Telephone Counseling for People with HIV
Doug Conaway and David Paisley

Telephone-based counseling—offering anonymity, as well as immediate, round-the-clock, and ongoing access—has been a traditional response to suicide prevention. In the context of HIV-related mental health services, telephone-based counseling can provide interventions not only to prevent suicide, but also to deliver a broad range of crisis-related emotional support. Working in cooperation with other agencies, a telephone-based program can be an essential component of integrated case management.

The AIDS/HIV Nightline, a project of San Francisco Suicide Prevention, provides telephone based emotional support and crisis intervention to people with HIV-related concerns. The Nightline was created in response to the increasing number of HIV-related calls to the Suicide Hotline. As a result, it is staffed by volunteer counselors trained not only in crisis intervention and suicide prevention techniques, but also in HIV-related issues such as death, illness, sexuality, and drug use.

The Nightline’s approach reflects general crisis intervention principles that affirm the individual’s right to self-determination and focus on developing confidence and control. By offering a safe, nonjudgmental forum for people to discuss their feelings, the Nightline helps validate and normalize these feelings. Rather than simply providing advice to alleviate the crisis, counselors encourage callers to identify concerns and possible courses of action. To reach individuals who are not imminently suicidal, but who may be at increased risk of suicide, or those who might be inhibited from calling because of the stigma associated with the word “suicide,” the Nightline is publicized broadly as an emotional support hotline and not as a suicide hotline.

This article, based on the experiences of Nightline counselors, defines the characteristics of telephone-based counseling, the types of calls counselors receive, the appropriate responses to HIV-related suicide calls, and the training necessary for telephone counseling.

Aspects of Telephone Counseling
Telephone-based counseling has several characteristics that distinguish it from face-to-face services. First, it is more available, especially for those with mobility impairments or transportation problems. In rural areas or communities with limited HIV-sensitive or general mental health services, telephone-based counseling may be the only support available. The use of a wide-area, toll-free number further increases access for those who might otherwise have no services available.

Telephone-based counseling also provides immediate support, limited only by its hours of operation. Since many emotional crises are temporary, an immediate response can be critical to avoid serious repercussions. Telephone operations, often providing services during the night and on weekends, act as a safety net when other mental health agencies are closed.

The anonymity guaranteed by telephone-based services allows callers to discuss feelings they might hesitate to mention to face-to-face counselors or therapists with whom they have ongoing relationships. Callers always have the option to remain anonymous, and that option is particularly important for difficult issues such as suicide, sex, drug use, or partner abuse. For example, clients may fear that mental health providers in face-to-face sessions may report any mention of suicidal thoughts to supervisory staff to ensure appropriate clinical and legal responses. Others may fear legal repercussions when discussing illegal drug use or feel inhibited when discussing sexual activity in person.

Types of Calls
As a result of broad public outreach advertising emotional support, the majority of calls to the Nightline are not from individuals at immediate risk of committing suicide. While each call is unique, there are several general categories of calls that illustrate some of the uses of telephone-based, HIV-related counseling.

For many callers, the focus of the call is HIV-related education and support. The fact that someone is calling in the middle of the night with a basic question about transmission or testing, however, often indicates the presence of emotional issues. Exploration of the events that prompted the call usually reveals an anxiety- or other emotion-laden experience, such as a first-time sexual encounter or recent possible exposure to HIV. Many Nightline callers use informational questions to “feel out” the service before raising deeper issues.

Telephone-based counseling is an effective and relatively inexpensive way to provide immediate, accessible emotional support and to complement face-to-face services.

Telephone-based counseling, because it is anonymous, can provide critical support to those who are awaiting antibody test results and those who have recently tested seropositive. Nightline callers often seek reassurance for their decisions to be tested or further information about the test. Individuals awaiting results, generally ineligible for HIV-specific services, may need immediate emotional support during the period before they receive their results. Seropositive callers are often too overwhelmed during post-test counseling to comprehend the complex emotional and practical consequences of HIV disease. The Nightline, because it is available on demand, is able to assist these callers at the moment they are ready to face these issues.

Some of the most challenging calls come from individuals with severe HIV dementia or chronic mental illness. Rather than relying on the standard approach of encouraging the callers to explore their feelings, the counselor responds by trying to deescalate the immediate crisis and, if possible, help the caller connect with appropriate mental health services.

Telephone-based services are likely to attract frequent callers. Frequent callers, often with chronic mental illnesses, are identified through the pattern of calls, sound of voice, given name or pseudonym, or other information recorded on call logs. To ensure a consistent and beneficial response to subsequent calls, Nightline clinical staff and volunteers work together to develop a counseling “directive.” Directives usually include diagnostic information, recommended approach, and limits on frequency or length of calls, and are available to all volunteers.

The Nightline can become an integrated component of fre-

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quent callers' mental health care. Callers may give permission for their outside therapists to work with staff in developing directives. Therapists also refer clients to the Nightline for off-hour support.

Responding to Suicide Calls

The response to HIV-related suicide calls follows a standard suicide prevention approach, but requires a sensitivity to the implications of HIV disease. Nightline counselors assess each call for suicide risk by considering the subject of the call, the severity of the emotional issues involved, and common suicide risk indicators, such as past attempts, mental illness, and significant stress. Counselors frequently broach the topic themselves, asking callers if they have been thinking about suicide. The direct approach helps normalize suicidal feelings and gives suicidal callers immediate permission to talk about them.

On the telephone, it is impossible to assess the rationality of a threatened suicide. Counselors treat all suicidal feelings as valid and free from judgment, regardless of the caller's condition or the counselor's beliefs about suicide. Since callers have sought out emotional support, however, counselors interpret all suicidal calls as "cries for help" to find alternatives to suicide. In keeping with the Nightline's philosophy of self-determination, counselors try to get callers to generate their own alternatives and suggestions for coping, thereby building self-worth and a sense of control.

Since most suicidal episodes are time-limited, the primary goal is to negotiate a contract with a caller to delay any suicide attempts. Because the process recognizes and validates the caller's control over his or her life, it usually results in the caller agreeing to some step, even if only a promise not to make an attempt while still on the line. As long as the caller is on the phone, the attempt is delayed, and the counselor works with the caller to find ways to mitigate feelings of helplessness and hopelessness.

For HIV-related suicidal callers who face the more immediate prospect of incapacity and death, this may be particularly difficult. Suicidal callers with HIV disease, even those who are asymptomatic, may have greater difficulty than other suicidal callers learning over time to cope and to reduce their suicidal feelings. Counselors focus on the immediate future to counter feelings that callers have little time left, and on helping callers regain control within the limits of potential permanent limitations on physical and mental capacity, and financial independence.

Special Training for Telephone Counselors

Telephone counseling differs in approach and training from face-to-face counseling. Physical separation prevents the use of body language, facial expression, or touch. Instead, counselors must create rapport with callers by verbalizing what is often shown through gestures, stating explicitly, for example, "Yes, I want to listen to you," or, "Your concerns are important to me." They must also learn to use tone of voice, murmurs, and even silent pauses to convey their willingness to listen and their concern.

Similarly, separation prevents telephone counselors from using callers' physical expression of emotion to assess calls. Instead, counselors rely almost exclusively on "active listening" techniques, such as continually paraphrasing and restating callers' comments, to encourage them to verbalize feelings that would be obvious if there were visual contact.

In order to clearly define callers' feelings and needs and to communicate appropriate responses, telephone interactions may be lengthy and involve simpler and more direct conversation than face-to-face encounters. To help counselors develop active listening skills and overcome the limitations of physical separation, training includes extensive role playing, particularly where "caller" and "counselor" are sitting back-to-back.

In a single shift, a counselor may listen to calls from a frightened teenager discovering his or her sexuality, a bereaved family member, a relapsing injection drug user, a closeted gay man, a patient near death, and a lonely caregiver. To respond to the variety of callers and issues, training not only introduces counselors to common HIV-related psychosocial issues, but also to issues of cultural diversity, gender, sexuality and sexual development, and addiction and recovery. Because the lack of visual cues exacerbates the risk that counselors will make assumptions based on callers' demographic characteristics, training reinforces the idea that each caller is unique.

Nightline counselors are prohibited from making outside contact with callers, primarily to preserve the guaranteed anonymity of the service. To protect their privacy, counselors use only their first names (or pseudonyms) and do not give out information about other counselors, such as their work hours. Training emphasizes the role of the Nightline as a consistent, immediately available source of crisis intervention rather than as a mechanism for callers to develop a relationship with individual counselors. To achieve this goal, counselors must be interchangeable.

Because anonymity allows callers to use a telephone service as a dumping ground for their most troubling issues, counselors may handle a significant number of stressful calls including, in addition to emergency and suicide calls, hostile calls. The control that callers have over the interaction—they can hang up at any time—can compound counselors' feelings of frustration. Finally, because contact is anonymous and limited, counselors are not likely to witness the resolution of callers' concerns.

The variety and volume of potentially stressful calls make it necessary to develop ongoing support mechanisms for counselors. During shifts, staff or other volunteers are available to offer emotional support. Regular case conferences, support groups, and social events provide an important forum for counselors to share their experiences and feelings with each other, and simple techniques such as keeping a "shift journal" give counselors an outlet for their emotions.

Conclusion

As the epidemic grows and people with HIV disease live longer, there will be an increasing demand for already overburdened HIV-related mental health services. Telephone-based counseling is an effective and relatively inexpensive way to provide immediate, accessible emotional support and to complement face-to-face services. Many communities have existing suicide and crisis lines or HIV information hotlines, either of which might serve as a source of HIV-specific emotional support, particularly in terms of HIV-related crisis and suicide prevention. By collaborating to adapt existing programs, HIV counseling and crisis intervention professionals can ensure that emotional support is only a phone call away.

Doug Conaway is former Director of the AIDS/HIV Nightline and is a writer and HIV educator currently living in San Juan, Puerto Rico. David Paisley is the Director of the AIDS/HIV Nightline. For more information on the AIDS/HIV Nightline, contact San Francisco Suicide Prevention at (415) 752-4866.

FOCUS Changes in September

Next month, FOCUS will grow to eight pages, adding an editorial column, expanded resources and references, and more Recent Reports. These additions will strengthen our ability to deliver a comprehensive overview of a particular topic. For those of you who appreciate FOCUS for its brevity, be assured that these changes will not diminish our commitment to clarity or our respect for your time; our new design will make FOCUS more accessible and easier to read.
Physician-Assisted Suicide

Lee R. Slome, PhD and
Jeffrey Moulton, PhD

HIV disease has added momentum to an already increasing interest in euthanasia, a patient's right-to-die, and physician-assisted suicide.¹² Many health care providers receive requests from end-stage HIV-infected patients to facilitate suicide, and anecdotal accounts suggest that physicians do in fact respond to these requests.

Current standards, however, provide only limited help in addressing the accompanying legal, ethical, and policy dilemmas. While it is no longer a crime for individuals to commit suicide, it is a felony in many states, including California, to deliberately aid, abet, advise, or encourage suicide. Codes of professional ethics in the United States clearly forbid active euthanasia, but these are evolving and reflect a more tolerant stance toward practitioners who choose to facilitate "rational suicide" to end suffering.¹³

Physicians' Attitudes

In a recent study of physicians' attitudes toward assisted suicide, participants responded to a hypothetical case in which they were asked whether they would facilitate a patient's suicide. Sixty-nine clinicians from the San Francisco County Community Consortium (CCC), a community-based clinical research organization whose member physicians care for patients with HIV infection, completed a self-administered, anonymous questionnaire. As a comparison, 86 physicians randomly selected from the mailing list of the California Medical Association (CMA) also completed the questionnaire. The following case vignette was presented to study participants:

Tom is a 30-year-old gay male computer programmer diagnosed with AIDS two years ago. He has severe wasting syndrome and painful oral ulcers, and responded poorly to treatment for his third episode of Pneumocystis carinii pneumonia. There is no evidence of neurological impairment, and it is clear that Tom is mentally competent. His mood is mildly depressed, but the depression is not pronounced given the seriousness of his condition.

Tom has been in a primary relationship for eight years and worked until several months ago. As his personal physician since his diagnosis, you consider Tom a thoughtful, intelligent patient who does not appear to have any significant psychopathology. During Tom's biweekly clinic visit, he asks you to prescribe a lethal dose of narcotics for possible use at some future date.

In response to the case vignette, 23 percent of the total physician sample indicated they would be likely to assist Tom by prescribing the drugs upon his initial request. If Tom were to become adamant, 27 percent of both groups would respond by granting his request, and more than 50 percent of both groups would respond by referring him to a mental health professional. Forty-one percent of the total sample would refer the adamant patient to the Hemlock Society. CCC members, who are very involved in AIDS care, would be more likely to respond to Tom's adamant request for a lethal dose of medication (35 percent), than would CMA physicians (20 percent), who are less involved in AIDS care. CMA physicians would be more likely than CCC physicians to refer Tom to another physician.

Adherence to certain ethical beliefs predicted an intention to assist Tom in committing suicide. A derived variable, descriptively named "universal acceptance," was the strongest predictor of physicians' intention to assist in the suicide. Statements comprising the universal acceptance variable included: if it were more accepted by my peers, I would assist my terminally-ill patients in committing suicide; if it were legal, I would assist my terminally-ill patients in committing suicide; in keeping with humane care, it is acceptable to hasten a patient's death upon their request; and assisted suicide is in keeping with the medical principle of relief of suffering.

Variables indicating an identification with the patient also significantly predicted a physician's intention to assist Tom. These included: homosexual orientation, felt similarity to one's AIDS patients in terms of lifestyle, beliefs, and philosophy of life, and perceived risk for contracting HIV disease due to personal/lifestyle factors. Identification may solidify the doctor-patient alliance since identified physicians may have a greater empathic understanding of the patient's experiences and desires. Patient-identified practitioners, however, may have greater difficulty objectively assessing a request for assistance.

Variables that were not predictive of physicians' intentions to assist were notable and surprising. They included: estimations of when a cure for HIV disease would be developed, feelings of helplessness in treating HIV disease, and personal and professional experience with death and dying.

Evaluating a Suicide Request

Clinicians facing decisions about whether to assist in a patient suicide must evaluate their patients' mental status and motivation to determine whether the suicidal wish is "rational." Do patients have gross psychopathology, for example, histories of depression or other affective disorders, psychiatric hospitalizations, or suicide attempts? Are there indications of HIV-related dementia or other neuropsychological complications? Are patients responding to pressure from family or friends to end their lives? Is the suicidal wish temporary, that is, in reaction to short-term complications in patients' lives, for example, grief resulting from multiple losses?

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Providers must monitor their subjective responses to a suicide request and remember that these responses can interfere with an assessment of a patient's status and motivation. Crucial to this process is deciding whether the provider can tolerate the moral and legal implications of choosing to aid in a death. Clinicians struggling with such decisions should seek objective consultation and advice from colleagues and ethics boards.

Toward a More Universal Approach

Physician-assisted suicide is occurring throughout the United States as doctors express a compassionate desire to help rational patients die a painless and dignified death. The research cited in this article, however, suggests that the community standard of care regarding assisted suicide for people with AIDS is anything but "standard" and that widespread discussion is required to resolve this inconsistency.

Lee Slome, PhD is a Psychology Associate of Outpatient Psychiatry at California-Pacific Medical Center in San Francisco and a Post-doctoral Fellow of Psychology at Kaiser Permanente Medical Center in Oakland. Jeffrey Moulton, PhD is a clinical psychologist in private practice and the former Director of Psychological Services for the HIV Evaluation and Treatment Team at Letterman Army Medical Center in San Francisco.

References
Recent Reports


Following the suicide of a patient, most psychotherapists changed their approaches to therapy, according to a survey in which 39 percent of respondents reported having treated a patient who committed suicide.

The survey of 105 therapists, included participants at a conference on mood disorders and staff therapists at the Menninger Clinic in Topeka, Kan. Subjects had a median age of 40 to 49, and a median of 11 to 15 years of professional experience.

After hearing about a patient's suicide, therapists' most common reactions were shock, sadness, anger, a sense of guilt, anxiety, and doubts about competence. Almost all therapists who experienced a patient suicide reported dealing with the incident by discussing it with colleagues. Nearly a third sought formal consultations, and five percent sought treatment.

Therapists changed their work by using more conservative, thoughtful counseling approaches; listening more seriously to suicidal ideation; being more vigilant about patients' comments reflecting hopelessness; keeping more clinical notes and seeking second opinions more often; acting more quickly to hospitalize patients; and accepting more often suicide as a possible outcome.

The article, using respondents' comments and a review of the literature, goes on to discuss the frequency of patient suicide, the phases of therapist response, and coping strategies for therapists.


Thirty percent of subjects seeking HIV antibody tests—including equal proportions of those who tested seropositive and seronegative—reported suicidal ideation, according to a New York City study. Far fewer expressed suicidal wishes or intent, and testing suggested that these subjects were clinically depressed.

Researchers interviewed 301 subjects who had engaged in high-risk behaviors and were unaware of their infection status when the study began. Forty-nine subjects (16 percent) tested antibody positive and 252 subjects (84 percent) tested antibody negative. Participants, most of whom were men and most of whom were White, had a mean age of 33, and had been recruited by advertising and by notices sent to medical clinics. Psychological testing included the Beck Depression Inventory.

For seropositive subjects, suicidal ideation—thoughts about committing, wishes to commit, or intention to commit suicide—was reported among 29 percent at the time of testing, 27 percent one week after notification, and 16 percent two months after notification. Ideation was reported for 31 percent of seronegative subjects at the time they tested, but fell in the follow-up surveys to 17 percent and 16 percent, respectively. Two percent of the seropositive subjects expressed suicidal wishes at the time they tested; this rate fell to zero at two months. One seropositive subject expressed the intent to commit suicide at the time of testing, but no subjects expressed this intent in follow-up interviews.

Rates of ideation or changes in ideation in this group may be different from other groups because of the study's recruiting methods and the extensive pre- and post-test counseling provided.

Suicide among Long-Term Survivors. New York State Psychiatric Institute and Columbia University (Oral Presentation, M.D.105 from the 7th International Conference on AIDS, June 1991).

A study of 53 gay men who were diagnosed with AIDS at least three years earlier found that nearly half had thought about committing suicide since diagnosis. Three of the subjects had attempted suicide during this period.

The majority of study participants, who had a mean age of 39, were White men and college graduates. All were clients at a New York City AIDS service organization.

Forty-three percent stated they had thought about ending their lives since being diagnosed with AIDS. Nearly three-quarters of the men reported having periods of a week or more when they thought a great deal about death; only 12 percent of these subjects had such thoughts before their diagnosis. Thoughts of death generally occurred in the context of acute illness or pain, after witnessing deaths of friends or lovers, or when subjects were in the hospital or alone at night. The group rated in the mild range of psychiatric distress scales.

Subjects cited several factors explaining the psychological resilience that enabled them to avoid suicide, including having at least one confidante, having insurance, and receiving excellent medical care.

AIDS, Euthanasia, and Grief. Netherlands Institute of Mental Health and University of Leiden (Oral Presentation, M.D.55) from the 7th International Conference on AIDS, June 1991.

Researchers in the Netherlands interviewed the relatives of 59 deceased people with AIDS and found that euthanasia had been discussed with 60 percent of the patients, that it was performed 23 percent of the time, and that in another 31 percent of cases, treatment was withheld while pain medication continued to be administered. (Euthanasia, although illegal in the Netherlands, is tacitly accepted by Dutch courts, and euthanasia guidelines are published by the Royal Dutch Medical Association.)

The researchers also found that while the decision to proceed with euthanasia was never simple, euthanasia did not appear to complicate the grief process. When this process was complicated, however, it was because the patient had died immediately after the administration of medication, the patient had died after hours of suffering, or the relative, rather than the patient's doctor, had administered the medication.

Next Month

The media center at the Seventh International AIDS Conference in Florence this June was bristling with stories on AIDS in the era of vaccines, the continued success of ZDV and its siblings ddI and ddC, and new forms of treatment for PCP and other opportunistic conditions. Little of the coverage, however, offered insights into the implications for counselors of the conference's more than 5,000 presentations.

In September, to inaugurate our new design (see box on page 2), the FOCUS editorial staff offers health care providers an interpretation of conference findings that puts reports of epidemiological, basic science, treatment, and psychosocial information into the context of daily health care practice.