HIV Medical Advances and Couples
Robert H. Remien, PhD

Both partners in a couple are affected by dramatic shifts in either partner's life, and the presence of HIV in relationships has always raised challenges to couple formation and maintenance. The success of combination antiviral therapy is a new factor that can have a profound effect on a couple's dynamic.

Improvements in health following combination therapy are often accompanied by a renewed sense of hope, leading many people, for the first time, to view HIV disease as chronic, not life-threatening. At the same time, some people either have experienced the benefits of treatment only briefly, enduring treatment “failure” shortly thereafter, have not responded to the new therapies, or have never initiated treatment. As the health or perceptions of health of one partner shifts, both partners may experience changes in the roles they play in the couple, in the pace and content of daily life, in expectations for the future, and in the types of immediate and long-term planning they undertake. This article examines these changes, how they affect both mixed status couples and couples in which seropositive partners respond differently to treatment, and how therapists can help couples adjust to what, in many cases, is wonderful news.

Adjusting Expectations
To understand how treatment success may change partnership dynamics, it is useful to note the challenges couples face because of HIV disease. Among these are difficulties associated with future planning, fear of HIV transmission, lack of sexual spontaneity and satisfaction, pregnancy and child-rearing, disclosure to others, fantasies of fleeing and fear of abandonment, fear of increased intimacy in the context of potential loss, current or anticipated illness, caretaking concerns, and feelings of sadness, guilt, and rage.

Many couples, who have been together for many years, have had time to come to some resolution regarding these challenges and to adapt to actual illness, pending illness, or the expectation of illness. This adaptation often includes the establishment of, or shift in, caregiving roles and expectations, and a reduced focus on long-term planning. When both members of the couple are living with HIV, often one is viewed as the “ill” or “more advanced” of the two—whether or not there is an AIDS diagnosis—and thus, dynamics can be similar to those of serodiscordant relationships. Many who have learned to cope with illness, impairment, and impending decline now face unanticipated improvements in physical functioning. These changes may have a significant impact on dynamics within the dyad, particularly when one partner was seen as the “caretaker” and the other in need of “special” care.

For example, when one member has been ill and has lost optimal physical functioning, he or she may have adjusted by “scaling back” in daily activities, moving to part-time work, or going on disability. The relationship may have accommodated such changes, for instance, by allowing the “ill” partner to take on more of the “at-home” chores while the “healthy” partner is out earning sufficient additional income to support the couple. Other subtle changes may have also occurred to allow each partner to contribute comfortably to the relationship. Renewed health may upset this balance. The formerly “ill” partner may want to return to work, return to school, shift careers, or simply to be out of the house more often. Any of these scenarios will alter established roles, routines, and expectations, and require adjustments.
Editorial: Discord and Discordance
Robert Marks, Editor

I know someone (or two) who came back from the dead, and whose primary relationship fell apart. A mixed blessing? Is the glass half-empty or half-full?

For many couples in which HIV interjects itself, the primary relationship becomes the central source of HIV-related emotional and practical support. Often, these relationships, if they precede the intercession of HIV disease, undergo dramatic and difficult change as a result of it—evolving in order to adapt to a vision of a truncated future.

There is a significant body of literature regarding “magnetic” or “serodiscordant” couples, primarily relationships in which one partner is seropositive and the other is seronegative. The presence of HIV as a third partner affects roles within the couple, the partnership dynamic, and the couple’s conception of the future.

In magnetic couples, the uninfected partner often takes on a caretaking role if the seropositive partner becomes symptomatic, conflict in the couple may be handled differently than it had been, and the couple’s life together may focus on the present and near-future, if not the moment.

Strong relationships have weathered such change. In fact, one of the definitions of their strength may be the ability to confront change and remain intact. But, for many serodiscordant couples, treatment success has altered all of this: recovery of ability and health has shaken the couple’s dynamic and what may have become comfortable roles well-suited to the uncomfortable situation of living with HIV. The result is that beneath the surface of elation about renewed health hides an often unexpressed confusion about each partner’s identity within the couple and the viability of the relationship itself.

Treatment success may also lead to “treatment discordance,” a term I’ve started to use to describe the situation in which two seropositive partners have different responses to combination therapy or in which one undergoes therapy and the other does not. This may result in the “miraculous” recovery of only one partner. As in magnetic couples, partners in such circumstances may have become used to roles defined by failing health, and they may face upheaval as one partner heals and the other is “left behind.”

Half Empty? Half Full?

In this issue of FOCUS, Robert Remien examines the effects of treatment success on primary relationships for both serodiscordant and treatment-discordant couples. He focuses on the silence that may invuge a relationship—based on fear or guilt or false assumptions—and the role of the therapist in helping partners express their confusion. Norman Sohn looks at the “blame cycle” and describes an approach that may help to bridge the gap between partners.

Certainly, health is better than illness, and evolution is better than stasis. But the familiar, however unpleasant, is often more comfortable than we might imagine. Half empty? Half full? Probably both, and doubly so. It may be that the most important task of therapists is—to paraphrase an Indigo Girls lyric—to ensure the water does not spill as the partners pass the glass back and forth.

In mixed status couples, in particular, these changes become complicated if partners have avoided talking about many of the more emotionally charged issues that relate to HIV. It is often the case that such couples have not discussed directly their long-term goals, desires, and expectations for themselves and for each other. What were their mutual and independent goals and long-term expectations for the future? How have they changed? While many have learned to cope with some uncertainty as they have adjusted to HIV, coping with uncertainty in the context of dramatically improved health marks a shift in the context of what is already one of the most difficult psychological challenges for couples.

Re-Evaluating Relationships and Behavior

When there is a shift in expectations about survival, one or both members of the couple may find him or herself seriously re-evaluating the relationship. This most often occurs when there is a history of instability and lack of satisfaction in the relationship. It is not uncommon for two people to maintain a relationship when there is illness or an expectation of a significantly shortened life span for one of the partners, in spite of pre-existing problems with the partnership. Echoing what has become a cliché of an earlier generation, couples may stay together not “for the children,” but for the “illness.” This is often done out of sincere concern, and at times it may be accompanied by guilt at abandoning someone who is unwell. For the less-well partner, there are also motivations to stay together. This partner may believe that he or she will be unable to find and attract another partner, or fear the possibility of living alone at a time when caregiving by another person may be crucial.

Renewed health may lead to a renewed sex drive and improved sexual function-
Couples may resist discussions about illness, caretaking, and treatment failure, because of each partner’s desire to protect the other from these thoughts.

Couples may have adapted to a reduced level of sexual activity, and now that adjustment may be challenged. One partner may have become more content than the other with the frequency and type of sex. Alternately, one partner may have found other sources of sexual gratification, for example, with outside partners, and may find it difficult to be responsive to his or her partner again.

For couples who have readjusted to a stable and active sex life in the aftermath of renewed health, consistent maintenance of protected sex may be difficult to achieve within committed relationships. Partners may perceive condoms as barriers to intimacy and as constant reminders of HIV infection, interfering with the spontaneity and pleasure of sexual expression. Many couples have said that using condoms is like “bringing death into the bedroom” because of all of the emotional associations attached to protected sex. This perspective may be heightened in couples in which renewed sexual energy may further propel the desire for unprotected sex, an act conceived of as life-affirming. Not using condoms, or engaging in risky sexual behavior may also be perceived as exciting and a “true” expression of love and commitment.

With the achievement of viral load levels below detection, couples may find themselves engaging in more risky behaviors. This may be due to the mistaken belief that equates “undetectable” viral load with an inability to transmit the virus or that suggests that science is close to a cure for HIV, making the prospect of being HIV-infected or reinfected less serious than it was in the past. One or both members of the couple may feel this way, but the partners may have avoided talking about their beliefs; the result is that they may be unclear with each other about how to behave sexually.

Treatment Decisions

The mixed status couple may find themselves dealing with an “emotional roller coaster ride,” feeling ecstatic and hopeful when the positive partner initiates treatment, only to feel disappointed and demoralized if treatment fails or becomes ineffective over time. When both members of the couple are seropositive and both initiate treatment, one but not the other may respond to the therapy, or, over time, one may thrive and the other may experience physical decline. Any of these scenarios may make any adjustment more difficult and may drive an emotional wedge between the partners.

Members of a couple, whether one or both are infected, often have different opinions about treatment strategies. One may want to rush to begin a “highly active antiretroviral” regimen, while the other may advocate for delaying therapy or using less potent combinations as an initial therapy. Even if both agree on a potent regimen, they may disagree on which particular medications to use. Each treatment has its unique eating and sleeping scheduling demands and side effect profile that may affect both members of the couple and their daily routine. Also, partners may find that they have different views about the future—some may anticipate ongoing health; others may be more pessimistic—and this disparity may become a significant source of conflict.

Helping Couples Adjust

Whether working with individuals from the dyad or with the couple itself, it is important for counselors to recognize the challenges presented by the scenarios described above in order to help members of the dyad take the perspective of “the other.” Working with couples about HIV treatment decisions or changes wrought by successful treatment is essentially the same as intervening under other circumstances. The therapist must gauge a couple’s ability to confront themselves and the issues, and must believe in the advantage of working with the couple as a unit rather than as individuals focusing on individual needs. By “normalizing” the emotional impact of HIV infection, of the new medical therapies, of all the shifts associated with the new treatments, and of uncertainty, such therapy may also address many of the other issues that arise intimate relationships.

While a couple’s dynamic—the ways in which the partners communicate, and express their needs and their emotions—is the focus of most couples therapy, the specific content of the sessions is also significant when working with HIV. The therapist may need to be the one who raises unexpressed issues, for example, concerns about HIV transmission, renewed health and associated doubts, changes in
outlook, the challenges associated with new treatment regimens and their impact on quality of life, the potential for treatment failure and illness, and feelings of uncertainty. Alternately, HIV cannot and should not be the sole focus of the therapy.

It is important for therapists to speak about sex frankly and directly, including questions about frequency of sex; sexual satisfaction (what feels good and what does not); knowledge and thoughts, both rational and irrational, about riskiness of specific behaviors; and possible changes in sexual activity associated with medical treatment. Typically, couples will resist a discussion of concerns about illness, caretaking, and the potential for treatment failure, because of each partner’s desire to protect the other from these thoughts. Talking about their fears can be reassuring and can increase feelings of intimacy and caring, particularly when each partner recognizes that both partners have had similar thoughts and fantasies, but have been hiding them from each other.

Conflict may arise about the degree of each partner’s involvement in the other’s health care, in particular, concerning decisions about care for the seropositive or less healthy partner. The couple may also need to address distress regarding uncertainty about treatment choices and future outlook.

The therapist should encourage partners to voice their personal goals and desires, as well as their expectations of each other and the ways in which these may be changing. It is also useful for partners to identify and discuss how they take care of each other. The therapist may need to emphasize the variety of ways in which caring may occur and the fact that caring goes both ways. This last point is important in ensuring that the healthier partner does not automatically get pigeon-holed as the caretaker in the relationship.

Finally, therapy needs to validate the emotional concerns of both partners and the legitimacy of the couple. By increasing each partner’s sense of their identity as a couple, therapy can strengthen the couple’s ability to respond to HIV and change. It is useful for therapists to facilitate discussion between the partners about who they are as a couple, what makes the couple special, and what are the couple’s strengths. It may also be necessary to facilitate frank discussions of potential reasons to end the relationship.

The therapist, through both verbalization and modeling, can help the partners recognize that there is room for both direct discussion of HIV-related fears and for living with some sense of “normalcy,” focusing on the other aspects of their lives and their relationship. The therapist may find that this concept—that HIV is just one of many identifying characteristics of a relationship—may need to be stated in a variety of ways and in many different contexts.

Conclusion

Couples, like individuals, are not static over time, and growth and development are necessary to maintain the integrity of such relationships. Development involves confronting new circumstances and stressors, such as HIV disease, and the shifting beliefs, expectations, and emotions associated with the changing face of HIV-related care. These challenges will either drive a wedge between two partners or, with time, strengthen their bond. It takes time and honest exploration—an open expression of emotional and practical needs—to meet this challenge and to assess the ultimate outcome for each couple. The therapist is in an ideal position to objectively witness a couple’s dynamic and offer the stability necessary to integrate change.

References


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References


Guilt can be unbearable, and getting rid of it becomes an immediate priority. Making it someone else’s fault—blaming—is an easy way of doing this. The recipient of blame, however, may be inclined to escalate the exchange by responding similarly, and this may result in the seemingly hopeless patterns that bring couples to therapy.

Control Mastery Theory is a particularly effective lens through which to view intimate relationships and couples counseling, and is especially useful in defining the role of HIV in primary relationships. This article reviews Control Mastery theory and focuses on its application to the “blame cycle” and the case of a serodiscordant couple.

**Control Mastery and Couples Counseling**

Control Mastery, a cognitive, interpersonal, psychoanalytic approach, classifies as either "growth-promoting" or "pathogenic" the conscious and unconscious beliefs a person infers from childhood experiences. When a parent displays disapproval, for example, when a father condemns the son who prefers quiet indoor play to rough-and-tumble outdoor activities, the child may unconsciously come to believe that he should feel ashamed. Moreover, the child may generalize these feelings and conclude that he is to blame for his parent’s unhappiness. In this way, pathogenic beliefs warn that certain thoughts and actions endanger the parent-child relationship and give rise to unpleasant affects such as guilt, fear, shame, anxiety, remorse, and helplessness.

Since Control Mastery theorists believe that clients have a conscious or unconscious plan to disconfirm their pathogenic beliefs and that these individuals will seek to do so whether inside or outside of therapy, the therapist’s primary task is to infer how to assist in the disconfirmations. Clients generally implement their plans through two forms of unconscious testing. In "transferring," the client behaves in a way similar to what he or she believes caused his or her parent to administer the trauma. In "passive into active," the client does to the partner, the therapist, or both, what the parent did to him or her to cause the trauma. In individual therapy, the therapist is the main focus of testing; in couples therapy, partners may test each other as well. Whenever the partner or therapist reacts to these tests by neither traumatizing the person testing nor being him or herself traumatized, the pathogenic belief loses some of its authority.

**Breaking the Blame Cycle**

The dynamics of blame often involve a shame/rage cycle, and ironically, in couples, this manifests as a form of mutual identification. As the result of an interaction with his or her partner, an individual may experience irrational and unconscious guilt, a retraumatization of a childhood experience. In that person’s effort to fend off the painful feelings associated with the guilt, he or she may ascribe blame to the partner. The partner may then unconsciously experience irrational guilt when blamed and seek to defend against it by “counter-blaming.” There are a variety of childhood foundations for irrational blame including: a parent unreasonably blames the child for the parent’s suffering; or, the child infers blame when he or she suffers parental neglect, fostering the irrational belief that he or she is deserving of neglect. If the parents’ relationship to one another was punctuated with blame, the client may have the irrational belief that to blame his or her partner is to be loyal to his or her parents—a form of survivor guilt.
The therapist assists in the disconfirmation of pathogenic beliefs in several ways: by passing tests; by interrupting the blame cycle promptly, modeling how the cycle can be broken; and by explaining to the couple—from the perspective of the clients’ histories or from clinical inference or from both—why it is understandable that each be particularly vulnerable to irrational blame and would behave defensively in response to blame. Offering specific suggestions for and coaching clients in breaking the cycle can also be useful. For example, the therapist might encourage one partner to say “Let’s not fight,” leading to non-guilt-inducing mutual identification: as one partner frees him or herself of blaming, the other unconsciously identifies with the first and also relinquishes blaming. Finally, the therapist should emphasize the strength that comes from apologizing, decreasing the irrational belief that mistakes make a person weak and deserving of blame.

The Case of Jack and Dan

Jack and Dan, two partners both in their thirties, can recount years of mutual blaming. Although he is seropositive, Jack’s health has improved dramatically. He protests that he is being smothered with attention by Dan who is seronegative. When Jack’s health was seriously impaired, Dan had taken pride in meeting his partner’s needs, and Jack was more able to accept care. Their conflict brings the partners into therapy with Ron Sampson, PhD.*

Early in therapy, Jack reveals that his father held him responsible for every mishap. Jack’s father was an alcoholic who was verbally and physically abusive towards Jack’s mother. In addition, when Jack was three, his infant brother died. Neither parent acknowledges Jack’s homosexuality. Dan’s parents also had an unhappy marriage. His father labeled Dan a sissy and was unloving except when Dan did him favors. His mother’s preoccupation with suffering left Dan feeling neglected.

Based on these histories and the couple’s interactions, Sampson attempts to predict the major traumas for each partner, the pathogenic beliefs that follow from these traumas, how each client is likely to “test,” and the insights that might be most helpful to the couple. In therapy, Jack and Dan test one another on issues of blame. Jack complains that Dan’s caretaking is neither necessary nor desired. Because of their childhood experiences, each partner fails these tests by counter-blaming. Dan counters that Jack is rejecting; Jack counters that Dan is too sensitive. Sampson helps Jack and Dan explore the pathogenic beliefs underlying their behaviors. In so doing, he avoids taking sides, interrupts the traumatizing experiences, and models empathy—all of which contribute to safety in the sessions.

Sampson suggests Jack is feeling unconsciously guilty because his health is improving while other people are still dying. This echoes his childhood experience and the unconscious belief that he had no right to his parents’ attention because his brother was dead and his mother was depressed. His survivor guilt led to his current self-denying behavior, even though his medical condition still requires Dan’s attention at times. This process reflects a transferring test to determine if it is reasonable for Jack to feel deserving of attention. Sampson also suggests that Jack is unconsciously being loyal to his father who was a “blamer,” thereby warding off guilt about Jack’s having a better relationship than his father.

Dan experiences Jack’s blaming as similar to his feelings when his mother blamed him for not paying enough attention to her. Sampson suggests that Dan’s counter-blaming reflects his compliance with the irrational belief that he is deserving of blame for not making Jack happy, and that his caregiving excess reflects his own survivor guilt for being HIV-negative. These explanations give the partners greater control over their behaviors, and both gain the optimism necessary to interrupt the blame cycle.

Conclusion

At a time when antiviral treatment success is causing radical change, therapists may be called upon to help couples re-establish their relationships and adjust to new circumstances. Attention to the unconscious, irrational beliefs underlying their behavior can ease these transitions.

References


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*None of the characters or names in this case study are related to actual people.
Choosing Partners of Different HIV Status

Although there are a variety of healthy reasons why people of different serostatus enter into relationships with each other, according to a review article, for many, these choices are influenced by codependency. Seronegative people who habitually put other people’s needs before their own may select seropositive partners and then put their time, energy, and savings into nurturing the seropositive partner.

Other theories explaining serodiscordant relationships are gay-specific. For example, one proposes that because many gay teenagers tend to be left out when their peers are developing heterosexual dating and relationship skills, their lack of practice in negotiating these relationships can impair their ability to make healthy relationship choices as adults. In addition, those who feel rejected or victimized by family and peers sometimes develop dysfunctional conceptions of healthy relationships and subconsciously choose partners who are more likely to abandon them, even through death.

Finally, because their sexual orientation is ridiculed and invalidated by society, gay men may believe on an unconscious level that they are “sick” and thus may be unconsciously drawn toward partners who are “sick.” Such a choice can reinforce the unconscious belief that gay relationships are shameful and meant to be hidden. Similarly, as victimized members of an oppressed group, uninfected gay men may subconsciously be drawn to seropositive partners in order to save them from the “victimization” of HIV.

Managing HIV in Committed Relationships

The ways in which HIV serodiscordant couples manage the HIV-related symptoms of seropositive partners depend on the interpersonal dynamic of their relationships, according to in-depth interviews with gay men in serodiscordant, committed relationships. In managing symptoms, couples sought to protect each other from losses and maintain the seropositive partner’s sense of independence.

Researchers interviewed nine couples in which at least one man was diagnosed with symptomatic HIV infection or AIDS. Five couples were identified as “mixed couples”—in which one partner was seronegative—and the remaining four were labeled “two-positive couples.” All of the participants lived with their partners. Their ages ranged from 25 years old to 47 years old and the ethnic composition of the group—80 percent were White—reflected the racial distribution of AIDS among gay men throughout the United States. To collect and analyze data, researchers applied “grounded theory,” a qualitative research approach that infers theories of human behavior based on the points of view of study participants.

Symptom management often involved a struggle on the part of the seropositive partner to maintain his independence. The couples, for the most part, strove toward egalitarian relationships, but they found it increasingly difficult to maintain equality as the seropositive partner became more symptomatic and the caregiving partner became more engaged in monitoring the seropositive partner’s activities and health. The caregiving partner frequently tried to convince the seropositive partner that the seropositive partner was acting more independently than he actually was. At the same time, the seropositive partner would complicate matters by “hiding” symptoms in order to spare the caregiving partner undue worry.

As the health of the seropositive partner deteriorated, he was faced with the prospect of accepting a degree of dependence on his partner. The caregiving partner, in turn, was compelled to take over symptom management in a more proactive manner. For example, one caretaker
took greater responsibility in ensuring that his partner was following proper drug regimens. Seropositive partners reported decreased self-esteem, and increased anger, humiliation, and depression as they lost a sense of independence and ceded responsibilities to caregiving partners.

These results suggest that understanding couple dynamics is essential to effective intervention. The study concluded that if significant others are involved in the caregiving of seropositive clients, clinicians should consult caregiving partners when forming strategies to address symptom management. In addition, researchers studying symptom management should consider the couple as a unit of analysis and focus on the issues of control, mutual protection, and interdependence.

**Group Support for Magnetic Gay Couples**


According to a small study of gay male couples, couples in primary relationships face a range of sexual risk factors similar to individuals, and they can be as profoundly affected as individuals by group interventions with other couples. Meeting with other couples to share coping strategies and model safe behaviors can lead to enhanced communication between partners, increased satisfaction within the relationship, and risk reduction.

As part of a larger study of 100 serodiscordant male couples, researchers conducted five focus groups (one in Spanish) and a follow-up telephone survey of the 15 couples. This smaller study included eight White couples, four Puerto-Rican couples, and three couples of mixed ethnicity (one Puerto Rican partner and one White partner). The mean age of participants was 37. The mean length of the couple relationship was 20 months (ranging from four months to 12 years), and 73 percent of the couples were living together.

As is true for individuals, there are many interrelated factors that determine sexual risk behaviors in serodiscordant relationships, including age and ethnicity, length of the relationship, previously established behaviors, communication patterns, and substance use. Intrapsychic factors include feelings of depression and hopelessness, personal preferences in sexual behavior, personal perceptions of risk, and motivation for change.

Participants expressed a desire to “protect” their partners by avoiding discussions of HIV-related concerns and HIV progression. They perceived condoms as a reminder of the seropositive status of one of the partners, and for these couples, the desire to suppress awareness resulted in a cycle of unsafe sex, remorse, wish to change, and denial of risk. In addition, as a relationship progresses over time and emotional intimacy deepens, the perception that one partner may be harmed by the other diminishes. Alternately, partners within serodiscordant couples, may share the terror of becoming infected or infecting the seronegative partner.

Although the focus groups were not intended as clinical interventions, participants derived positive results from them. Participants reported that the groups helped reduce their feelings of isolation, identify and share coping strategies, model safe and intimate behaviors, and develop group norms regarding risk. Some were able to express sentiments in the groups that they were unable to express directly to their partners, and the groups also provoked discussions about sexual behavior that, for many couples, had never taken place before.

**Next Month**

There is an epidemic of HIV among youth; every policy paper, newspaper, and study tells us this is true. But this statement is as relevant to effective HIV prevention as is the fact that women get pregnant is to the development of effective prenatal care. To meet clients where they are, we must be armed with more than just imprecise demographic data. In the May issue of *FOCUS*, Steven Tierney, EdD, Executive Director of the San Francisco organization Health Initiatives for Youth, exposes generalizations about the youth epidemic to more rigorous analysis, identifying the subpopulations affected by the epidemic and the distinct characteristics of the risks they take.

Also in the May issue, Teresa Betancourt, Youth Health Educator, and Jaime Diego Chavez, Youth Outreach Worker, both for Latinos en Extasis, a program of the Mission Neighborhood Health Center in San Francisco, describe an innovative peer-based health program for Latino youth.
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