Informal Caregivers and the Intention to Hasten AIDS-Related Death

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Objectives: To determine the extent to which homosexual men dying of the acquired immunodeficiency syndrome (AIDS) receive medication intended to hasten death. To assess the impact on caregivers of administering medications intended to hasten death.

Methods: In a prospective study of caregiving partners of men with AIDS (n=140), characteristics of the ill partner, the caregiver, and the relationship were assessed at baseline and 1 month before the ill partner’s death. Three months after the death, caregivers were asked if they had increased their partner’s narcotic and/or sedative-hypnotic medication dose and if so, what had been the objective of the increase, and their comfort with the medication decisions.

Results: Of 140 ill partners who died of AIDS, 17 (12.1%) received an increase in the use of medications immediately before death intended to hasten death. Diagnoses and care needs of ill partners who received increases in the use of medications to hasten death did not differ from those of ill partners receiving medication for symptoms. Fourteen increases (10%) in use of medications were administered by caregivers. These caregivers did not differ from those administering medication for symptom control in level of distress, caregiving burden, relationship characteristics, or comfort with the medication decision, but they reported more social support and positive meaning in caregiving.

Conclusion: The decision to hasten death is not a rare event in this group of men. There is no evidence that it is the result of caregiver distress, poor relationship quality, or intolerable caregiving burden; and it does not cause excessive discomfort in the surviving partner. This study, although small, has implications for the policy debate on assisted suicide.

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PARTICIPANTS AND METHODS

PARTICIPANTS

To be included in the study, caregiving men had to identify themselves as homosexual, be in a committed relationship and share living quarters with the ill partner, be willing to be tested for human immunodeficiency virus (HIV) antibodies, have no more than 2 symptoms of HIV disease, and not be an injection drug user. The partners of the caregiving men had to have a diagnosis of AIDS, need assistance with at least 2 instrumental tasks of daily living, and be living at home. Subjects were self-selected in that they were recruited through print and electronic media advertisements, as has been reported previously. Subjects were told that the study was intended to elucidate the sources of stress for men caring for their partners ill with AIDS and to understand how caregivers coped with the stresses of caregiving and bereavement. All subject records were identified by code only. Caregivers were assured that any accounts of death would not be individually identifiable.

Two hundred fifty-three caregiving men enrolled in the study. During the course of the study, 156 ill partners died; their bereaved caregivers constituted the study population for the examination of terminal care and hastened death.

DESIGN

The primary study was designed to explore the stresses of caregiving and strategies for coping used by homosexual men caring for partners dying of AIDS. Each caregiving man was interviewed bimonthly for a 2-year period between April 1990 and November 1994. This report is based on data collected in 4 of these face-to-face interviews: (1) at study entry, (2) at the last bimonthly interview before the partner died, which took place in accordance with the consent process that asked participants to notify project staff when their partner died, (3) within 2 weeks following the partner’s death, and (4) at a “dying process interview” 3 months after the partner’s death using a protocol developed when the study was already under way, in response to issues arising in the interviews. Both the primary study and the dying process interview were reviewed and approved by the Committee on Human Research at the University of California, San Francisco.

MEASURES

Characteristics of the Ill Partner

The duration of the ill partner’s diagnosis of AIDS and the nature of the partner’s illness and the circumstances surrounding his death were assessed at study entry; and care needs of the care recipient were assessed at entry and before the ill partner’s death by asking whether the ill partner needed assistance with each of 7 daily instrumental tasks. Characteristics of the circumstances surrounding death were assessed at the interview 2 weeks following the ill partner’s death.

Characteristics of the Caregiver

A Caregiver Distress Index was administered, composing of assessments of depressive mood, positive and negative affect, state of anxiety, and state of anger. Perceived social support was assessed with the Social Support Questionnaire and coping was assessed with the Ways of Coping Questionnaire. Caregiver burden was assessed with the Caregiver Dislocations Scale. Positive meaning of caregiving was assessed with a 6-item measure. All the above were administered at entry and during the month before the ill partner’s death.

RESULTS

DEMOGRAPHICS

The mean age of caregivers was 38.9 years and that of ill partners was 38.8 years. Ninety percent of both caregivers and ill partners were white. Caregivers had a median education level of some college. Approximately one third of the caregivers were seropositive for HIV. The median duration of the relationship between caregivers and their ill partners was 7.1 years. The ill partners had had a formal diagnosis of AIDS for approximately 2 years.

DECISIONS REGARDING TERMINAL CARE

Among the 140 bereaved caregivers who completed the dying process interview, 122 (87.5%) reported their partners had set limits on the medical treatments they would accept for their illness. The discussion about treatment limitations was initiated by the ill partner in 63% of the cases, by the caregiver in 17% of the cases, and by the partner’s physician in only 11% of the cases. The caregivers were supportive of the decision to limit treatment; 83% agreed “completely,” 11% agreed “quite a bit,” and 6% agreed “somewhat.” Sixty-two percent of the men died in their own homes; other sites of death were the hospital (25%), inpatient hospice (11%), and other (2%). Most ill partners (76%) had not wanted to be hospitalized for terminal care.

CAREGIVERS REPORTING INCREASED USE OF MEDICATIONS

Sixty-seven bereaved caregivers (47.8%) reported that their partner had received a dosage of medication that had been increased beyond the prescribed amount. In general, this medication was a schedule II narcotic analgesic (65%), morphine sulfate being the most common example. The second most frequently used drug group was the benzodiazepine agents (29%). Caregivers were not systematically asked to report the dosages used. The 67
Characteristics of the Caregiver–Ill Partner Relationship

Years in relationship and extent of joint finances were assessed at study entry. Couple adjustment was assessed with a modified version of the Dyadic Adjustment Scale at study entry and before the ill partner’s death.

Medication Administered to Hasten Death

The caregiver’s report in the dying process interview that an increased dose of narcotic analgesic medication and/or sedative hypnotic agent was given with the intention of hastening death was the primary dependent variable. Caregivers were asked to identify up to 2 analgesics and up to 2 sedative hypnotic agents that their ill partners were receiving at the time of death. The caregivers were then asked the following sequence of questions: “Did your partner want you to increase the dosage of (the first analgesic) beyond what was prescribed?” “Did you go ahead and increase the dosage?” “Did someone, other than you or the patient’s physician go ahead and increase the dosage?” “Who administered the increased dose?” The objective of the dose increase, whether administered by the caregiver or someone else, was assessed through 2 questions, “Was the increased dosage given to treat pain?” and “Was the increased dosage given to hasten death?” The response options for each question were no, yes, and unsure. The caregiver could answer yes to both questions, indicating that the increase in the use of medications was administered to control symptoms and to hasten death. We categorized caregivers who indicated that the use of medication was increased to hasten death and that they themselves had administered the medication as personally providing aid in dying regardless of their answer to the symptom control question.

Caregiver Comfort With Dosage Increases

The impact on the caregiver of administering an increased medication dosage before the ill partner’s death was addressed in 3 questions with Likert scaled responses asked during the dying process interview: “How did you feel about administering an increased dose before you actually did it? How did you feel afterward? How do you feel now?” Possible answers were “completely comfortable,” “somewhat uncomfortable,” “quite uncomfortable,” and “extremely uncomfortable.”

STATISTICAL ANALYSIS

Between-group differences among the means of continuous-dependent variables were examined with analysis of variance. The Pearson χ² nonparametric test was used when the dependent variable was categorical. The intervals between interviews varied among subjects. Therefore, time was covaried using random effects analysis of covariance for intergroup analyses, and random effects analysis of covariance with repeated measures for within-subjects analyses. These analyses were performed with the BMDP-5V program for random coefficient growth curve models with variable random effect design matrixes among subjects.

Of the 136 caregivers whose partner died during the 2-year assessment period, 140 (89.7%) completed the dying process interview that provided the data about use of medications at the time of the ill partner’s death. The analyses reported herein are based on the reports of these 140 bereaved caregivers.

caregivers who reported dosage increases did not differ from those who did not in age, employment status, income, ethnicity, HIV serostatus, religion, number of years in the relationship, and time since the ill partner’s diagnosis of AIDS.

CHARACTERISTICS OF THE ILL PARTNER ASSOCIATED WITH INCREASED USE OF MEDICATIONS

Ill partners who received an increase in the use of medications beyond the prescribed amount did not differ from ill partners who did not in any of the demographic variables, disease or treatment preference characteristics, or time since a formal diagnosis of AIDS.

OBJECTIVE OF INCREASES IN THE USE OF MEDICATIONS

In 55 (82.1%) of 67 cases, the increased doses of medications were given by the caregiver himself. In 42 (62.7%) of the 67 cases, the objective of the increase in the use of medications was solely to control symptoms; however, in 17 (25.4%) of the 67 cases, increases in the use of medications were intended in part or exclusively to hasten death. In 8 cases (11.9%) the caregiver was unsure of the objective; 5 of these deaths occurred in the hospital or hospice and the caregiver may simply not have known the reason for the increase in the use of medication. Most caregivers discussed the plan to increase use of medications with the patient’s physician; a similar proportion of caregivers intending to hasten death (75%) and those attempting to control symptoms alone (67%) discussed the medication increase with the physician. Of the 17 caregivers who reported increases in the use of medications intended at least in part to hasten death, 14 (82.3%) reported that they had administered the increased dosage themselves. These 14 individuals represent 10% of all bereaved caregivers who provided data about increases in the use of medications.

The site of death was specified in the caregiver’s narrative for 61 ill partners. Five (21%) of the 21 caregivers whose partners died at a hospice or in the hospital were unsure of the purpose of preterminal increases in the use of medications compared with 3 (8%) of the 38 whose partners died at home. This presumably reflects the personal caregiver’s greater distance from the decision to increase dosage in institu-
Among the 53 caregivers who reported that they were sure of the objective of the increase in the use of medications, 1 (13%) of the 8 ill partners who died in a hospice received an increase in the use of medications to hasten death compared with 4 (25%) of the 16 ill partners who died in a hospital and 9 (25%) of the 36 who died at home.

**CHARACTERISTICS OF ILL PARTNERS WHO RECEIVED INCREASES IN USE OF MEDICATIONS TO HASTEN DEATH**

Ill partners who received increases in the use of medications to hasten death did not differ from ill partners who received increases in the use of medications solely to control symptoms with respect to preferences in terminal care, the site of death, length of time since a diagnosis of AIDS was made, median number of diagnoses of AIDS, or type of diagnoses of AIDS. The median number of AIDS-related diagnoses was 2 in both groups. As would be expected, the specific diagnoses are hallmarks of advanced disease such as wasting, AIDS dementia, cytomegalovirus infection, and *Mycobacterium avium intracellulare* complex. Specific diagnoses did not distinguish the patients who received medications intended to hasten death and those receiving medications for symptom control. Likewise, the 2 groups were comparable with respect to the need for assistance both at the initial interview (scale score, 8.39 vs 7.81) and at the interview shortly before death (scale score, 13.73 vs 12.94).

Only the medication the ill partner received differed among patients receiving medication for symptom control, those for whom the use of medication was intended to hasten death, and those for whom the caregiver was unsure of the objective of the increased use of medications. Use of benzodiazepine agents was considerably more common among ill partners receiving increases in the use of medications intended to hasten death; 8 (57%) of 14 ill partners who received medications to hasten death were given benzodiazepine agents compared with 7 (17%) of 41 of those given increases in the use of medications to control symptoms and 3 (38%) of 8 for whom the objective of the increase in the use of medications was unknown (P = .01).

**CAREGIVERS WHO ADMINISTERED INCREASED DOSES TO HASTEN DEATH**

Caregivers who administered increased doses of medication at least in part to hasten death differed significantly from those who used medication solely for symptom control in only 3 ways: they reported more positive meaning of caregiving at the initial interview many months before the ill partner’s death; at the interview before the ill partner’s death they reported seeking more social support; and they reported more perceived social support at study entry and before the partner’s death (Table 1). The groups were comparable in their HIV serostatus: 6 caregivers (35%) who administered increases in the use of medications to hasten death were HIV positive, compared with 14 caregivers (33%) using medications solely for symptom control. As would be expected with the progression of the ill partner’s disease, all caregivers became significantly more distressed and reported greater caregiver burden between the initial interview and the last interview before the death of the ill partner, but the 2 groups did not differ on these variables at either occasion.

**RELATIONSHIP CHARACTERISTICS ASSOCIATED WITH INCREASED DOSE TO HASTEN DEATH**

Relationships in which medication had been administered at least in part to hasten death did not differ from those in which medication was administered solely for symptom control in the number of years in the relationship, the extent of joint financing, or the level of couple agreement at the initial interview or at the interview before the ill partner’s death (Table 2).
IMPACT OF INCREASE IN THE USE OF MEDICATIONS ON CAREGIVERS WHO ADMINISTERED INCREASED DOSES

At the time of the dying process interview, 11 caregivers (69%) whose ill partners received increased medication dosages to hasten death and 28 caregivers (70%) who increased use of medications solely for symptom control described themselves as having been “somewhat,” “quite,” or “extremely” uncomfortable with the increases before their administration (Table 3). When asked how they were feeling at the time of the interview, the proportion of caregivers in the 2 groups reporting any discomfort had dropped to 3 (19%) and 11 (28%), respectively.

No previous studies have systematically documented the incidence of hastened death in AIDS or any other illness or characterized the psychological state of the caregivers before the decision to hasten death. This study indicates that increases in the use of medications intended to hasten death are not rare, at least in this sample of men in committed relationships dying of AIDS in San Francisco. Of those caregivers whose ill partners died during the study, 12.1% reported that narcotic or sedative-hypnotic medications had been administered to hasten death. The frequency with which medications were administered to hasten death in this study is likely to be an underestimate because caregivers are presumably reticent about disclosing this objective.

The decision to increase the use of medications to hasten death was typically made by the ill partner himself and was carried out by the caregiver, after discussion with the patient’s physician. As described by the caregivers in our study, the controversial practice of provision of aid in dying is both more common and more integrated into the long-term caregiving relationship than generally acknowledged. Our hypothesis that increases in the use of medications to hasten death would be more common among patients being cared for at home was borne out; hospitalized patients were as likely to receive augmented medication doses that were perceived by the caregiver as intended to hasten death. In contrast, administration of increased narcotic and/or sedative-hypnotic doses intended to hasten death was uncommon among ill partners receiving residential hospice care; this is consistent with the explicit values of hospice care.22

There is no evidence that the decision to increase use of narcotic or sedative-hypnotic medications to hasten death is the result of caregiver’s intolerance of the burdens of caregiving, burnout, depression, or anger on the part of the caregiver or any disturbance in the relationship between the caregiver and his ill partner. To the contrary, the higher scores of the caregivers who ultimately assist in their partners’ deaths on the Positive Meaning of Caregiving scale and their comments during the interviews suggest the opposite: that the men who assist their partners in dying are especially committed to caregiving and see caring for their partners as an expression of love.

The potential for guilt, depression, and other deleterious consequences of assisting death among surviving friends and family has led some commentators to regard aid in dying as inadvisable even when both the patient and his or her loved ones request it. Again, we saw no evidence of harmful psychological repercussions in short-term follow-up of the caregivers. It has been noted that inability to communicate freely about events preceding death may lead to complicated grieving after euthanasia.23 Interestingly, we noted an increase in social support immediately before the ill partner’s death among caregivers who ultimately assisted their partners in dying. This may reflect a greater openness of communication on the part of caregivers who acknowledge using medications to hasten death and may facilitate the rapid resolution of discomfort we saw after bereavement in the caregivers who provided increases in the use of medications intended to hasten death.

Several limitations to internal validity must be acknowledged. First, the information about increases in the use of medications is based entirely on caregivers’ self-report. Caregivers may not accurately represent whether increases in the use of medications were given and what the motivations were. It does not seem likely, however, that caregivers would report an intention to hasten death when, in fact, none existed. In addition, the retrospective nature of the dying process interview raises the possibility of recall bias. The interval between the ill partner’s death and the interview was only a few weeks, but it is possible that the caregiver’s recollection of his intentions and psychological state was affected by
his assessment of the comfort and peace of the ill partner's death. Second, we cannot determine whether the dose augmentation intended to hasten the ill partner's death was likely in fact to have done so. However, our purpose was to examine the intention to hasten death, not whether the augmented doses actually produced this effect. Third, we have minimal information on the psychological condition of the ill partner, thus it is possible that depression, fear, inadequate treatment of physical symptoms, or some other attribute of the ill partner led to the decision to hasten death. However, we did not see any evidence of this in the caregivers' descriptions of their partners' last days and hours.

Fourth, the design of the parent study limits the information available on the exact nature of the physician's involvement. The caregivers report discussion of increase in the use of medications with the ill partner's physician but it is not clear how many practitioners proposed, endorsed, opposed, or simply permitted increases in the use of medications. Fifth, the small number of ill partners who received increased medication doses with the objective of hastening death limits the statistical power of the analyses. It is also possible that multiple comparisons have led to a type I error.

There are also limitations to the generalizability of these results to all individuals with AIDS and to persons with terminal illnesses other than HIV infection. The racial uniformity and high level of education distinguish this population from other communities with a high prevalence of AIDS.

Furthermore, the experience of dying of AIDS in San Francisco may be different than in areas where the gay community is smaller or less vocal and where AIDS predominantly affects drug users and their sexual partners. In a study of physicians caring for people with AIDS in the San Francisco Bay Area, 53% reported that they had at least once acceded to a patient's request for physician-assisted suicide. In most other circumstances in which individuals with terminal illnesses are being cared for at home, the caregivers are women, usually members of the biological family. We do not know if men and women respond differently to caregiving or to the issues of hastened death. It is also noteworthy that one third of the caregivers have the same disease of which the ill partners were dying from; this resonance undoubtedly affects the experience and possibly the decisions of the caregiver. It is, therefore, not clear that our results will extend to people with other terminal illnesses being cared for at home.

Our study has at least 2 lessons for physicians and other practitioners caring for individuals with HIV and other terminal illnesses. First, the study demonstrates that the care of people dying at home involves not just the conventional physician-patient dyad but also a triad. From the vantage point of the bedside, the personal caregiver is a central agent. Physicians must develop skills in collaborating with caregivers, recognizing their importance as the actual agents of care, and recognizing and responding to caregivers as "hidden patients." As long as the interests of the home caregiver and the actual patient are congruent, physicians should be as attentive to their relationship with the home caregiver and as responsive to his or her questions, apprehensions, and needs as to those of the patient.

Second, concern with the issues of assisted suicide and euthanasia were virtually universal in this sample of dying patients and their caregivers. As with other preferences in late medical care, these topics may be ones that worry many patients and their families but that they regard as the physician's responsibility to bring up. Physicians should be prepared to open the discussion. For example, a physician might say, "Many of my patients have asked, when they became extremely ill, if I would ever give a pill or an injection to help them die. Have you ever thought about this?" Initiating a discussion does not in itself create an obligation for the physician; in fact, the clarification of expectations may provide the physician who would never participate in physician-assisted suicide or euthanasia an opportunity to explain his or her legal constraints and moral principles to the patient.

As a corollary, clinicians typically have little appreciation for the dilemmas and, ultimately, the crisis of conscience that may be faced by personal caregivers providing terminal care at home. While some friends, lovers, and family regard the provision of terminal care as their responsibility and their right, others are deeply distressed and should not be expected to function in this role. We need to discover effective and appropriate ways to support these most qualified caregivers in their work.

This small study indicates that we have important misconceptions about the nature of assisted dying and that current policy initiatives, both those intended to liberalize and those intended to restrict the practice, may be misdirected. Despite the focus on physician-assisted suicide in policy discussions, personal caregivers played the central role in the last moments of the ill partners in our study. It did not appear that physicians were entirely uninvolved; most of the time, after all, the increased medication dose was discussed with the treating physician. However, at the time of death, the physicians were not at the bedside. The control exerted over management by the personal caregivers has important implications for policy.

Hastened death in our study occurred as an exceptional act in the context of a caring, committed personal relationship, with the input from a distance of the treating physician. It was not a medical act. In contrast to hastened death as it occurred in this study, proposals to legalize assisted suicide medicalize the act and exert control by regulating the conduct of physicians. One class of argument against assisted suicide as public policy as currently envisioned is the profound effect it has on the nature of medicine. Are the benefits of public policy sanctioning assisted suicide sufficient to justify the transformation of the role of the physician and the relationship of physicians to gravely ill patients that would follow? The arguments in favor of permitting physician-assisted suicide in some instances include the enhancement of patient autonomy; the minimization of abuses by increased oversight and accountability; decreased instances of failed and protracted suicide at-
tempts; and decreased guilt and distress among friends and family who would no longer be required to act as the agents. In 17 instances of hastened death, we saw no evidence that any of these concerns was a significant problem. Ill partners desiring increases in the use of medications obtained them. There was no evidence that the decision to act on the request of the ill patient represented anything other than an extreme of loving caregiving; as described by the caregivers, death followed within hours of the administration of medication as it did for caregivers using medication preterminally for symptom control. Finally, the caregivers who increased the use of medications to hasten death did not suffer extraordinary distress consequent to their role as agents. It may be, as suggested by Annas, that the status quo of private, occasional assistance in dying accomplished by persons with loving connections to the patient, with physician input, is optimal public policy.

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