
Cancer Prevention Counseling on Telephone Helplines

D. MICHAEL ANDERSON, PhD, MPH
KATE DUFFY, MPH
CYNTHIA D. HALLETT, MPH
ALFRED C. MARCUS, PhD

Dr. Anderson is Prevention Research Officer with the Division of Cancer Prevention and Control, and Ms. Duffy is Chief of the Cancer Information Service, both at the National Cancer Institute (NCI). Ms. Hallett was formerly with NCI and is now with the Los Angeles County Department of Health Services. Dr. Marcus is with the AMC Cancer Research Center, Denver, CO.

Tearsheet requests to Dr. D. Michael Anderson, National Cancer Institute, 218 Executive Plaza North, 9000 Rockville Pike, Bethesda, MD 20892, telephone 301-496-8577.

Synopsis

Since 1983, the National Cancer Institute (NCI) has collected data by means of its Cancer Information Service (CIS), a toll-free telephone helpline for health care professionals and members of the public who have questions about cancer treatment, diagnosis, and prevention. These data reveal infor-

mation about the characteristics of callers and their questions and about how inquiries reflect mass media promotions and secular trends.

A request for a publication is the most common type of inquiry, followed by information about specific cancer sites, smoking prevention and cessation, other types of prevention, cancer treatment, cancer symptoms, referrals to physicians, NCI clinical trials, hospital and clinic-based screening programs, and general counseling or coping. Breast cancer is the most common cancer of interest, followed by respiratory system cancers, colon and prostate cancers, leukemia, melanoma, nonHodgkin's lymphoma, cervical cancer, general or unspecified skin cancer, and ovarian cancer.

Responding to these other caller inquiries, CIS counselors may proactively guide callers to a desirable goal, such as screening mammography. Protocols have been developed to assist counselors' proactive efforts, and preliminary results are beginning to support this approach. The findings gathered in this study underscore the health education potential of telephone helplines and point to the need for controlled evaluation research on the effectiveness of proactive counselor advice.

TELEPHONE HELPLINES offer a channel of enormous potential for the dissemination of health information on a one-to-one basis that is hard to duplicate in terms of large-scale accessibility and personalization of messages. The telephone is an affordable, easy-to-use, private, and almost universally available technology. People seeking health information may see the telephone's anonymity as nonthreatening and as a way to maintain some control in an unfamiliar area of knowledge (1).

There are two basic types of helplines: (a) those with pre-recorded messages and (b) those with interactive service by trained counselors who respond directly to each caller's inquiries (2). Like the mass media, another technology frequently considered for its educational applications, helplines offer blanket coverage of the target audience, user anonymity, and convenience of time and place (3). Interactive helplines are particularly attractive from a health education perspective because they have the flexibility to shape each message into a uniquely personal intervention (4).

Interactive telephone helplines, at least for health matters, deal with two basic types of calls. The first is counseling patients on the meaning and outcomes of medical diagnosis and treatment. Use of the telephone for patient counseling and management, especially for certain acute, self-limiting conditions, is very common (5). For example, in some medical practices up to 70 percent of problems are dealt with solely by telephone (6). The second basic type of call involves questions about the prevention of disease and promotion of healthy lifestyles. Help may include advice on weight loss or a more nutritious diet or steps to take to quit smoking or where to find local resources or support groups.

This article embodies a discussion of the National Cancer Institute's Cancer Information Service (CIS) that has gathered what is probably the largest data set available on telephone helplines (currently more than 3.2 million records), as an example of the interactive type helpline. These data, gathered nationally through a network of

local offices, illustrate who uses a health related helpline, and what information they seek.

Historically, the role of counselors on the CIS has been to respond to a specific question or request generated by callers for information on cancer. As such, the counselors have played a significant part in the dissemination of cancer information and have been a critical link to the public in times of need. As an example, when President Reagan was treated for colon cancer in July 1985, calls from the public concerning the warning signs and treatment of colon and rectal cancer increased by 24.4 percent (5,905 calls) over the previous month (7).

Recently, however, NCI scientists and other researchers have begun to explore the possibility of using the CIS not just reactively but more *proactively* as a means of disseminating information on cancer prevention and control and of providing referrals, when appropriate, to help callers overcome barriers to action. This analysis examines some effects of a proactive approach.

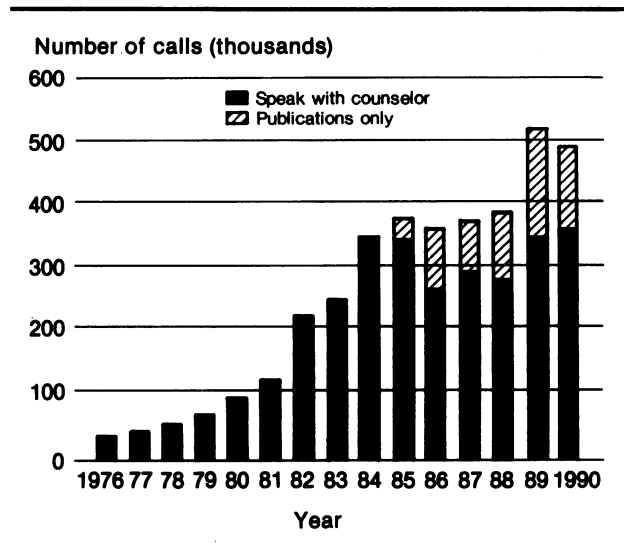
Methods

Since 1983, all CIS offices have been collecting data on a nationally standardized call record form consisting of a few administrative items and several caller-specific variables. These variables include type of caller (a patient, a significant other person, a professional, a member of the general public, and so on), subject of the caller's inquiry, cancer site of interest, behavioral suggestions, referrals to another agency, how the caller found out about the CIS, and demographic information (8). Data we report were collected from all 30 offices that provided interactive counseling service between 1983 and 1990. Excluded from this analysis were the 624,992 calls routed to the Publications Ordering Service office in Washington, DC, that handles publication requests only and does not offer interactive counseling.

While records of CIS calls used in this analysis form a large data set (N = 2,576,868), subjects were self-selected and caution should be taken when making generalizations to a larger population. Similarly, the degree to which actions that were taken after a call is attributable to that call cannot be estimated from these data, and assumptions about cause and effect relationships should be made with care.

The number of calls received by CIS offices has increased dramatically since the Service's inception in 1976, as shown in figure 1. Total call volume

Figure 1. Annual total of all information requests to the National Cancer Institute's Cancer Information Service, 1976-90



has risen from about 47,000 inquiries in 1976 to more than 506,000 calls in 1990. Calls to the Publication Ordering Service (a dialing option for callers who are interested in publications only) have increased from 33,709 (8.6 percent of all calls) in 1985 when it was introduced, to 135,979 (26.9 percent of calls) in 1990. This service frees CIS counselors to devote more time to callers requiring interactive counseling.

Most CIS callers are white (88.5 percent), female (71.3 percent), and have a high school education or more (88.3 percent). The age group that calls most frequently is the 30-39 group (24.1 percent), and all but 6.9 percent of the sample are adults. This approximates other studies that have shown the uses of pre-recorded telephone messages (9). White CIS callers somewhat exceed their distribution in the U.S. population, whereas black, Hispanic, Asian and Pacific Islanders, and American Indian CIS callers fall somewhat short of their proportion in the U.S. population.

Members of the general public historically constitute the largest group of callers, accounting for 38.5 percent of all CIS calls between 1983 and 1990. As shown in the table, their proportion of the total call volume has decreased since 1985, however, due to the creation of the Publication Ordering Service (POS). Although callers from the general public frequently require only a publication, those who remain on the line have spoken with a counselor, usually about a prevention related issue. Conversely, the proportion of calls by spouses, friends, and relatives of diagnosed pa-

Annual percentage of inquiries to the National Cancer Institute's Cancer Information Service helpline, by type of caller, 1983-90¹

Years	General public (N = 985,930)	Significant others (N = 703,938)	Diagnosed patients (N = 369,756)	All others (N = 503,161)
1983	37.1	26.8	11.6	24.5
1984	51.4	20.2	9.3	19.1
1985	51.2	20.5	9.6	18.7
1986	33.4	30.5	14.9	21.2
1987	36.8	29.0	14.7	19.5
1988	31.7	30.3	17.2	20.8
1989	27.6	33.5	20.1	18.8
1990	35.5	30.4	17.9	16.2

¹ Excluding calls to the Publication Ordering Service.

tients, and by diagnosed patients themselves, all of whom frequently require detailed and personalized counseling, have increased since 1985 (10).

Other caller groups to the CIS include symptomatic but undiagnosed people (6.6 percent); health care professionals, including physicians, nurses, and social workers (7.0 percent); other professionals such as educators, students and parents, members of the clergy, and representatives of the media (3.7 percent); and other callers, including members of Congress or members of their staff, and other CIS offices (2.4 percent). Their information requests display a wide range of interests, including prevention, treatment, rehabilitation, and continuing care.

As shown in figure 2, the 10 most common subjects inquired about were publication requests (21.1 percent of calls), cancer site information (16.2 percent of calls), smoking prevention and cessation (12.8 percent), other primary prevention (9.1 percent), general cancer treatment (9.1 percent), cancer symptoms (6.3 percent), referral to a physician (5.9 percent), information about clinical trials (5.7 percent), hospital and clinic screening programs (5.4 percent), and counseling or coping advice (4.8 percent).

As shown in figure 3, the 10 most common cancer sites for which information was requested were breast (15.6 percent of all calls), lung, trachea, or bronchus (5.6 percent of calls), colon (4.8 percent), prostate gland (3.8 percent), blood (2.2 percent), skin (1.9 percent), lymph glands (1.9 percent), cervix (1.7 percent), general or unspecified skin (1.4 percent), and ovaries (1.3 percent). Breast cancer calls have consistently been the most common site inquiry since 1983, which may be attributable to both the high prevalence of the disease, and the fact that women are much more likely to use the CIS than men (11).

Helplines' Proactive Function

Two examples of CIS telephone helpline counselors doing more than reacting to information requests are (a) when they detect the caller's needs and counseling opportunities from the context of a call and are able to refer the caller to a program of clinical trials and (b) when the caller is determined to be in a population that would benefit from obtaining a screening mammogram.

Referral to clinical trials. In 1988, the National Cancer Institute's Division of Cancer Treatment set as a goal doubling the number of patients entering clinical trials by 1992. The underlying rationale for raising patient accrual is that by increasing participation, researchers would be able to expand the number of trials being run, shorten the time span of any particular trial, and ultimately move therapeutic results out of the experimental stage and into routine practice more quickly. A critical objective in achieving this goal is to increase public awareness, especially of patients and their families, about clinical trials.

When NCI announced this goal, CIS staff members recognized it as an opportunity to take a proactive approach with appropriate calls. Up to this point, the suggestion that a patient consider a clinical trial was generally not offered by the CIS staff person until the caller specifically stated an interest in "new" or "experimental" treatments.

Due to the personal nature of a decision to enter a clinical trial, CIS information specialists needed thorough training to emphasize that their role is not necessarily to encourage patients to enter trials. Rather, it is to introduce the option when appropriate and provide callers with the information necessary to make the decision on whether or not to participate in a trial. The clinical trials training program included a Counselor's Response Model protocol that was designed to identify which callers should receive information on clinical trials, how the subject should be introduced, and how much information should be provided based on the needs of the patient as articulated by the caller. The training program also included extensive background information on clinical trials, explaining the advantages and disadvantages of participation, eligibility criteria, insurance coverage, and potential concerns that patients may have about participation in a trial. The training was developed in the summer of 1988, pre-tested in the fall of 1988, and conducted for CIS staff members across the United States in January 1989.

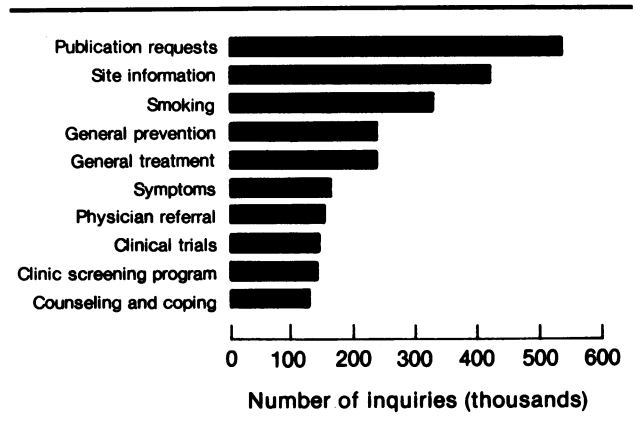
Data presented in figure 4 illustrate that overall call volume on clinical trials has risen steadily from 1983, and especially since 1986. In that year, 8,474 callers were proactively introduced by a counselor to the option of a clinical trial, representing 33.4 percent of all calls about trials. By 1988, based upon increased NCI emphasis, counselor suggestions to consider clinical trials climbed to 22,900, an increase of 270 percent from 1986. In 1989, the first year following implementation of the clinical trials training program, proactive suggestions to consider a clinical trial increased to 43,944, or 27.1 percent more proactive suggestions to consider a clinical trial than caller-initiated inquiries about trials. In 1990, the second year following the clinical trials training program, there were 40,957 proactive suggestions to seek a trial, 29.5 percent more than passive responses to inquiries about clinical trials.

Clearly, the proactive efforts of a telephone helpline can result in large-scale dissemination of complex and deeply personal information to a highly targeted audience.

Mammography screening protocol. To learn more about the effects of proactive counseling, in 1987 NCI funded a 3-year study on the implementation and evaluation of a proactive telephone counseling protocol to promote screening mammography among age-eligible women callers. These callers were randomized into one of two groups, based on alternating months within a 14-month accrual period. The control group received usual or standard service that could include a screening mammography recommendation from the CIS counselor, but only in response to a specific request or question from the caller, such as a question about breast cancer or breast cancer screening. In contrast, the intervention group received both the usual service and a proactive screening mammography promotion protocol that included both behavioral counseling and a followup mailing to reinforce the counseling session. Both groups were interviewed at 6 to 8 months afterwards to determine compliance with screening mammography guidelines.

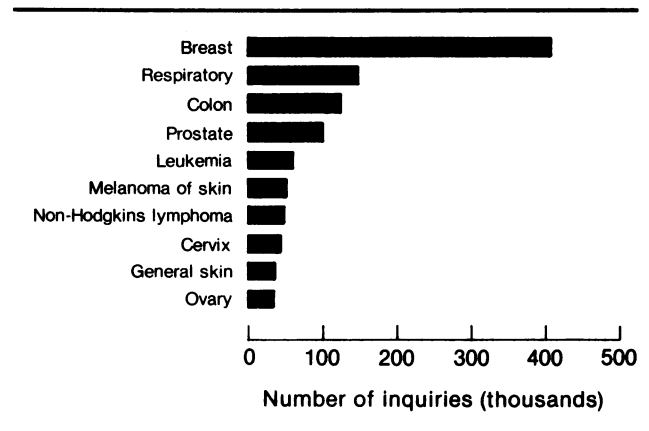
All women callers were considered eligible for the protocol if they were ages 40 or older, calling initially for reasons unrelated to breast cancer or breast cancer screening, had no previous history of breast cancer, had made no previous calls to the CIS during the accrual period, and were calling during an intervention-group month. Preliminary analyses of the telephone followup interview data indicate that the proactive counseling protocol

Figure 2. Ten most frequent information requests by subject of inquiry, National Cancer Institute's Cancer Information Service, 1983-90¹



¹Excluding calls to the Publication Ordering Service

Figure 3. Ten most frequent information requests by cancer site, National Cancer Institute's Cancer Information Service, 1983-90¹



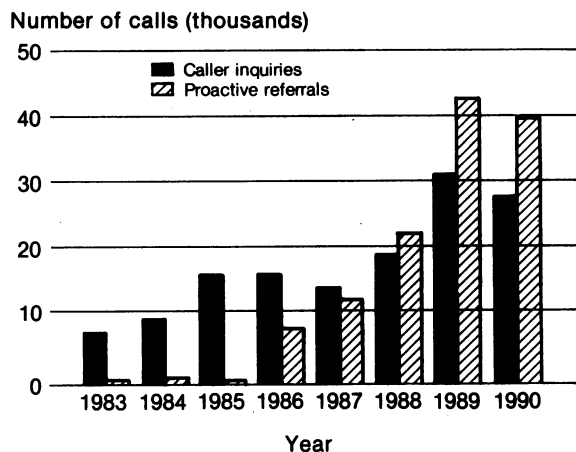
¹Excluding calls to the Publications Ordering Service

significantly increased self-reported screening mammography, but only among CIS callers reporting a total family income equal to or greater than \$30,000 a year (12). This subgroup accounts for approximately 60 percent of all eligible CIS callers in this study. In addition, it was found that the vast majority of CIS callers (>90 percent) recommended that the CIS continue providing screening mammography information in a proactive fashion.

Discussion

The future holds many opportunities for exploring the proactive use of telephone helplines as a source of both patient counseling and health promotion messages, including information that might not have been contemplated by the caller and may be unrelated to their initial subject of inquiry.

Figure 4. Caller inquiries for clinical trials versus proactive counselor referrals to clinical trials, National Cancer Institute's Cancer Information Service, 1983-90¹



¹Excluding calls to the Publication Ordering Service

From a public health viewpoint, helplines have the potential to cause a large effect because of the sheer volume of contacts with people that are made possible.

There are other advantages that should result in positive effects as well. Counselors are able to followup their personalized interaction with a reinforcement message (13,14). This opportunity is particularly attractive with certain behaviors such as smoking, because cessation is a cyclical and dynamic process of quitting and relapse (15,16) that benefits from ongoing support (17). Furthermore, people are more likely to change their behaviors and maintain changes if they have taken an active part in planning their behavioral goals (18), and a good helpline counselor can facilitate inclusion of each client in planning his or her own unique course of action. To measure effects, however, all helplines must incorporate some basic evaluation procedures. Operators of helplines need to set measurable objectives with practical criteria for planning, and they should exploit what works for improving and replicating effective efforts.

It should be noted that telephone helplines have the potential to function as laboratories for communications research and hypothesis testing, as well as providing an important service to specific communities and target groups (19). For example, randomization of callers into a proactive intervention versus a usual-service control group can provide a strong basis for scientific evaluation of particular promotion or counseling strategies, especially when combined with a followup survey or other mechanisms for assessing outcomes.

Included among the key communications issues that could be studied are

- assessing the efficacy of providing proactive behavioral counseling to population subgroups who call the helpline for reasons unrelated to the behavioral counseling in question;
- determining the extent to which a mass media campaign tagged with a helpline telephone number influences the behavior of people who never call the CIS, like smokers who quit, for example; and
- assessing the efficacy of various promotion campaigns and strategies to reach underserved populations. Including population subgroups that have traditionally underutilized telephone helplines, such as low-income or minority groups, should be one of the highest priorities.

Adding a communications research component to existing telephone helplines may, in the long term, be one of the most important strategies for maximizing their impact nationally.

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Predicting and Reinforcing Children's Intentions to Wear Protective Helmets While Bicycling

JOANNE OTIS, MSc
 DOMINIQUE LESAGE, MSc
 GASTON GODIN, PhD
 BRUCE BROWN, MD, MPH
 CELINE FARLEY, MSc
 JEAN LAMBERT, PhD

Four of the authors are with the Department of Community Health, Charles LeMoine Hospital, Greenfield Park, Quebec, Canada. Ms. Otis is a health promotion adviser as well as a doctoral candidate in the Department of Social and Preventive Medicine, Université de Montréal. Ms. Lesage is a Research Assistant. Dr. Brown is Coordinator of the Trauma Prevention Program. Ms. Farley is responsible for the Bike-Helmet Promotion Program.

Dr. Godin is Professor of Nursing, Laval University. Dr. Lambert is Associate Professor, Department of Social and Preventive Medicine, Université de Montréal.

Tearsheet requests to Joanne Otis, MSc; DSC, Hôpital Charles Lemoyne, 25, boul. Taschereau, bureau 200, Greenfield Park, Quebec, Canada J4V 2G8; tel. (514) 987-7874.

BICYCLE-RELATED INJURIES are an important health problem among 5- to 14-year-olds (1-4), accounting for about 8 percent of all deaths in this age group in the Province of Quebec (5).

Head injury is responsible for about 80 percent of deaths from injuries incurred while bicycling (6, 7). More than 60 percent of hospitalizations for injuries related to bicycle riding are head injuries

Synopsis

The researchers undertook to identify the factors that are most likely to influence children's intentions to use bicycle helmets. To determine the most important intention influencing factors, a random sample of 797 students in grades 4 through 6 completed a self-administered questionnaire concerning their beliefs about helmet use. They were asked about their perceptions of the risk of riding bicycles unprotected, the severity of possible head injuries, and about other bicycle-safety related behaviors.

Factors that best predicted the student's intentions to use bicycle helmets involved both behavioral beliefs and normative beliefs. Analysis of factors influencing those with low intentions to use helmets, compared to those with high intentions, suggests the most effective messages that health planners can provide preadolescents to influence them to use helmets. They are that helmet use is fun and attractive, helmets provide a new look and a sporting image, and friends approve of and value this behavior. Parents, and particularly mothers, can reinforce their children's intentions to use helmets and their involvement should be encouraged.

(5, 8). Helmet use reduces both frequency and severity of head injuries among cyclists (9-11). Although the use of bicycle helmets by children can be increased by promotional interventions (12-16), the level of helmet use among children is low, varying from 2 to 4 percent of bicycle riders of that age across North America (17, 18).

Studies have identified factors linked to use or