathizing with the client's experience.

Psychodynamic Psychotherapy

Israel Katz presents a more "classical" ego-psychological psychodynamic model in the treatment of Robert, a White seronegative man who was putting himself at risk by having unsafe sex with his partner and by failing to assert himself in the relationship with his partner. In the psychodynamic approach, instincts such as aggression and sexuality fail to be expressed directly because of prohibitions from the superego, which embodies rules and regulations from parents and society, and because of anxieties about expressing these instincts. These anxieties include fear of loss of the significant relationship and of the other's love, fear of bodily harm, and fear of punishment. The ego mediates between the id and the superego and erects defense mechanisms to deal with the anxieties engendered by sexuality and aggression.

Psychodynamic psychotherapy emphasizes conflict between instincts and defenses rather than deficit (the failure of psychic features to develop) and deemphasizes the lack of empathic attunement from important figures in the creation of psychopathology. The main purpose of psychotherapy is to explore transference, that is, how the past reflects itself in the present relationship with the therapist, and to examine the anxieties and fantasies connected to the expression of aggression and sexuality—the goal being the freeing of the ego to be able to express these instincts appropriately. The psychodynamic psychotherapist tries to avoid giving direct advice or suggestions to the client.

Time-Limited Psychotherapy

In another case study, Israel Katz describes time-limited dynamic psychotherapy in his discussion of Enrique, a thirty-year-old seropositive Latino man who is mandated to enter therapy by the court. Time-limited dynamic psychotherapy (TLDP) is based on a