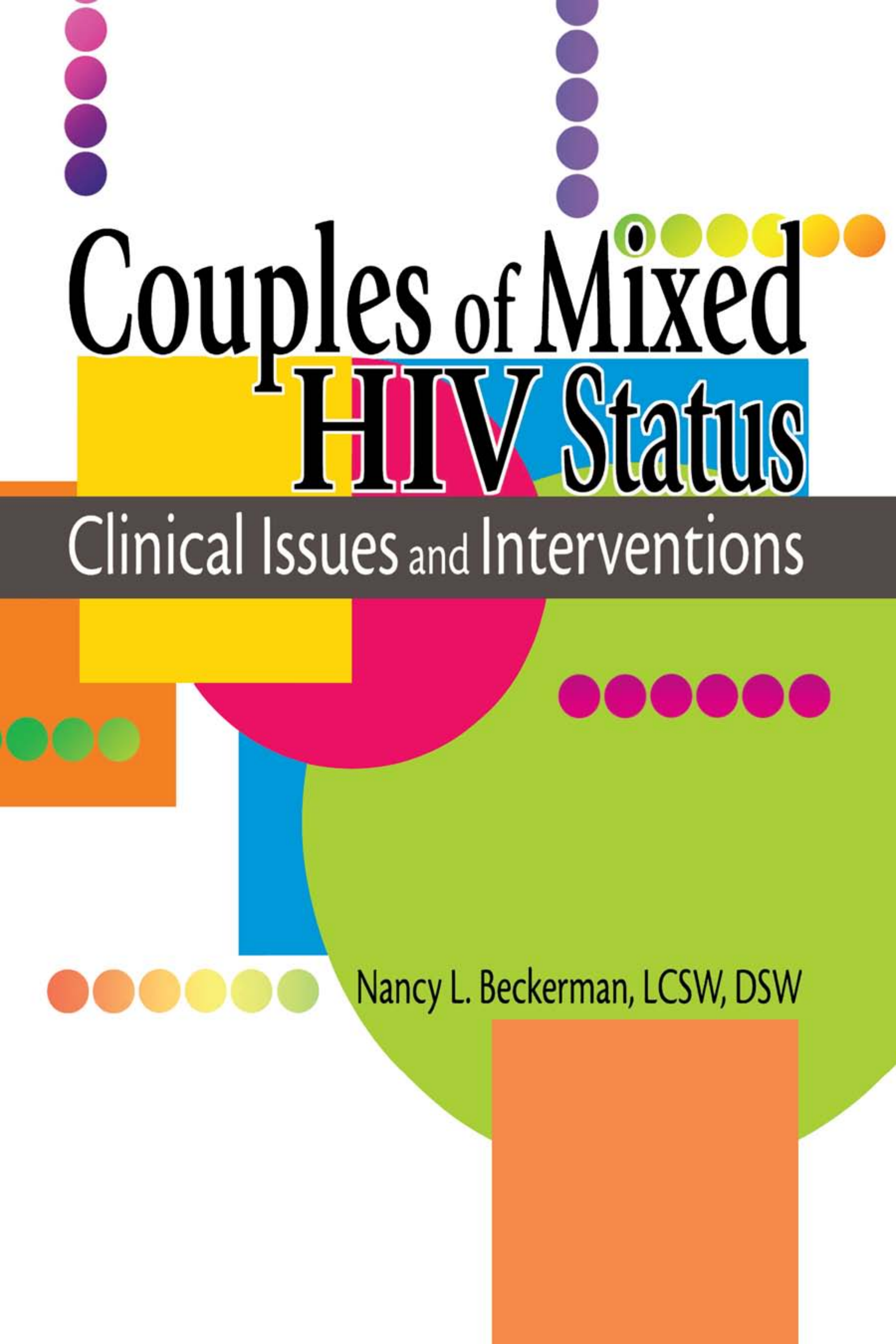

Couples of Mixed HIV Status

Clinical Issues and Interventions

Nancy L. Beckerman, LCSW, DSW

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CONTENTS

ABOUT THE AUTHOR

Nancy L. Beckerman, LCSW, DSW, is an associate professor at Wurzweiler School of Social Work, Yeshiva University in New York. In her private practice, she provides clinical services to the HIV/AIDS community. She is a consultant and supervisor, specializing in couple and family therapy. Dr. Beckerman has published extensively on HIV/AIDS, couple and family therapy, and health and mental health in social work. Her research, practice, and supervisions center around couple therapy and in particular, the psychological impact of chronic illness on couples' relationships.

Prologue

RATIONALE

In my experience as a clinician providing couple therapy to numerous couples affected by HIV, certain issues repeatedly emerged in therapy that were both universal and unique to couples of mixed HIV status. The psychosocial impact of illness may pose intrapsychic and dyadic challenges, such as coping with uncertainty and the shifting of emotional and functional roles, regardless of the nature of the medical illness. When turning to relevant literature and research to help refine techniques with this population, I found that the literature largely reflected the era prior to combination therapies, identifying relationship issues such as loss and bereavement and caregiving. My clinical experience suggested that the relevant literature lacked discussion about the types of dyadic emotional challenges that were emerging in clinical practice and the theoretical frameworks that could be applied effectively. Issues such as fear of HIV transmission between partners, disclosure of HIV status to each other and to others, issues of mistrust and betrayal provoked by the HIV diagnosis, and the impact of an HIV diagnosis on family planning could be further studied and clarified for clinicians providing services to this population.

A research study of forty-four serodiscordant couples in the Northeast served as a starting point for this inquiry of distinctive relationship issues confronting couples of mixed HIV status. This book provides an overview of the findings from this research, as well as an application of those couple-therapy approaches that have proved particularly effective in the treatment of couples of mixed HIV status. Based on this research and extensive case studies, this book provides an introduction for therapists who are interested in (1) understanding the unique emotional challenges of couples of mixed HIV status, and (2) gaining a theoretical base that can inform their practice with couples of mixed HIV status. Information about what couples may experience and relevant theoretical applications can be used by any marriage or family therapist to guide the nature of their interventions with this population. This book will also be helpful to the student of counseling and health-related services, as well as the lay reader who may be in a serodiscordant relationship, or the friends or family members of couples living with HIV.

PLAN OF THE BOOK

This book is organized to introduce the therapist to the unique emotional challenges that may face couples of mixed HIV status and provide a range of theoretical approaches that can be employed effectively. The historical context of HIV/AIDS and couples of mixed HIV status and relevant literature are provided as a foundation in Chapters 1 and 2. Chapter 3 includes the historical and current overview of couple therapy frameworks that are of particular relevance to therapists counseling couples of mixed HIV status. The central frameworks of emotionally focused couple therapy (EFCT), integrative couple therapy (ICT), medical family therapy, and structural couple therapy are discussed in detail and other relevant approaches are also reviewed. The reader is then introduced to the research methodology and findings in Chapters 4 and 5. Chapters 6 through 11 are each devoted to one of the six issues commonly identified. Each chapter identifies and analyzes the findings, both empirical and qualitative. After identifying each issue in each chapter, case studies are used to further illustrate how these issues may manifest themselves differently with diverse couples and how theoretical frameworks can be applied differentially depending on different issues and varied sociocultural and characterological factors. The case studies are used to demonstrate how these variables may be addressed in the dynamic context of the clinical realm. In the epilogue, the conclusion provides a summary of key findings and implications for the therapist providing couple therapy to couples of mixed HIV status. This book can be used as a resource for therapists working with today's couples of mixed HIV status.

Chapter 1

Introduction

> Disease may destroy only a few cells or an entire organism, and with it, the individual. For this reason, man suffers and is afraid: disease reminds him that he is mortal . . . that he is alone and must die sooner or later. Elementary fears . . . come from the depth of the unconscious, breaking through the thin crust of security.
>
> H. E. Sigerist (1943, p. 6)

The crisis of physical illness comes to each individual and each couple in ways both universal and unique. When one partner in a relationship has been diagnosed with HIV, the couple may experience a unique tier of relationship conflicts above and beyond what any couple facing another physical illness may experience.* Because of the populations affected, unpredictable treatment, stigma, and transmissibility, couples of mixed HIV status must contend with a range of emotional reactions both individually and as a dyad. The distinct nature of HIV/AIDS creates conflicts and intensifies preexisting conflicts in the relationship in its own unique way.

Based on a research study (forty-four couples) with couples of mixed HIV status,** this book provides an identification and analysis of the types of relationship issues that commonly arise for serodiscordant couples. Some of these issues are universal, such as shifts in

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*The term *HIV* throughout the book will refer to asymptomatic HIV. When *HIV/AIDS* is used, it will refer to disease progression marked by HIV-related illness.

**The term *couples of mixed HIV status* will refer to couples in which one partner has tested HIV positive and one partner has tested HIV negative. At times, relevant literature refers to this phenomenon as *serodiscordant couples.*

emotional intimacy due to the diagnosis and coping with uncertainty, and some are particular to what a couple of mixed HIV status might contend with, such as fear of HIV transmission between partners, disclosing a partner's status, feelings of betrayal, and family planning issues. The analysis of these HIV/AIDS issues in couples as demographics and treatments continues to evolve.

The focus of this book is on identifying and clarifying the unique emotional issues common to couples of mixed HIV status. Once presented, assessment and intervention are discussed from several couple-therapy frameworks, primarily that of emotionally focused couple therapy (EFCT) and integrative couple therapy (ICT). These and other couple-therapy frameworks are reviewed and illustrated in their application to several couples in practice. In this way, practitioners can conceptualize how they might employ practice principles with both the universal and unique emotional challenges couples of mixed HIV status may face.

KEY EMOTIONAL ISSUES

The dyadic issues of couples of mixed HIV status often are superimposed on issues or conflicts that predate the HIV diagnosis, maybe even predate this particular relationship. Multifaceted variables such as characterological tendencies and illness in family of origin must be considered, as well as the impact of illness issues experienced by the individual and his or her partner in the face of a potentially life-altering illness.

As any medical social worker knows, psychosocial issues such as coping and adaptation, denial and acceptance, independence and dependence, and hope and despair are at the vortex of emotional reactions to illness affecting not only the individual, but the couple and family as well (Baider and Sarrell, 1984; Baider and Spexiele, 1997; Campbell and Patterson, 1995; Frazier, Davis-Ali, and Dahl, 1995; Gotay, 1984; Krausz, 1988; Lyons, 1995; McDaniel, Hepworth, and Doherty, 1995; Moos and Tzu, 1977; Parker, 1993; Rolland, 1994; Sabo, Brown, and Smith, 1986; Spexiele, 1997). Although broad conceptual frameworks may have informed social work practitioners through such reactions, specific sensitive challenges exist that singularly affect couples of mixed HIV status. These issues may include: how and when one partner contracted HIV, issues of mistrust or betrayal, fear of HIV transmission within the relationship, stigma, and disclosure issues. Family planning dilemmas have emerged in the more recent literature on couples of mixed HIV status (Avert, 2002; Beckerman, Letteney, and Lorber, 2001; Katz, 1997; Leask et al., 1997; Klitzman, 1997; MacDonald, 1998; Pasquier et al., 2000; Scarce, 1999; Williams-Saporito, 1998).

Through the 1980s and 1990s, couples of mixed HIV status have had to cope primarily with issues surrounding physical and psychological impacts of illness, loss, caregiving strains, impact of stigma, mourning, and bereavement (Burgoyne, 1994; Christ and Wiener, 1984; Foley et al., 1994; Folkman, Chesney, and Christopher-Richards, 1994; Geis, Fuller, and Rush, 1986; Lippmann, James, and Frierson, 1993; Pearlin, Semple, and Turner, 1993; Powell-Cope, 1995; Rowe, Plum, and Crossman, 1988; Shelby, 1992; Stulberg and Buckingham, 1988).

There has been only limited discussion of family systems and self-psychology as effective approaches with the intrapsychic and interpersonal issues in the realm of HIV/AIDS (Walker, 1991; Shelby, 1992). Social workers have counseled their clients through the developmental cycle starting with the crisis of HIV testing, and moving through numerous health crises until sadly reaching grief and bereavement after the loss of a partner (Buckingham, 1987; Burgoyne, 1994; Folkman, Chesney, and Christoper-Richards, 1994; Powell-Cope, 1996). HIV/AIDS social workers and other mental health practitioners who counsel couples coping with HIV in their lives have applied systemic and psychotherapeutic approaches, but relied predominantly on a psychosocial model based on principles such as coping and adaptation to illness and loss from crisis intervention and bereavement approaches (Bor, Miller, and Goldman 1993; Grace, 1994; Hoffman, 1991; Rait, Ross, and Rao, 1997; Shelby, 1995; Winiarski, 1991).

The knowledge base and practice skills adapted from crisis intervention and bereavement provided effective conceptual frameworks for practitioners for the first 20 years of HIV/AIDS. However, given the compelling advances in HIV/AIDS treatments that have consistently lowered AIDS deaths since 1997 (CDC, 1998, 1999, 2000, 2001), crisis and bereavement frameworks may no longer be the exclusive or most effective framework for counseling couples of mixed HIV status. For those who have responded well to new combination therapies, many are returning to life-affirming activities and relationships. Those already in long-term relationships are more able to shift their emotional energy away from illness and dying, and more toward maintaining and enhancing their primary relationships (Anderson and Weatherburn, 1998; Beckerman, Letteney, and Lorber, 2001; Greenan and Tunnell, 2003; Mancilla and Troshinsky, 2003; Mayer and Wells, 1997; Moore et al., 1998; Pomeroy, Green, and Van Laningham, 2002; Powell-Cope, 1996; Remien, 1998; VanDevanter, Clearly, and Moore, 1998; Van der Straten et al., 1998). Theoretical approaches, such as medical family therapy, emotionally focused couple therapy (EFCT), and integrative couple therapy (ICT), that have been particularly effective with these issues are introduced and illustrated through each chapter and each case study.

INTRODUCTION TO RESEARCH STUDY

The identification of emotional issues common to couples of mixed HIV status is based on findings from an exploratory research study of forty-four couples of mixed HIV status, as well as the clinical immersion (numerous cases) of therapeutic contact. Six primary issues are identified. Respondents from the study were asked to answer open-ended questions, and their narrative responses are provided to further illustrate the types of emotional issues that have been consistently identified by couples of mixed HIV status. Couples who have been treated, duly disguised, are presented through case studies to provide further depth and context of how ongoing relationships are affected when one partner is HIV positive. These trends and case studies are shared and analyzed to assist practitioners in refining their conceptual framework and skill base for practice with couples of mixed HIV status.

HOW THIS BOOK IS ORGANIZED

Chapter 2 provides a historical context of HIV and couples, and reviews the empirical and nonempirical research and literature on the topic. In Chapter 3, selected theoretical orientations within couple therapy are reviewed to provide a more responsive treatment approach to some of the common issues couples of mixed HIV status may present. The methodology of the study, including the design, data collection, the instrument, and data analysis are provided in Chapter 4. The identification and explanation of the results are introduced in Chapter 5 and analysis and discussion of the six commonly identified emotional issues are found in Chapters 6 through 11. Salient clinical issues are analyzed to provide illumination for couples and potential guidelines for practitioners at the end of each of these chapters. The epilogue provides a summary of clinical issues and interventions for conjoint therapy with couples of mixed HIV status.

For those providing individual and couple counseling around HIV issues, the book will provide information and insight into a broader conceptual framework of the issues that are likely to present with couples of mixed HIV status, and theoretical orientations within couple therapy that can be used effectively when treating serodiscordant couples. This book can be used for any individual or couple affected by HIV/AIDS, as well as family members, parents, siblings, and friends of any couple affected by HIV/AIDS who may wish to better understand and cope with their emotional experiences surrounding HIV in their lives.

Chapter 2

Literature Review

HISTORICAL CONTEXT OF HIV/AIDS AND COUPLES

To appreciate how couples of mixed HIV status are affected by HIV in their lives, one needs to understand the potent historical context of HIV/AIDS in the United States. The heady air of gay sexual liberation of the 1970s is now understood as the ironic prologue to 1979, the year that marked the very first mysterious moments of a serious set of maladies affecting young men. Symptoms such as dermatological rashes and lesions, a rare form of unusually potent pneumonia, and enlarged lymph nodes puzzled and stumped the first set of physicians exposed to this phenomena (CDC, 1981; Curran, 1983). Within months, this handful of physicians on both coasts of the United States noted another trend in their respective patients: they were all gay men. As Greenan and Tunnell (2003) explain, the uprising of the gay community at the Stonewall Inn in 1969 brought being gay into the public spotlight, but AIDS brought gay male couples to the forefront of media attention.

The first article on HIV that appeared in the mainstream press *(The New York Times)* was printed in 1981: “Rare Cancer Seen in 41 Homosexuals” (Mass, 1987). This “rare cancer” appeared to be deadly. Those studying this phenomenon assumed it had something to with the gay social behaviors of its recipients and dubbed it gay related immune disorder or GRID (Curran, 1983). GRID received startlingly little coverage in the first few years: seven articles in *The New York Times* over eighteen months when the number of reported AIDS cases went from forty-one to 1,200. This was experienced as a direct message by some in the gay community that their deaths were unimportant and perhaps, wanted by some outside of the gay community (Kramer, 1989).

Those living and dying with GRID or the "gay plague," as it was referred to inside and outside of the gay community, had little or no information about an illness that struck swiftly and decidedly and appeared to be working its way through circles of friends (Curran, 1983; Dowdle, 1983). GRID, and then in 1983, under the new name of acquired immune deficiency syndrome (AIDS) challenged mainstream society to confront mortality in an era that was becoming accustomed to almost routinely conquering death with the use of life-sustaining treatments, such as respirators, dialysis, and transplantation.

Individuals living with AIDS were flooded by feelings of fear and terror. There were no explanations of the origin or any possible treatments for this swift, disfiguring terminal illness. In addition to intense fear, those affected by AIDS experienced intense stigma by friends and family. Even those in the health care system and many communities across the country saw the disease as gay related. Intense stigma resulted in repeated scenarios of violence and discrimination toward those diagnosed with AIDS (Bacon, 1987; Christ and Wiener, 1986; Hausman, 1983; Kaisch and Anton-Culver, 1989). In some circumstances even those related to the identified patient were victimized with acts of hate and violence (Bacon, 1987; Martin, 1989; McKusick, Horstman, and Carfagni, 1983). Many people living with AIDS withdrew and chose not to disclose their health status (Hausman, 1983). The partners of those living with AIDS experienced intense trepidation about the disease progression and impending loss, as well as feelings of despair and isolation in the face of the widespread stigma associated with the disease (Christ and Wiener, 1986; Rowe, Plum, and Crossman, 1988; Stulberg and Buckingham, 1988).

Through the mid-1980s, the demographic face of HIV/AIDS shifted to include spiraling rates of HIV-infected women. In the United States, cumulative demographics of HIV-infected gay men (or in CDC terminology, men who have sex with men) totaled 368,971, and the number of women who were exposed through heterosexual contact was up to 57,396 from 7 percent of overall HIV population in 1985 to 26 percent in 1993 (CDC, 2001). The medical community, public health structures, and mainstream media began to understand this was no longer a "gay plague" but an indiscriminate, transmissible virus that seriously, even fatally impaired one's immune system. Heterosexual couples with women almost exclusively of childbearing age and their male partners became a growing focus of media attention.

During the 1980s, community-based organizations, AIDS service organizations, and hospitals serving people with AIDS still largely conceptualized HIV/AIDS as an individual plight. Support groups were separately provided for people with AIDS (PWAs) and care partners respectively. The gay male culture still emphasized individual autonomy and was not typically welcoming to couples coping with HIV/AIDS. The larger heterosexist culture still has not affirmed gay male couples, not offering legal or religious sanctions or financial benefits. This has to be understood as a historical and current component in the range of psychosocial conflicts in serodiscordant relationships among gay males. Although the mainstream media, largely television and film entertainment, has shifted in many superficial ways to include the gay community, even profitted from it in the television market (*Will & Grace, Queer Eye for the Straight Guy,* etc.), much of what is now accepted is still wildly stereotypical and does not signify a fundamental inclusion marked by social, religious, and legal measures that provide equity with the heterosexual community.

Another component in the lives of serodiscordant couples is the changing treatment of HIV/AIDS over the years and how it affects the individual and dyadic functioning of the couple. With the introduction of AZT in 1987, the mortality rates of those living with HIV/AIDS improved significantly for a short period (CDC, 1989; CDC, 1990). Couples still were challenged by emotional reactions to diagnosis, fear of HIV transmission within the relationship, issues surrounding disclosure and caregiving, and were now faced with new and different emotional challenges regarding medication (Broder, 1989; Mancilla and Troshinsky, 2003; Mayer and Wells, 1997; Pearlin, Semple, and Turner, 1993; Strug, Grube, and Beckerman, 2002). These included adherence to often complicated medication regimes and the impact of how these regimes often intruded on a sense of normalcy. In many circumstances, intensely uncomfortable side effects caused more complications than disease progression. Fear often loomed for the serodiscordant couples that the medications would be intolerable, or if tolerated, abruptly diminish in ability to keep one's viral load low. Couples continued to struggle with persistent and painful levels of uncertainty about their futures.

As HIV/AIDS treatments advanced with the introduction of protease inhibitors in combination with reverse transcriptase inhibitors (highly active antiretroviral therapy or HAART) in 1996, AIDS mortality rates were significantly reduced (CDC, 2001; Swanstrom and Erona, 2000; Vitinghoff et al., 1999). There have been ever-changing combinations of antiretroviral drug regimens, each with different success rates of lowering viral loads and decreasing HIV-resistant mutations. For those who have had access to these treatments and have been able to tolerate a range of potent side effects, the quality and length of life has been improved. Those responding well have shifted from anticipating death to trying to live with HIV/AIDS with guarded optimism (Beckerman, Letteney, and Lorber, 2001; Mancilla and Troshinsky, 2003; Remien, 1998).

It is important to note that there has been an increase in HIV-associated illnesses, such as hepatitis C. Hepatitis C is a liver disease caused by the hepatitis C virus (HCV), which is spread by contact with the blood of an HCV-infected person. The virus can remain dormant in the liver system until it is triggered by a range of behavioral activities, such as alcoholism, drug overdose, or a depleted immune system. In fact, researchers and medical practitioners who specialize in liver disease and HIV/AIDS suggest that HCV should be seen as an opportunistic infection (Dietrich, 2001). Nationally, an estimated 33 to 40 percent of people with HIV/AIDS are also infected with HCV, and HCV has become one of the leading causes of death among persons with HIV/AIDS (Carruthers et al., 2001). Typical symptoms of HCV include jaundice, acute fatigue, abdominal pain, loss of appetite, and nausea. It can be life threatening if an individual cannot tolerate the juggling of medication regimes. This represents an additional significant biopsychosocial challenge for those living with both disease processes (Carruthers et al., 2001).

Nevertheless, there continues to be optimism about the overall improvement found in combination therapies since the mid-1990s. With more effective treatment advances, long-term HIV survivors are turning their attention back toward career and relationship challenges (Grube, Beckerman, and Strug, 2003; Remien, 1998; Powell-Cope, 1995). Recent research on couples of mixed HIV status is provided