ABSTRACT

This prospective study of a cohort of human immunodeficiency virus positive (HIV+) and HIV negative (HIV−) caregiving partners of men with AIDS examined the contextual effects of caregiving and bereavement on coping and the association between coping and positive and negative mood during the five months leading up to their partner's death and the five months following their partner's death. Participants used more problem-focused types of coping and more cognitive escape avoidance during caregiving than during bereavement. Six of the eight types of coping that were assessed were associated with negative mood, controlling for prior negative mood. These associations differed as a function of context (caregiving versus bereavement). Five types of coping were associated with positive mood, controlling for prior positive mood. HIV serostatus did not affect the relation between coping and mood.


INTRODUCTION

Acquired immune deficiency syndrome (AIDS) is currently the leading cause of death among young adults aged 25 to 44 (1). The cumulative total of AIDS cases in the United States since the start of the epidemic has exceeded 500,000 (2), and estimates of the number of people in the United States infected with human immunodeficiency virus (HIV), the virus that causes AIDS, range from 1 million to 1.5 million (3). As the AIDS epidemic has progressed, there has been a concurrent rise in the number of people caring for a loved one with AIDS. Estimates from a national survey indicate that 3.2% of the general U.S. population and 5.2% in a central cities sample have cared for a friend, relative, or lover with AIDS (4). For homosexual and bisexual men, the proportion who has been caregivers is much greater (12,13). Further, because AIDS has had such a disproportionally high impact on the gay community, many caregivers have had close friends and acquaintances die from AIDS (14). In addition to essentially unremitting grief, this repeated bereavement may result in the depletion of social networks and the loss of valuable emotional resources that could have buffered the effects of the death of the partner.

AIDS. These men experience two of the most profoundly stressful life circumstances humans encounter: providing care to a partner who is in the final stages of a horrific terminal disease, and then enduring the loss of that partner. Although providing care to an ill partner or spouse is always stressful, caregiving for a person with AIDS can be especially trying (5). The symptoms associated with AIDS are often especially brutal and uncontrollable. The course of the disease is unpredictable, with bouts of infection and severe illness followed by periods of seemingly good health. The tasks involved with AIDS caregiving are often emotionally as well as physically exhausting, especially if the caregiver has not had previous experience in caring for a seriously ill person. Persons with advanced AIDS may experience severe diarrhea, wasting, pain, neuropathies, and cognitive impairment that require the caregiver to perform medical tasks for which he has little formal training. This lack of training can lead a caregiver to question his ability to care for his partner and result in even higher levels of stress. Another characteristic of caregiving for a partner with AIDS that makes it uniquely stressful is the stigma associated with AIDS and the widespread prevalence of homophobia (6). Fear of discrimination may lead caregivers to refrain from revealing their caregiving activities to relatives or coworkers. Therefore, they may miss out on potentially valuable sources of social support and may experience additional stress in the effort to keep their caregiving a secret. Finally, many caregivers are themselves infected with HIV. Their partner's disease progression is a vivid reminder of what may be ahead for them (4,7).

The death of a spouse or partner can take a devastating toll on the surviving partner. Studies of bereaved spouses have shown that severe depression, decreased immune function, and even mortality are not unknown in the time immediately following the spouse's death (8-10). In the context of AIDS, the bereaved partner is often young, and the bereavement is therefore "off time" (11) compared to the norm in which bereaved spouses are in their 60s or 70s. People who become bereaved at a younger age tend to have more intense grief reactions and poorer adjustment than those who are bereaved when they are elderly (12,13). Further, because AIDS has had such a disproportionately high impact on the gay community, many caregivers have had many close friends and acquaintances die from AIDS (14). In addition to essentially unremitting grief, this repeated bereavement may result in the depletion of social networks and the loss of valuable emotional resources that could have buffered the effects of the death of the partner.

Coping as Mediator of the Impact of Stressful Situations

Clearly, then, caring for a loved one with AIDS and the eventual death of that loved one are two of the most profoundly stressful life events that people experience. The way in which an individual copes in a given stressful situation has been iden-
tified as one of the determinants of adjustment to a stressful experience (e.g., 15, 16). Coping can be conceptualized in various ways but, in general, there are two types of coping: problem-focused and emotion-focused (15, 17). Problem-focused coping responses address the problem directly, whereas emotion-focused responses address the emotional concomitants of the problem.

There are a myriad of studies concerning the effect of coping on emotional well-being in various stressful situations such as exams (18,19), surgery (20,21), and adjustment to college (22). Characteristics of the stressful situation such as perceived controllability, importance, stressfulness, and amount of situational self-efficacy have been found to influence the coping responses that are used (17–19, 22, 23), as well as the effect of those responses on various outcomes (24–27). In general, problem-focused responses and positive reappraisal tend to be related to positive outcomes and emotion-focused responses such as distancing, escape-avoidance, and self-blame tend to be related to negative outcomes.

**Coping with Caregiving:** The majority of studies of the role of coping in adjustment to caregiving look at elderly caregivers of family members suffering from Alzheimer’s disease or other forms of dementia. Most of the studies have looked at the relationship between coping and negative outcomes such as anxiety or depressive mood, although a few have examined the effect of coping on positive outcomes such as life satisfaction or positive mood.

In general, the studies of coping in caregiving situations have found that emotion-focused coping responses such as emotional discharge (28), wishful thinking (29–31), and escape-avoidance (32) are positively associated with depressive mood and anxiety. Problem-focused types of coping such as logical analysis, information-seeking, problem-solving (26), and instrumental coping (30) are typically found to be negatively related to depression and anxiety and positively associated with life satisfaction and positive mood (26, 30). In addition, positive reappraisal, which is usually categorized as an emotion-focused response (18, 33) but is positively correlated with problem-focused responses (e.g., 24, 34), has been found to be related to positive mood in caregiving situations (32).

The relationship between coping and mood in the context of caregiving may be more complex than it would appear based on the findings reviewed above, however. Williamson and Schulz (35) found that the effect of coping on depressive mood depended on which aspect of the caregiving situation was the focus of the coping efforts. For example, in coping with memory deficits, relaxation was negatively related to depressive mood, but wishfulness was positively related to depressive mood. In addition, contrary to the results of other studies of coping with caregiving which found that problem-focused responses were beneficial, Williamson and Schulz found that direct action was associated with increased depressive mood when coping with memory deficits and unrelated to depressive mood when coping with loss of communication or decline of a loved one. These apparent contradictions may be a function of the degree to which the specific stressor is controllable by the caregiver. For example, using problem-focused coping to deal with memory deficits, something that is largely out of the caregiver’s control, may result in frustration and increased depressive mood.

**Coping with Bereavement:** Although a significant amount of bereavement research has focused on adjustment to the death of a spouse, few studies have looked specifically at the role of coping. The results of the studies that have been done, however, tend to be consistent with the findings of studies of coping with other types of stressful situations: problem-focused responses are related to positive outcomes, and emotion-focused responses are related to negative outcomes. For example, Gass and Chang (36) examined the effect of problem-focused and emotion-focused coping on psychosocial health dysfunction (a measure of adaptation to conjugal bereavement) in elderly widows and widowers. Problem-focused coping was negatively related to dysfunction, and emotion-focused coping was positively related to dysfunction. Jacobs et al. (37) looked at seven types of coping in elderly people whose spouse had recently died or had a serious illness. They found that participants who reported less problem-focused planning shortly after their spouse’s death or illness were more likely to experience depression 13 months later. Mattlin, Wethington, and Kessler (27) found that respondents who reported the use of situational reappraisal and religion in response to a death in the past year were less likely to experience symptoms of depression and anxiety. Their results indicated that problem-focused responses such as active cognitive and active behavioral coping were not significantly related to depression or anxiety when dealing with the death of a loved one.

Thus, the role of various types of coping in adjustment to the death of a partner is not clear. In some studies, it appears that problem-focused responses are beneficial; in others, emotion-focused types of coping appear to be beneficial. In addition, the extent to which these results will apply to bereaved caregivers in the context of AIDS is not known. The nature of the illness may call for qualitatively different types of coping, and therefore, coping may play a different role in the adaptation of the bereaved caregiver than in other bereavement situations.

**Purpose of the Present Study**

Despite the amount of research that has examined the situational influences on coping and the effects of coping on outcomes, many questions remain unanswered with respect to coping under conditions in which the stress is profound and enduring, such as in the contexts of AIDS-related caregiving and bereavement. In the present study we examine two general questions. First, what is the effect of the stressful context on coping? Specifically, does coping change significantly over the course of caregiving and bereavement or is it relatively stable? Second, to what extent is coping related to mood and does the extent of the association differ as a function of context? It may be that under extremely stressful conditions, the context overwhelms any potential effect of coping. If there is an association between coping and mood, it may vary as the stressful context changes, either from caregiving to bereavement or even within caregiving and bereavement.

We addressed our hypotheses in a prospective study of a cohort of gay men who were their partner’s primary caregiver. These men were followed over a ten-month period that included the five months leading up to their partner’s death and the five months following their partner’s death. Participants reported coping and mood bimonthly throughout this period. These frequent reports allowed us to examine situational influences on coping and its relationship to mood in two ways: first, we could examine intradividual changes in coping during caregiving and during bereavement; second, we could determine whether the relationship between coping and mood differed during caregiving and bereavement. In addition, we were able to examine