# Cancer Counseling by Telephone Help-Line: the UCLA Psychosocial Cancer Counseling Line

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This paper describes the Psychosocial Cancer Counseling Line (PCCL) of the University of California at Los Angeles, a National Cancer Institute-supported communications project in which the feasibility of providing psychological support to cancer patients and their significant others by telephone has been explored. Staffed by a combination of professional and paraprofessional volunteer counselors, the PCCL provides (a) direct telephone

counseling to cancer patients, their families, and their friends; (b) referrals, when necessary, to community resources relevant to the psychosocial needs of callers; and (c) telephone consultation and information to health professionals.

Call-record data reveal that the service is used mainly by family and friends of patients (45 percent of callers) and by patients themselves (23 percent), who represent a wide range of cancer diagnoses. Demographically, the modal caller is a well-educated, white, non-Hispanic woman in her thirties. Among the many different psychosocial concerns presented by callers, the most frequently discussed issues are requests for referral to a support group, anxiety associated with the disease or its treatment, family problems engendered or exacerbated by illness, and difficulties in doctor-patient communications

On the basis of the PCCL experience, the author argues that a telephone counseling service can perform important functions within the broad spectrum of psychosocial services needed by cancer patients and their families. These functions include provision of information, needs assessment, linkage to health professionals, psychological interventions during intervals between in-person contacts, provision of continuing emotional support not available elsewhere, and outreach to psychologically underserved populations.

T HE INCREASING ATTENTION GIVEN to the psychosocial needs of cancer patients and their families in recent years has produced a concomitant concern with development of appropriate service-delivery models to address these needs. To date, these efforts have included consultation-liaison services to oncology settings (I), professional education on psychological aspects of cancer for medical and nursing personnel (2,3), and various types of individual, family, and group psychotherapy offered directly to oncology patients (4-6).

During the past 6 years, the Office of Cancer Communications at the Jonsson Comprehensive Cancer Center, University of California at Los Angeles, has implemented a project that provides psychosocial support to cancer patients and their significant others via telephone. The telephone has been long recognized as an effective tool for providing mental health interventions, particularly crisis counseling and suicide prevention (7-9), and it has also been used in several health education applications (10-13). Only recently, however, has this medium been applied to cancer counseling.

This paper describes the UCLA Psychosocial Cancer Counseling Line (PCCL), a specialized help-line designed to provide (a) short-term telephone counseling to cancer patients, their families, and their friends; (b) referrals, when necessary, to community services relevant to the psychosocial needs of callers; and (c) telephone consultation and information to health professionals. Drawn from records of 2,108 calls received by the help-line dur-

ing the first 6 months of 1983, data are presented on selected characteristics of callers as well as the nature and relative frequency of their psychosocial concerns. Finally, the special role that a telephone help-line plays within the broader spectrum of psychosocial services needed by cancer patients and their families is considered.

#### **Project Background**

The PCCL is part of a nationwide Cancer Communications Network consisting of 21 regional Cancer Information Service offices (14-16). Callers from portions of the country not covered by a regional CIS, and all callers during evening hours, are handled by a national backup line at the National Cancer Institute. The CIS telephone number throughout the continental United States is 1-800-4-CANCER. The only exceptions to the nationwide toll-free number are the CIS offices serving Washington, DC, and suburbs (202-636-5700), Hawaii (808-524-1234) and Alaska (1-800-638-6070). The CIS system provides an efficient means by which the public can receive up-to-date. accurate, free information about cancer. Since the system's inception in 1976, CIS staff have answered more than a million inquiries. In 1984, the system received an average of 28,000 calls per month.

The CIS was designed primarily as a health education resource, not as a counseling service. It has billed itself as an information resource for questions about cancer prevention, etiological factors, diagnosis, and treatment. Since the University of Southern California already had established a CIS, cancer center personnel at UCLA decided to provide a specialized cancer line for Southern California (area codes 213, 805, 619, 818, 714) that would focus explicitly on the psychological and interpersonal dimensions of living with cancer.

Since the founding of the PCCL in 1978, more than 20,000 calls have been answered, 4,000 of them during 1984. At present, approximately 350 calls are taken per month. The line is staffed Monday through Friday during normal business hours; at other times messages are taken by a phone answering service. Counseling calls average 20–25 minutes in length. Additional off-the-phone time is needed, of course, for recordkeeping, mailing of printed materials, followup calls to referral resources, and other procedures. Approximately 20 percent of the callers are repeat users of the service; the remaining 80 percent of the calls come from first-time users.

PCCL phone counselors complete a record form for each call. The form includes selected demo-

graphic information, disease site, referral source, a narrative description of the caller's concerns and replies given by the counselor, behavioral suggestions and referrals, and required followup actions such as call back and mailing of printed matter. All of this information is later coded and computer tabulated for reporting purposes.

#### Staffing Patterns and Training

The PCCL currently uses a combination of volunteer counselors and paid professional staff.

The professional staff consists of a clinical psychologist responsible for the overall project, a parttime clinical social worker, and a communications assistant.

Volunteer counselors are recruited and trained once per year. At present, the volunteer corps consists of 40 women, each of whom is asked to commit at least 1 year of service to the line and to work one 4-hour shift per week. (Major volunteer support has been provided since 1981 by the Junior League of Los Angeles.) Each volunteer first completes a screening interview with a member of the professional staff. If accepted, she is then assigned basic cancer information to be read prior to the volunteer training program.

The 39-hour, 13-session training program, taught by faculty from the UCLA School of Medicine and PCCL professional staff, consists of three main components: basic disease and treatment information, psychosocial aspects of cancer, and communications skills training. Volunteer counselors are "certified" after completion of a series of written tests and after successful role playing in a series of mock phone calls. The training program places heavy emphasis on proficiency in active listening skills. Regularly scheduled continuing education sessions and a test-call system are used to ensure the proficiency of the paraprofessional counselors answering the lines. A board of experts from the university serves as a backup resource to provide information to the counselors about medical or psychosocial issues needing further clarification. In answering callers' requests for routine information. counselors use materials produced by the National Cancer Institute or standard oncology reference texts.

#### Caller Characteristics

Who uses the PCCL?

Table 1 presents selected demographic data on the callers. The majority are women (71 percent), as

Table 1. Demographic characteristics of callers to the UCLA Psychosocial Cancer Counseling Line, January through June 1983

Demographic characteristics	Number	Percent
Total callers	2,108	100.0
Sex:		
Male:	611	29.0
Female	1,497	71.0
Callers asked about age	<sup>1</sup> 1,473	100.0
19 or less	26	1.8
20–29	242	16.4
30–39	358	24.3
40–49	269	18.3
50-59	261	17.7
60 or more	317	21.5
Callers asked about education	<sup>1</sup> 1,368	<sup>2</sup> 100.1
Less than high school graduate	75	5.5
High school graduate	273	20.0
Some college	432	31.6
College graduate	358	26.2
Postgraduate education	230	16.8
Callers asked about ethnicity	<sup>1</sup> 1,447	<sup>2</sup> 99.9
White, non-Hispanic	1,231	85.1
Black, non-Hispanic	90	6.2
Asian or Pacific Islander	48	3.3
Hispanic	70	4.8
American Indian	8	0.5

<sup>&</sup>lt;sup>1</sup> The number for demographic variables varies because (a) repeat users of the service are not asked this information, and (b) the telephone counselors do not ask this information in situations where they deem it inappropriate.

is true for most telephone counseling services. Very few young (under 20) people call the PCCL, but all adult age categories are well represented. The distribution of ages for all callers is, however, skewed somewhat more toward younger adults than is the distribution of ages for callers who are cancer patients. PCCL callers include many persons besides patients (for example, family members of patients, health professionals, and the "worried well"). The educational level of the callers is worthy of note: 43 percent report having received a college degree or

more education. Only 15 percent of PCCL callers are from ethnic minority groups.

Table 2 classifies various types of callers. Spouses, relatives, and friends of diagnosed cancer patients constitute the largest category of callers (45.1 percent), and diagnosed patients themselves represent another 23 percent of the callers. Thus more than two-thirds of the calls come from nationts or persons personally involved with patients. This proportion is considerably higher than the proportion of calls from these categories reported by other cancer information service facilities (15.16). Almost 11 percent of the calls come from an undiagnosed person with cancer symptoms or from someone concerned about such a person. Nearly 7 percent of the calls come from professionals, usually seeking information about community psychosocial resources. Other callers are representatives of the media, students, representatives of health agencies, and other members of the general public.

#### **Referral Sources**

How do members of the public find out about the PCCL?

Because of the specialized nature of the PCCL's mission, the line is not promoted directly to the public. However, flyers, posters, and other promotional material on the PCCL are distributed to oncology settings throughout the community. The largest proportion of calls comes from self-referred persons (29.5 percent), most of whom simply obtain the PCCL number from the phone book or from a telephone information operator. The second largest category of callers is those who learn of the PCCL through promotional material (18.0 percent), followed by those who obtain the number from another office within our own medical center (13.0 percent) or from a friend or relative (12.5 percent).

Table 2. Source of calls to the UCLA Psychosocial Cancer Counseling Line, January through June 1983

Source	Number of calls	Percent
Diagnosed cancer patient	484	23.0
Spouse, relative, or friend of diagnosed patient	951	45.1
Undiagnosed person with symptoms	169	8.0
Spouse, relative, or friend of undiagnosed person with symptoms	61	2.9
Health professional	143	6.8
Media representative	27	1.3
Other	273	12.9
Total	2,108	100.0

<sup>&</sup>lt;sup>2</sup> Does not add to 100.0 because of rounding.

Health professionals refer 11.7 percent of the callers. The Cancer Information Service for our geographic region, housed at the University of Southern California Comprehensive Cancer Center, routinely refers to the PCCL any caller perceived to have psychological concerns in addition to informational requests. Despite a relatively high rate of such calls referred to the PCCL, those that actually do reach the PCCL represent only 9.7 percent of all PCCL callers. (Approximately 40 percent of the callers who are referred to the PCCL for counseling by our regional CIS do not contact the PCCL.) The remaining 6 percent of the calls reach the PCCL via a variety of other sources.

#### **Disease Sites**

A specific disease site was discussed in 1,605 (76 percent) of the calls during the 6-month period covered by this report. As can be seen in table 3, breast cancer is, by far, the most commonly discussed disease site: it is the object of concern in more than one-quarter of the calls. Given the high proportion of female callers, the prevalence of breast cancer calls is not surprising. Calls about two other very common cancers, lung and colorectal cancer, are second and third in frequency, respectively. These frequencies are very similar to those previously reported for Cancer Information Services in Ohio (15) and California (16).

PCCL callers discussed a wide variety of other malignancies, each representing only a small percentage of the total calls. Some quite rare tumor sites have relatively high rankings in PCCL calls because of such factors as special clinical and research interests (for example, melanoma and cancer of the ovary) at our center or recent media attention (such as that given Kaposi's sarcoma).

The data available from our call record forms do not allow one to ascertain with any precision the stage or seriousness of the cancers being discussed. However, the counselor does record any indication from the caller that the case involves metastatic disease. Of the total sample of calls in the period studied, 25.7 percent of callers explicitly mentioned metastatic disease. If one narrows the focus to calls from patients and from relatives and friends of patients, the percentages increase to 28.8 percent among the callers who were patients and 40.1 among the friends and relatives of patients. Thus, not only are most of the callers to the PCCL directly involved with cancer as patient or significant other, but also a sizable portion of the cases presented by the callers involve metastic disease.

Table 3. Primary tumor sites discussed by callers to the UCLA Psychosocial Cancer Counseling Line, January through June

Primary tumor site	Number of calls	Percent	
Breast	438	27.3	
Lung, trachea, bronchus	198	12.3	
Colon, rectum	121	7.5	
Melanoma	81	5.0	
Lymphoma	59	3.7	
Leukemia	57	3.6	
Prostate	49	3.0	
Ovary	43	2.7	
Brain	42	2.6	
Kaposi's sarcoma	38	2.4	
Other sites	479	29.8	
 Total	1,605	199.9	

<sup>1</sup> Does not add to 100.0 because of rounding

#### Frequency of Psychosocial Concerns

Although the PCCL is, as its name implies, primarily a counseling service, callers to the line present a wide variety of disease- and treatmentspecific concerns as well as psychosocial issues. Therefore, a broad list of 79 "type of inquiry" codes is used in coding the call record forms; these categories include site-specific topics, etiology and prevention factors, diagnostic procedures, treatment methods, and a variety of other issues. Twenty-five type of inquiry codes (see box p. 312) are in the realm of psychosocial concerns. Though such an attempt at categorization is never fully adequate to capture the complexities faced by those living with cancer, it at least provides some indication of the nature, range, and relative frequency of the problems presented by the line's users.

Each call may receive from one to five separate subject inquiry codes. In the 6-month sample reported here, 1,071 calls (50.8 percent of the total) received at least 1 of the 25 psychosocial inquiry codes. In slightly more than half these cases (57.7 percent), only one psychosocial inquiry code was given. A total of 1,682 psychosocial concerns were coded for the entire sample, making the average number of psychosocial issues cited per call 1.57.

The 10 most commonly cited psychosocial inquiries are ranked in table 4. Neither one single problem category nor a cluster of a few issues accounts for a great majority of callers' concerns. Instead, psychosocial concerns are distributed rather evenly across a variety of areas.

## Categories Used for Coding Psychosocial Inquiries

#### Communications and relationship issues

- Relationship with physician or other health care professionals
- Family conflicts and problems associated with serious illness
- Other (nonfamily) social network concerns

#### Treatment-related issues

- Coping with hospital or clinic environment and procedures
- Adherence to recommended medical regimen or other compliance problem
- Interest in unproven methods
- · Coping with treatment side effects
- Adjustment to changes in body image or physical functioning
- · Concerns about future course of disease
- Pain management

#### Miscellaneous areas of psychosocial concern

- Sexuality
- · Alcohol or drug use, or both
- · Bereavement, grief
- Suicidal thoughts, gestures, attempts
- Death-related thoughts, feelings, attitudes
- Financial demands
- Insurance

#### Predominant emotions expressed

- Sadness, depression
- Anger, hostility
- Anxiety, fear
- · Loneliness, alienation
- · Guilt, remorse

#### Seeking psychosocial resources or referrals

- Cancer patient, family support groups
- Professional psychotherapy (individual, group, or family therapy)
- Hospice, home care

Taking the psychosocial inquiry codes in order of frequency, it can be seen that requests for referrals to cancer support groups head the list, occurring in about one-fifth of the cases. It is very common, for instance, to have callers begin with the relatively "safe" gambit, "Please give me information on cancer support groups in my area." In many cases this will be followed by elaboration of other psychosocial concerns.

The second most frequent theme is expression of anxiety associated with illness. It should be noted that this code refers to cases in which the caller explicitly and spontaneously voiced this feeling, not to cases in which callers were judged to be anxious by the phone counselor.

As would be expected, the category of family problems associated with serious illness is high on the list. Included here are concerns about family role changes, communicating with a spouse or child about the illness, and other stresses to the family structure brought on by serious, chronic illness.

Difficulties in communicating with physicians and other physician-patient relationship problems are expressed by approximately 10 percent of the callers. Many callers perceive their physicians, rightly or wrongly, as cold, distant, uncommunicative, or uncaring. On the other side of the coin, many callers admit to being tentative, diffident, or anxious in the presence of physicians, responses that contribute greatly to their frustration and dissatisfaction in the relationship. A brief telephone intervention focused on clarifying informational needs and allowing the caller to practice assertive communication can aid the caller in his or her interactions with the physician.

Feelings of sadness, sometimes accompanied by other symptoms of depression, are also frequently revealed. Surrounded by friends and family members urging them to be "positive" about their illness, patients sometimes turn to the PCCL simply to have an empathic response to their tears and feelings of desperation.

Financial problems facing the families of cancer patients—an area often neglected by mental health professionals—are the sixth most frequent concern. Though PCCL counselors are attentive to financial issues, there is little direct help that can be offered except referral of those who qualify to public assistance programs.

Death-related feelings are explicitly expressed by 7.7 percent of the psychosocial callers. Given the relatively large number of calls to the line that concern metastatic disease, this number might seem quite low. However, discussion of thanatological themes is still considered a relatively intimate and, to many, threatening matter.

Interest in unorthodox methods of treatment, ranging from dietary schemes to psychic healing, is voiced in 6 percent of the cases. Few of the callers express a desire to abandon conventional care altogether, but many wish to augment their treatment with some form of unorthodox therapy. About the same number of callers state that they are facing difficulties coping with chemotherapy, radiation therapy, or other forms of treatment. It is often this group who also voice interest in unproven methods.

Table 4. Psychosocial concerns most frequently mentioned by callers to the UCLA Psychosocial Cancer Counseling Line,
January through June 1983

Concern	Number of Rank calls¹ Percent		
Request for referral to support group	1	210	19.6
Anxiety or fear associated with illness	2	190	17.7
Family problems associated with illness	3	133	12.4
Patient-physician relationships	4	110	10.3
Sadness or depression associated with illness	5	105	9.8
Financial demands of illness	6	91	8.5
Death-related feelings, thoughts	7	82	7.7
Interest in unproven treatment methods	8	64	6.0
Coping with treatment and side effects	9	63	5.9
Request for referral to professional psychotherapy	10	56	5.2

<sup>&</sup>lt;sup>1</sup> The total number of calls coded for psychosocial concerns was 1,071. Some callers expressed more than 1 concern.

The list of the 10 most frequent psychosocial concerns is rounded out by requests for referral to professional psychotherapy (individual, family, or group). These requests are less than one-third as frequent as requests for referral to self-help groups. Financial factors probably play a role here, as does the stigma, still present in some circles, associated with "needing" a mental health professional's assistance.

Psychotherapists typically pay attention to what is not being discussed by their patients as well as what is being discussed. If that perspective is taken here, the following topics are found to be rarely discussed (that is, mentioned in 2 percent or less of the calls): coping with the hospital or clinic environment, coping with body image or changes in physical function, sexual concerns, alcohol or drug abuse, bereavement, suicide, feelings of guilt or remorse associated with illness, and employment and insurance concerns. Each of these is, of course. an important issue for seriously ill persons and has been noted and discussed by clinicians and researchers working with cancer patients in other contexts. For some of these problems (for example, sexuality and feelings about body image) more time for building rapport than that afforded by a telephone contact may be required. It is unclear, however, why other concerns in this list are not raised more often.

#### The Special Role of a Help-Line

A telephone help-line is certainly not sufficient or appropriate to address all of the psychosocial issues faced by oncology patients and their families. Nonetheless, this type of program can play a useful role within the broader array of needed psychosocial and rehabilitative services. Since the PCCL may be thought of as functioning in lieu of other psychosocial services, the acronym IN LIEU might be used to summarize and illustrate the special functions of the line.

I = Information. Lack of accurate, easy-to-understand information about one's illness and medical treatment can exacerbate anxiety in the seriously ill patient and his or her family. Though people vary in their readiness and willingness to receive explicit medical information in stressful circumstances, most will benefit psychologically by having an accurate conceptual framework within which to understand what is happening to them medically and to make necessary decisions about their cases. The telephone affords an anonymous, easily available means to give people basic information, when they want it. Publications, free from technical jargon, are also distributed to callers to reinforce and extend telephone information.

N = Needs assessment. Entwined in the multiple exigencies of serious illness (exigencies that range from the mundane to the profound), the cancer patient and his or her family often need help in clarifying and defining their concerns, setting priorities, and deciding on a plausible course of action. A telephone counseling service can help them evaluate the nature and severity of their problems and clarify what steps can be taken toward resolution of the problems.

L = Linkage to health professionals. This is perhaps the most practical and most easily recognized special function of a telephone counseling line. Through a phone contact the caller can find out about the nature and availability of psychosocial services and receive up-to-date, accurate referrals.

The telephone counseling line can be a first, sometimes tentative, step toward seeking psychological help. Trained telephone counselors can help the caller overcome initial resistance to seeking further help. Furthermore, the caller can begin to define what he or she wants to accomplish and what type of help is required. The caller can be assisted in choosing from the sometimes confusing array of self-help groups and mental health professionals.

Identification of existing psychosocial resources is an important function of a service of this nature. Approximately 250 psychosocial services are listed in the PCCL referral files, including a variety of support groups, rehabilitation services, American Cancer Society programs, and hospice services. These files are constantly updated.

Referral involves more than simply giving out names and numbers. Patients and family members often do not know what services they really need. the nature of the services, and how best to match their needs, preferences, and style with the proper resource. As far as possible, PCCL counselors try to match callers, concerns, and problems with the appropriate type of referral. Among the 1,071 psychosocial calls in the 6-month period reported on here, 432 callers (40.3 percent) were referred for counseling, either to community-based self-help groups or to professional psychotherapists. Ninetyeight callers (9.1 percent) were referred to American Cancer Society programs (for example, patient visitation programs), and hospice referrals were given to 67 callers (6.3 percent).

The PCCL also plays an important role in linking callers to medical services. As noted earlier, approximately 11 percent of our callers are anxious about some as yet undiagnosed symptom. Many already diagnosed persons wish a second opinion or referral to a tertiary care center for consultation. In the 6 months covered by this study, the PCCL referred 397 callers back to their personal physician for further discussion; 695 callers received referrals to a comprehensive cancer center, cooperative group, or other National Cancer Institute-sponsored research trial; and 188 callers received information about obtaining a second opinion.

I = Interim intervention. When patients are hospitalized or under active outpatient care, they will be receiving frequent and intensive medical attention and may be receiving some form of psychosocial assistance. However, throughout the often lengthy course of illness, there are many periods in which patients and families can feel quite alone (some would say abandoned). The telephone can

help tie the patient or family to the medical center during these periods.

In addition, regional cancer centers serve persons from a large geographic area. By necessity, these patients limit their visits to the medical center to a minimum. It may be very difficult for them to drive long distances for regular psychotherapeutic sessions. Others are simply too sick or disabled to come to the medical center (or other agency) for psychosocial help. A telephone line can be easily used by these persons, as well, for interim support, advice, and information.

E = Emotional support. It would be a mistake to ignore the obvious point that what many cancer patients need and want is simply empathic emotional support. Well-trained counselors, attuned to the special concerns and feelings of cancer patients. can effectively meet this need. In addition to the informational, referral, and behavioral activities of the PCCL, there remains the fundamental core function—to buttress the patient's and family's ability to bear the burden of illness. It is not infrequent for callers—perhaps just seconds after the phone has been answered—to begin crying. The caller wants someone, even a stranger at the other end of a telephone line, to share his or her sadness. Or the caller, perhaps in the grip of acute anxiety and confusion when he or she calls, will confess, "I thought I was going crazy, until I talked over this situation with you." Interestingly, callers are so accustomed to being brushed aside by curt, impatient personnel answering telephones at medical institutions that they often try to rush their questions and condense background information, all the while apologizing for "taking too much of your time." They are not only relieved, but sometimes frankly puzzled, by a telephone service (especially one at a medical center) where someone actually wants to hear about their feelings, attitudes, needs, and wishes. Probably the most frequent and most effective "intervention" offered by PCCL counselors is nothing more or less than active listening.

U = Underserved populations. One of the special advantages and opportunities offered by the telephone counseling line concerns the possibility of reaching those populations that would otherwise go unserved. For instance there are those who are geographically isolated from mental health facilities and those who are homebound because of illness. Possibly the telephone could be used to reach ethnic and minority groups not usually served by counseling services, but a glance at the PCCL demographic

statistics makes clear that this is an unrealized potential in this instance.

It is obvious that many cancer patients and families of patients will require more extensive, direct forms of service from mental health professionals than can be afforded by telephone counseling. Nonetheless, it is a fact that only a small percentage of cancer patients, or patients' family members, will receive services from a mental health professional (17). Surveying oncology settings as a whole, one could safely claim that, from a psychosocial perspective, cancer patients in general are underserved. A large majority of cancer patients are treated in community hospitals and oncology practices away from comprehensive cancer centers. Most smaller hospitals, and certainly many outpatient settings, do not have psychiatric or social services available. Even within a large comprehensive center such as UCLA, which has a large psychiatry department and an active consultation liaison service, there are never sufficient personnel to see all patients.

It must be remembered, at the same time, that not every expression of intense affect, nor every emotional crisis in the course of chronic illness, nor every manifestation of temporary difficulty in coping requires referral to a mental health professional. Many of these people could benefit from an empathic listener who would help assess the problem, clarify and focus concerns, provide relevant information, and perhaps offer specific suggestions or other brief interventions that might be helpful. It is this type of aid that a telephone counseling line can provide.

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# Unreported Dog Bites in Children

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#### Synopsis .........

In 1981, more than 3,200 Pennsylvania children, ages 4 to 18 years, were surveyed about their dog bite histories and attitudes toward animals. Dog bites were much more common than previously reported: 45 percent of children had been bitten dur-