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Background

Traditionally, responsibility for providing care in the home for people with serious illness has fallen to women as wives, mothers, or daughters of the afflicted individual. Among the many societal repercussions of the HIV/AIDS epidemic has been the creation of a new group of caregivers—gay men who are the primary caregivers for their partners with AIDS. In the

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1980s and early 1990s, before the advent of protease inhibitors and the new antiretroviral treatments, AIDS was a pernicious, essentially uncontrollable terminal illness that manifested horrendous opportunistic infections. Caregiving during this period was challenging at every level: emotional, psychological, physical, and even spiritual. The tasks were daunting, highly stressful, and unremitting. The only predictable aspect of the disease was that it would claim its victim sooner rather than later.

How could these caregivers, many of whom were themselves infected with HIV, maintain their own sanity, and for those who were HIV+, sustain their own physical health, while facing the extraordinary challenges of AIDS caregiving? These were the questions that led us to design a study about this new group of caregivers. We felt that there was a great deal these men could teach us about coping with profound psychological stress that would help other AIDS caregivers as well as anyone who was faced with the profound stress of caring for someone with a serious illness.

Significance of the Research

This was the first major study of men as caregivers, and of gay men in particular. The study showed that nearly all these men remained committed to their partners and to taking care of them until the end. As caregivers, these men performed a wide range of caregiving tasks, many of which required high degree of clinical skill. Three findings surprised us:

- Caregiving and bereavement did not adversely affect the health of caregivers who were HIV+ any more than it did the men who were HIV-.
- Even though men experienced high levels of depressed mood throughout caregiving and bereavement, they did not become clinically depressed more often than people in the general population.
- Caregivers also experienced positive mood, even under these dire circumstances.

The men used a wide range of coping strategies to regulate distress and support positive well-being. Spirituality was important to a majority of the men in the study, especially at the time of the partner's death. Most of the men picked up the pieces of their lives after their partners died, and several years later were able to reflect on what they had learned and on strengths they had developed. Overall, the response of gay men to caregiving and bereavement was comparable to the response of heterosexuals who have been through similar experiences.

The findings of this research have led to new ideas about how people cope with chronic stress and have led to new theoretical conceptualizations of the stress and coping process. The findings are also being applied to helping people cope in other populations affected by HIV as well as populations coping with other kinds of chronic illness including cancer and multiple sclerosis.

Key Results

AIDS Caregiving

During the time of this study, AIDS was one of the most difficult diseases to manage: its symptoms were difficult to manage, and it produced serious debilitating and often disfiguring effects. In order to remain at home, many people with AIDS needed someone at home to help provide care. Caregivers provided support that ranged far beyond the assistance with daily activities that we normally associate with caregiving to include:

- Emotional support such as comforting, consoling, reassuring, soothing, cheering up, or just being there;
- Hands-on care such as pain relief, symptom management, assistance coping with vomiting and diarrhea, giving massages, adjusting beds, and helping the partner move;

- Clinical care which included ability to recognize symptoms, deal with disease manifestations, and adjusting medications;
- High tech nursing which included managing IVs, central lines, parenteral nutrition, and administering injections;
- Health care advocacy which involved dealing with the formal health care system and insurance issues.

Most caregivers acquired these skills on-the-job. As the ill partner's disease progressed, caregivers often took on responsibility for financial management, maintaining contact with the partner's family, and helping to resolve strained relationships with family members.

These caregiving demands created a burden in the sense that caregivers

had to give up other goals and activities such as full-time work, school, or social commitments in order to carry out their caregiving responsibilities. Caregivers whose partners had more care needs, who had poorer relationships with their partners, and who had other stressors in their lives were more bothered by having to give up other goals and activities. HIV+ caregivers reported being more bothered by caregiving than their HIV- counterparts.

The quality of the caregiver's relationship with his partner was especially important in easing the

sense of burden. Narratives about caregiving events showed how the caregivers' emotional connection to their partners motivated them to help in any way they could, contributed to the caregivers' capacity for sustaining caregiving, and helped them become effective caregivers.

Coping: what works and what doesn't?

One of the goals of the study was to determine which types of coping were useful at which points throughout the caregiving and bereavement process. The stresses associated with caregiving and bereavement elicited a wide range of coping responses—from problem-focused responses, in which the stressful event causing the distress was addressed head-on, to avoidant types of responses in which the participant concentrated on relieving the distressing emotions associated with the stressful event.

Problem-focused coping, which includes gathering information and resources, planning, making decisions, and taking action to solve or manage the source of the stress was especially helpful during periods of intense distress, such as the weeks just before the partner died. It often took the form of the proverbial "to-do" list, which helped provide a sense of mastery and control at a time when conditions were essentially uncontrollable.

Positive reappraisal, the act of finding something positive in the stressful experience, was associated with increased positive mood and decreased negative mood throughout caregiving and bereavement. Some examples of positive reappraisal are, "I came out of the situation a stronger person than when I went in" or "I looked for the silver lining." It may be that the ability to see the good coming out of a bleak situation helps the person remain engaged in the coping process, rather than simply giving up.

Finding positive meaning in seemingly ordinary events appears to be related to the maintenance of positive mood. Initially we focused exclusively on the stressful events in the participants' lives and what they did in response to these events. The participants, however, reminded us that there were other aspects of their lives that contributed to their well-being. By focusing only on the stressful events, we were only getting part of the picture. Therefore, we started asking participants to describe "something that you did, or something that happened to you, that made you feel good and that was



meaningful to you and helped you get through the day.” With a very few exceptions, participants were able to relate the story of a positive, meaningful event in every interview in which they were asked. The remarkable part of this is that these positive, meaningful events were occurring in the context of profound, unremitting stress. This finding suggests that the act of finding something positive, even if it is something as simple as a beautiful sunset or a kind word from a stranger, provides an important momentary time-out that helps restore the individual and enable him or her to continue coping with what from the outside appears to be unendurable stress.

In contrast, blaming oneself for the stressful events, cognitive escape-avoidance, behavioral escape-avoidance, and distancing were associated with poorer outcomes such as higher levels of depressive mood, decreased levels of positive mood, and more severe reactions to bereavement. Although such emotion-focused responses may seem useful in the short term as a way of reducing distress, in the longer term, they are clearly detrimental.

Spirituality

Spiritual beliefs and experiences at the time of bereavement, such as beliefs in a higher order, visions of the deceased, and belief in a continuing relationship with the deceased, are recognized as part of normal grief. So it was not surprising that spiritual phenomena were experienced by a majority of the newly bereaved caregivers during the days immediately surrounding their partners’ deaths. Caregivers used spiritual beliefs to help the dying partner with his approaching death. After the partner’s death, the spiritual beliefs helped the bereaved partner to be present with the body of the deceased and served as a resource in making sense of the partner’s death.

Spiritual beliefs were also used by more than 40% of participants to construct an account of the whereabouts and safety of the deceased partner and the nature of the relationship with the deceased partner. Culturally unique rituals of dying and death were enacted by the newly bereaved partners. These included division of ashes with multiple distribution sites, multiple memorials, self-designed and delivered religious and secular memorials, and private dispersion of ashes with the use of mortuary services. These rites of death reflect the mobile life style among

gay men in San Francisco as well as the drive for freedom and control of their own lives that is characteristic of gay liberation.

Three years later, even more participants expressed spiritual beliefs and experiences. The themes at follow-up were different than at the time of bereavement. They had more to do with the relationship with God or a higher power and with the self’s capacity for living and growing spiritually. The one theme that was evident both at bereavement and follow-up was belief in a continuing relationship with the deceased.

Are spiritual beliefs and experiences helpful? They were associated with adaptive forms of coping both at bereavement and three years later. At the time of the partner’s death, the expression of spiritual beliefs was associated with higher levels of distress, whereas there was no association with distress three years later. The increased distress associated with spiritual beliefs and experiences at time of bereavement may reflect a different cause-effect pattern. Rather than spiritual beliefs and experiences reducing distress at the time of bereavement, the difficult process of cognitive and emotional assimilation of loss may instead activate the spiritual beliefs and experiences, leading to the association with heightened distress. It may be only over time that such beliefs and experiences facilitate the assimilation process and thereby lead to reduced distress.

Future directions

The unexpected findings from this study suggest important directions for future research. First there was an absence of harmful effects on the physical health of HIV+ caregivers and on the mental health (in terms of clinical depression) of all caregivers. Second, there was the unexpected presence of positive mood despite the intense and enduring stress of providing care for a dying partner. In combination, these findings suggest an intriguing hypothesis, namely, that positive affect may be protective during severe stress.

This suggestion leads to two important lines of research. The first has to do with the mechanisms through which positive affect may confer protection on mental and physical health. This future research should explore physiological as well as psychological and behavioral pathways. The second has to do with the coping processes and the religious and spiritual beliefs that are

uniquely associated with positive affect during stressful times. What is the nature of these processes? Can they be taught? Answers to these questions will be important not only for people affected by HIV, but for people coping with diverse kinds of severe chronic stress.

Further Reading

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Materials Available

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