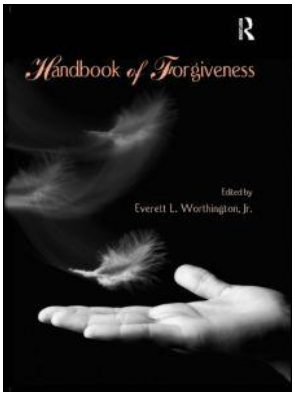

Handbook of Forgiveness

Everett L. Worthington, Jr.

Forgiveness and Health in Persons Living with HIV/AIDS

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Lydia R. Temoshok, Rebecca L. Wald
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Chapter Twenty

Forgiveness and Health in Persons Living With HIV/AIDS

Lydia R. Temoshok
Rebecca L. Wald

The HIV/AIDS epidemic constitutes an unprecedented phenomenon affecting not only health but all aspects of life for a person living with HIV/AIDS from marriage and intimate relations to child-bearing and parenthood, to work and social functioning, and to psychological and spiritual well-being. There is a large and growing literature on psychosocial and spiritual aspects of cancer, which is probably the disease most akin to HIV/AIDS in its inspiration of fear and its threat to life and well-being. It may be said that perceptions of HIV/AIDS are much like perceptions of cancer 50 years ago: a usually fatal, essentially incurable disease associated with stigma and a sense of hopelessness. Since 1996, advances in treatment options with combination therapies have improved the ability to treat a large proportion of HIV-infected individuals and significantly decrease mortality.

Unlike cancer, however, HIV is an infectious disease, transmissible by two of the most intrinsic human forces—sexuality and procreation. The intense fear and stigma surrounding transmission in these most intimate of human connections have cast the multidimensional concept of forgiveness in a central role for those living with HIV/AIDS and their loved ones. How does a person living with HIV or AIDS come to terms with—and forgive—the person who infected him or her and with God or other spiritual being who seemingly allowed this to happen? How does a person living with HIV or AIDS come to terms with the natural desires for sexual intimacy with one's partner and fears that HIV may be transmitted to a loved one by this most natural of acts? How does someone with HIV deal with the normal human goal to give life and to see life continue through one's children, and with the realistic fear that one's children may be born infected with HIV? How can a person living with HIV or AIDS forgive himself or herself if a partner or child is infected through his or her own actions, even if not intentional? Forgiving the self for becoming infected with HIV in the first place is especially difficult if infection occurred through the doubly socially stigmatized routes of sexual transmission in a same-sex relationship or transmission through injecting illicit drugs. To the extent that language and metaphor often reveal

deep mind-body connections, it may not be coincidental that one of the synonyms for forgiveness is *immunity* and that to be forgiven is *to be spared.*

OUR THEORETICAL APPROACH TO FORGIVENESS IN THE CONTEXT OF HIV/AIDS

Our understanding of the role of forgiveness in the lives of persons with HIV/AIDS is located within a biopsychosocial framework (Temoshok, 2004b). The existing body of theory and research on psychoneuroimmunology and HIV suggests that biological, psychological, and behavioral factors interact in a complex manner to affect clinical disease progression (Ader, Felten, & Cohen, 2000; Solomon, Kemeny, & Temoshok, 1991; Solomon & Temoshok, 1987). The main theoretical position of the first author is that more adaptive coping with stress—particularly the appropriate recognition and expression of emotion—is a key factor contributing to immunological processes that affect cancer and HIV outcomes (e.g., Temoshok, 1987, 1990a, 2000a, 2000b, 2002, 2004a; Temoshok & Dreher, 1992).

We hypothesize that the emotional and psychosocial consequences of forgiving and feeling forgiven or the converse—unforgiving/feeling unforgiven—have psychosocial/behavioral and psychoneuroimmunological/biomedical consequences for those infected with HIV, as well as other people they touch in their lives. The mechanisms by which psychosocial and spiritual factors could influence immunological function and disease outcome for a specific disease entity such as HIV remain to be defined. In Figure 20.1, we depict the hypothesized consequences of forgiving and feeling forgiven along two interacting cascades of processes: psychoneuroimmunological and psychosocial/behavioral (cf. Temoshok, 1995).

The hypothesized emotional, behavioral, and biomedical consequences of not forgiving/feeling unforgiven are presented in Table 20.1, which depicts four increasingly wider contexts for considering forgiveness and unforgiveness as multidimensional concepts within the specific situation of individuals infected with HIV/AIDS. Within each context, forgiveness or unforgiveness can be considered as a state or action emanating from the self or from others in relation to the self (i.e., forgiving vs. not forgiving and feeling forgiven vs. unforgiven). For the sake of simplicity, we have presented the contexts and hypothesized consequences for the negative end of the forgiveness/unforgiveness dimension.

Forgiving oneself is hypothesized to be associated with higher self-esteem and self-respect, states associated with more positive health outcomes, in contradistinction to states of guilt, self-hatred, and self-blame (Glaser, Rabin, Chesney, Cohen, & Natelson, 1999; Moulton, Sweet, & Temoshok, 1987). Low self-esteem has been associated with maladaptive ways of dealing with stress, such as substance abuse, which is a contributor to HIV infection and other sexually transmitted diseases, as well as to disease progression because a person using drugs, particularly injecting drugs, is more susceptible to bacterial infections and more likely to have poorer hygiene and nutrition.

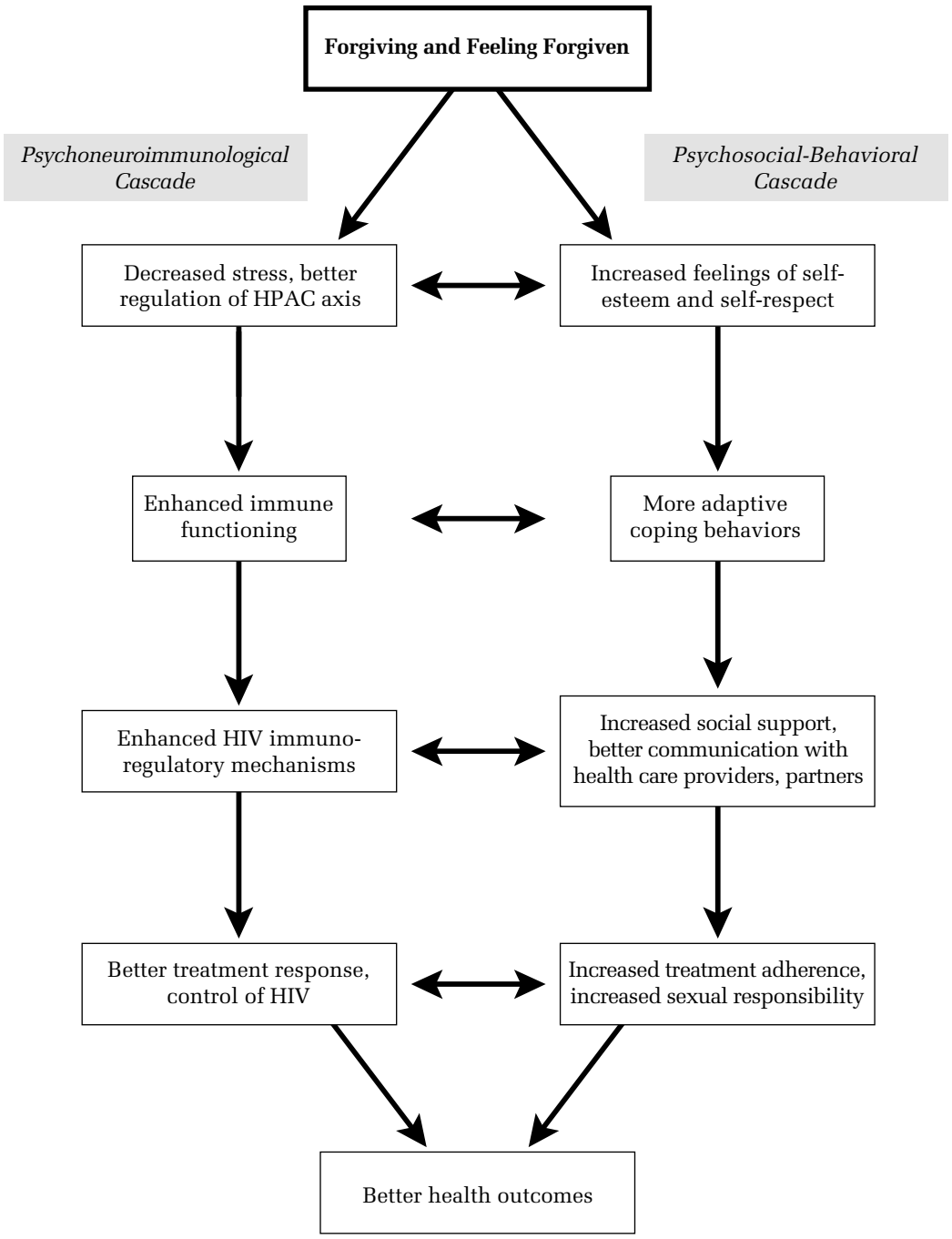

FIGURE 20.1. Hypothesized Consequences of Forgiving and Feeling Forgiven

TABLE 20.1. Contexts of Forgiveness for HIV/AIDS

Contexts of feeling unforgiven/unforgiving	Emotional and psychosocial consequences	Behavioral consequences	Biomedical consequences
Intrapersonal	Low self-esteem, guilt, helplessness, self-blame, depression	Self-destructive behaviors (e.g., drug and alcohol abuse)	Increased stress, immune dysfunction, disease progression
Interpersonal	Anger, resentment, lack of empathy, feeling unloved	Irresponsible sexual behaviors, transmission risk behaviors	Coinfection with other viruses (STDs); HIV "superinfection"; HIV transmission
Health care system and medical providers	Mistrust	Poor patient–provider communication; poor adherence to medical regimens/recommendations	Treatment failure; disease progression
Spiritual	Hopelessness, alienation, despair	Suicidal thoughts/behaviors, homicidal thoughts/actions, isolation, withdrawal	Multisystem breakdown (mental, biological, and social)

Note: Adapted from Temoshok & Chandra, 2000.

In the interpersonal context, a person who is able to forgive others and let go of unproductive feelings of anger, bitterness, resentment, or disappointment will probably be able to seek and receive social support more easily and effectively from others. Social support has been shown to be a key factor in maintaining good health in general and is particularly relevant for people living with HIV/AIDS, who often feel shunned or rejected by friends, family members, or society at large (Solomon et al., 1991; Zich & Temoshok, 1987).

The trusting and open, mutually forgiving communications that help maintain social relations with friends and family also apply to relations with medical providers. Hope, as a critical ingredient in biopsychosocial processes that result in recovery and healing, is a fragile product of verbal and nonverbal provider-patient communications and can easily turn into hopelessness and despair (e.g., Temoshok, 1996). Mistrust of medical systems and of information about HIV/AIDS promulgated by government agencies is unfortunately prevalent in disadvantaged and alienated groups (Temoshok & Chandra, 2000). This is especially true in some African-American communities whose leaders may remind them of the infamous Tuskegee medical study that observed the course of untreated syphilis in poor, largely African-American research "volunteers" (Temoshok, 1997). We hypothesize that mistrust of medical systems and bitter, unforgiving attitudes toward mainstream medicine for not finding a cure or effective HIV/AIDS treatment will lead to missed appointments and poorer adherence to the HIV medications that must be taken with over 95% accuracy to prevent the development of the drug-resistant virus (e.g., Bartlett & Gallant, 2003). Thus, not forgiving one's medical

providers and larger medical systems or feeling unforgiven for having contracted a stigmatized disease can exacerbate a cycle of mistrust, poor patient-provider communication, and withdrawal that can result in treatment failure and disease progression.

In the biomedical realm, being able to "forgive and forget," to let go of angry thoughts and feelings, may have physiological concomitants in being able to return inappropriately hyperaroused physiological systems back to more normal levels of homeostasis (Besedovsky, Herberman, Temoshok, & Sendo, 1996; Temoshok, 1990b, 1991, 2000a, 2002). Forgiveness is hypothesized to be associated with physiological relaxation and autonomic homeostasis, following the paradigm established in a study of physiological patterns associated with long-term survival in men with AIDS (O'Leary et al., 1989; Solomon, Temoshok, O'Leary, & Zich, 1987).

We postulate that being unforgiving or feeling unforgiven keep mental and physiological processes operating in a spiraling feedback loop of hyperarousal in the hypothalamic-pituitary-adrenal-cortical axis. Well-functioning nervous and immune systems are able to respond appropriately to stimuli or antigens—neither over- nor underreacting—and to return to a "resting level" that helps maintain an organism's basic integrity and growth (Temoshok, 2000a, 2002). Additionally, it is hypothesized that a "masked" forgiveness response that covers one's true feelings of unforgiveness will not resolve forgiveness events or dilemmas and will result in autonomic arousal and inappropriate immune activation (Temoshok, 2003a).

This cascade of biopsychosocial events is analogous to the processes theorized to underlie the negative health effects of the Type C pattern, which has been shown to be associated with worse health outcomes in malignant melanoma as well as HIV (Temoshok, 2003b, 2004c; Temoshok & Dreher, 1992). Type C proclivities include not recognizing that anything is wrong internally or externally (and letting stressful or problematic situations continue unaddressed and resolved), presenting a pleasant façade to the world and not expressing needs or feelings—particularly anger.

REVIEW OF THE RELEVANT THEORETICAL AND EMPIRICAL RESEARCH

In studies across a number of diseases, evidence is accumulating to suggest that psychosocial dimensions of quality of life, particularly hope (or its converse, hopelessness), perceived social support (or its converse, isolation and social inhibition), and fighting spirit (or its converse, resignation), can have striking effects on disease susceptibility as well as on recovery and survival time for persons with cancer, AIDS, and heart disease (Denollet et al., 1996; Greer, Morris, Pettingale, & Haybittle, 1990; Miller & Cole, 1998; Temoshok, 1985, 1993). Depression, life stress, and distress have been shown to be associated with poorer health outcomes in HIV (e.g., Balbin, Ironson, & Solomon, 1999; Evans et al., 1997; Ironson et al., 1994; Kemeny & Dean, 1995; Leserman et al., 2000; Lyketsos et al., 1993; Patterson et al., 1995; Vassend, Eskild, & Halvorsen, 1997). The inappropriate and maladaptive nonexpression, suppression, or

repression of emotions as the theorized pathogenic core of the Type C coping style (Temoshok, 2003b, 2004c) has been related to exacerbation of HIV and other immunologically mediated diseases (e.g., Cole, Kemeny, Taylor, Visscher, & Fahey, 1996; Mulder, 1994; Mulder, Antoni, Duivenvoorden, Kauffmann, & Goodkin, 1995; Nyklicek, Temoshok, & Vingerhoets, 2004; Solano et al., 1993; Solano et al., 2002; Solomon & Temoshok, 1987; Temoshok, 1985, 1991, 2003).

The effects of spirituality and of forgiveness more specifically on health outcomes have not been well studied, but an important recent study in Australia showed that self-reported or perceived religiousness was an independent and statistically significant protective factor for colorectal cancer in a population-based study of 715 colorectal cancer patients and matched community controls (Kune, Kune, & Watson, 1993). Concealment of homosexual identity may be related to multiple contexts of forgiveness, including concerns about social rejection (interpersonal unforgiveness), condemnation from religious communities (spiritual unforgiveness), and internalized feelings of guilt or shame (intrapersonal unforgiveness). HIV-positive men who conceal their homosexual identity have been found to have quicker disease progression, lower CD4+ counts (which indicate more HIV-related damage to the immune system), more symptoms of depression, and less social support (Ullrich, Lutgendorf, & Stapleton, 2003).

Nondisclosure of HIV status is directly related to fears of judgment and rejection by important social others; in other words, the fear that one's HIV status or circumstances of infection will be viewed as unforgivable in an interpersonal context. Persons with HIV who feel unable to disclose their status to important others have been found to have increased rates of depression (Armistead, Morse, Forehand, Morse, & Clark, 1999) and a poorer quality of life (Chandra, Deepthivarma, Jairam, & Thomas, 2003). HIV-related stigma may be experienced from important social others or may be internalized as shame, or intrapersonal unforgiveness. Internalized stigma has been associated with a greater use of avoidant coping and a decreased use of active coping, both of which in turn are strongly related to depression (Demarco, 1999), and has also been linked directly to depression, hopelessness, and anxiety (Lee, Kochman, & Sikkema, 2003). Lee et al. (2003) found that a high level of internalized HIV stigma is associated with a sense of HIV-related rejection (or unforgiveness) from important others. Perceived stigma from others is associated with chronic depression among HIV-positive persons (Lichtenstein, Laska, & Clair, 2002) and poorer utilization of health care (Chesney & Smith, 1999; Lee et al., 2003; Reece, 2003). Chesney and Smith (1999) reported that perceptions of HIV-related stigma may result in underutilization of HIV testing services by high-risk populations and delayed treatment in infected individuals, with both factors contributing to the spread of the epidemic. Thus, stigma (interpersonal unforgiveness) may have a profound negative impact on public health, in addition to having a negative psychological and physical impact on the stigmatized individual.

There is growing evidence that preventing further spread of HIV in families, partners, and communities is highly correlated with psychological and spiritual dimensions of quality of life (Temoshok & the WHOQOL Group, 1997). For example, anxiety

and depression can exacerbate problems of addiction and substance use, which, in turn, increase the risk of HIV transmission (e.g., Nannis, Philipson, & Temoshok, 1993). Fostering a sense of altruism and taking responsibility for protecting loved ones from infection have been discussed as ways to decrease HIV transmission to others and decelerate the rate of epidemic spread (Bayer, 1996; Temoshok & Patterson, 1996).

We conducted a partial test of our theoretical model of forgiveness and health among a sample of 131 adult patients in an inner-city HIV clinic in Baltimore, Maryland. Participants who rated themselves as more similar to forgiving vignettes and less similar to unforgiving vignettes (methods are described in more detail in the next section) reported fewer depressive symptoms as well as fewer current life stressors, and the stressors they reported were rated as being of lower severity (Wald & Temoshok, 2004a). On the World Health Organization's (WHO) Quality of Life (QOL) measure (WHOQOL), both global QOL and health QOL were significantly correlated with global vignette forgiveness scores. Thus, forgiveness was broadly associated with more positive psychological functioning and greater life satisfaction. These results remained significant after controlling for religious involvement, a factor that has also been associated in many health-related studies with lower rates of depression and higher quality of life.

Forgiveness was also found to be significantly related to critical health behaviors. Of the 91 patients who were prescribed antiretroviral medications, feeling unforgiven by important others was associated with significantly more missed doses of medication in the previous week. Because near-perfect adherence is required for successful treatment of HIV, these participants were at a substantially increased risk of treatment failure and hastened disease progression. Better patient-provider communication was the most significant factor predicting better adherence (Wald & Temoshok, 2004b).

In this same study, participants who identified more strongly with those vignette characters who were more forgiving of the people who infected them were significantly less likely to have unprotected sex, indicating that participants who were able to forgive those who infected them were more likely to take steps to protect others from infection (Wald & Temoshok, 2004a). Thus, forgiveness was found in this study to have positive health consequences for both the individual and society at large.

NEW RESEARCH DIRECTIONS AND PERSONAL THEORETICAL PERSPECTIVES

To our knowledge, most measures of forgiveness in the psychological literature have concentrated on the interpersonal context, with only a handful focused on self-forgiveness (see chapter 10 by Tangney, Boone, & Dearing and chapter 11 by Mullet, Neto, and Rivière). We believe that assessing forgiveness in the spiritual, community, or health care contexts, as we have outlined theoretically in Table 20.1 and implemented empirically in our research on HIV/AIDS (Temoshok & Chandra, 2000; Wald & Temoshok,

2004a, 2004b), widens the scope of considering forgiveness and potentially increases the opportunity to reveal relationships with a number of different constructs.

Such a comprehensive approach, however, entails the danger of respondent burden by having multiple measures, as well as the validity of self-report assessment of value-laden constructs. The first author was similarly challenged in the mid-1980s to come up with a more valid method than self-report to assess the Type C coping style (Temoshok & Dreher, 1992), which is highly correlated with social desirability (Kneier & Temoshok, 1984; Temoshok et al., 1985). This was a conundrum because respondents can hardly be expected to report accurately on emotions and thoughts of which they are not conscious or those they are inclined to report positively.

To address this Type C assessment problem, the first author devised the Vignette Similarity Rating method, in which respondents are asked to rate (on scales of 1–5 or 1–10) how similar or dissimilar they are to the person in each vignette, who is described as thinking, feeling, and behaving in ways that depict someone who is avoiding or repressing awareness of problematic emotions or thoughts and focusing instead on what other people may be feeling or needing and how to please these others. Because the vignettes are about other people, being asked to rate similarity to their emotions and behaviors (rather than rating directly one's own emotions and behaviors) appears to circumvent or minimize defensiveness about reporting socially less desirable states and behaviors. Vignettes may be tailored to use language and other details specific to a given culture or population. This vignette method has been shown to be more successful than self-report measures at capturing the complex emotional, cognitive, interpersonal, and behavioral coping proclivities inherent in the Type C construct, is much more accepted and liked by study participants (good face validity), and yields significant predictors (indicating high predictive validity) of health outcomes, such as HIV progression (Solano et al., 1993, Solano et al., 2002; Temoshok, 2003b, 2004c).

For our research on forgiveness in people living with HIV/AIDS, the authors have constructed and validated a series of forgiveness vignettes, using the Vignette Similarity Rating method described above (Wald & Temoshok, 2004a, 2004b). Our instrument presents respondents with 12 scenarios depicting forgiveness and unforgiveness for the different contexts depicted in Table 20.1 (intrapersonal, interpersonal, health care system, and spiritual). It asks them to rate their degree of similarity to each vignette's main character. Vignettes were written in terms of forgiving, unforgiving, feeling forgiven, and feeling unforgiven for each of these contexts. Thus, we have made no theoretical assumptions about bipolarity (i.e., a hypothetical forgiving-unforgiving dimension or a feeling forgiven-feeling unforgiven dimension), allowing for real-life complexity.

We have found excellent respondent acceptance of the vignettes and generally very quick identification or nonidentification with the character in the vignette ("I'm just like that person!" or "That is no way like me!"), as well as more nuanced responses ("I'm like her in some ways but not others; but it's closer to being like her, so I'll rate this "8"). All respondents preferred the vignette method over self-report questionnaires (e.g., of religiousness or forgiveness). From our data analyses, it was apparent

that social desirability was still somewhat a problem, in that individuals who were more Type C also tended to report they were more forgiving and felt more forgiven—a hallmark of the Type C style. Our data suggest, however, that this is less of a problem for the vignette method than for the more transparent self-report measures.

Our future research on assessment in this arena will focus on fine-tuning less socially desirable traits and actions of unforgiving characters in vignettes to make it easier for strong Type C copers to recognize and report that they are like these characters. We will also work on validating vignettes to capture "masked forgiveness" (in which the person is more or less conscious about presenting a façade of not truly or genuinely felt forgiveness), as well as "premature forgiveness" (in which the person does not work through the stages and processes of forgiveness but jumps to an unsteady state of incomplete but reported forgiveness).

RELEVANCE FOR CLINICAL AND APPLIED INTERVENTIONS

Clinical Case Example 1

Mr. A was a 38-year-old African American with advanced AIDS, which he had contracted through homosexual behavior. Since early childhood, he was verbally abused and rejected by his father and older brothers over what they perceived to be his effeminacy. He came to regard his homosexuality as a profound moral flaw that had marked him for a lifetime of punishment, in which familial rejection and infection with HIV both played a part. A deeply religious Christian, Mr. A sought comfort from religion but did not feel that it was possible for God to forgive him. He was ambivalent about survival, neglecting to take his HIV medicines and sometimes expressing the belief that it would be better for him to die. With extensive psychotherapy focused on changing Mr. A's perception of himself as unforgiven and unforgivable, Mr. A began to see himself as worthy of life. Although multidrug resistance caused by his years of nonadherence meant that his HIV could not be brought under control, he became diligent about self-care and was adherent to all aspects of his medical regimen. He lived almost a year longer than his doctors predicted, and at the time of his death he felt accepted by himself and by God.

Clinical Case Example 2

Ms. S was a 50-year-old African American who had been infected with HIV by her unfaithful husband. Although Ms. S's physical health remained stable over the 10 years following her infection, lingering anger and resentment directed at her husband, now deceased, caused her substantial psychological distress. She spent much of her time ruminating over the circumstances of how she was betrayed and the unfairness of her situation. Gradually, her resentment toward her husband developed into a more generally

hostile attitude toward other people. She had difficulty making emotional connections to other persons with HIV, feeling that her situation differed from theirs because she "didn't do anything wrong" to become infected, and adopted a combative and suspicious attitude toward service providers. She felt that her suffering entitled her to services and benefits, and she became angrily defensive if her need for services was questioned or if she discovered that someone else was given benefits she did not receive. In moments of insight, Ms. S acknowledged that her lingering grudge against her deceased husband impaired her present chances for happiness; however, she was unwilling to consider the possibility of forgiving someone who had wronged her so greatly.

The stories of Mr. A and Ms. S reflect some facets of the powerful role that forgiveness and unforgiveness play in the lives of persons with HIV and AIDS. Individuals often struggle with questions of guilt and self-forgiveness as they come to terms with the role that their own choices and risk behaviors (e.g., intravenous drug use) have played in their illness. They wrestle with concerns about God's forgiveness and with feelings of anger and unforgiveness toward God. Often, as their disease progresses, they find themselves unable to free themselves from lingering feelings of anger and resentment toward the person who infected them, family members who are rejecting or unsupportive, or medical personnel who are unable to cure them. Thus, among persons with HIV/AIDS, forgiveness represents an important concept across multiple intra- and interpersonal contexts, and an individual may simultaneously experience the roles of victim and transgressor in different social relationships. These factors add considerable complexity to the task of conducting forgiveness-related research and clinical interventions with this population.

CONCLUSIONS

In patients with most organic medical disorders, functional health status is strongly influenced by coping skills and social support, yet it has been argued that the mental, emotional, and behavioral dimensions of illness are typically neglected by predominant medical approaches (Sobel, 1995). By helping patients manage not just their disease but also common underlying needs for spiritual meaning, including forgiveness, quality of life as well as health outcomes for the self and loved ones can be markedly improved and at significantly lower costs than when medical interventions alone are used. To the extent that quality of life (well-being across multiple dimensions) and quantity of life (surviving longer) are not only highly correlated but mutually enhancing, it would be important to develop interventions aimed at enhancing quality of life, including the significant dimensions of forgiving and feeling forgiven, and to evaluate the extent to which both quality and quantity of life improve.

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