

## RESEARCH BRIEF

# Conducting Intervention Research Through the Cancer Information Service: A Feasibility Study

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**Purpose/Objectives:** To determine the feasibility of conducting trials of educational interventions regarding pain and quality of life (QOL) with people who call the National Cancer Institute's Cancer Information Service (CIS).

**Design:** Descriptive.

**Setting:** North Central CIS, located at the University of Wisconsin Comprehensive Cancer Center in Madison.

**Sample:** Callers to the North Central CIS who self-identified as people diagnosed with cancer or as family members or friends of people diagnosed with cancer were eligible. 102 people with cancer and 103 significant others answered questions concerning the feasibility of a pain study, and 101 significant others completed questions about the feasibility of a QOL study.

**Methods:** Eligible CIS callers were invited at the end of usual service to participate in a research study. Those who agreed were asked structured questions regarding pain or QOL.

**Main Research Variables:** Response rate, length of time to complete recruitment, concerns about reporting pain and using analgesics, concerns about QOL, demographic variables, and willingness to join a hypothetical study.

**Findings:** The majority of callers had concerns about pain and QOL, and the vast majority (78%–89%) of participants indicated a willingness to join a future educational intervention study.

**Conclusions:** Using subjects recruited through CIS, conducting trials of brief telephone interventions designed to help patients overcome barriers to pain management or assist families in addressing QOL concerns may be feasible.

**Implications for Nursing:** Researchers may wish to consider the opportunities afforded by collaborating with CIS colleagues in planning and conducting studies of educational interventions.

### Key Points . . .

- The vast majority of participants calling the Cancer Information Service (CIS) responded that they would be willing to participate in a telephone-delivered educational intervention for either pain management or family quality of life.
- The numbers of willing participants and the short time to collect data support the feasibility of conducting telephone-based interventions through CIS.
- The number and types of concerns regarding pain management and family quality of life reported by patients and significant others calling CIS suggest a need for nursing interventions.
- These results provide researchers with data needed to demonstrate to funding sources that conducting a study of a telephone-delivered intervention using CIS would be feasible.

munications (Thomsen & Ter Maat). The CIS Research Initiative provides an avenue for subject recruitment to cancer control researchers. CIS has been involved in studies conducted by the CIS Research Consortium that have been completed successfully, with large numbers of participants recruited in short periods of time (Marcus, 1998; Marcus et al., 1998). These studies involved issues such as fruit and vegetable consumption as cancer prevention. Whether similarly

As the United States' foremost source for cancer information (Thomsen & Ter Maat, 1998), the National Cancer Institute's (NCI's) Cancer Information Service (CIS) communicates the latest research findings on cancer prevention, detection, treatment, and supportive care to patients, the public, and healthcare professionals. CIS has three ways of providing this information. The first is through a toll-free telephone number (800-4-CANCER) and the Internet using instant messaging technology. The second is a partnership program that collaborates with organizations to provide cancer information to minority and underserved audiences. The third is a Research Initiative in Cancer Com-

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successful recruitment would occur in studies of more emotionally difficult topics, such as pain and quality of life (QOL), is unclear.

Pain and QOL have been identified by oncology nurses and the National Institute of Nursing Research as top research priorities (Hinshaw, 2000; Stetz, Haberman, Holcombe, & Jones, 1995). In addition, NCI and the Office of Cancer Survivorship are promoting QOL research. Further, a growing body of nursing research indicates that families and significant others of patients with cancer report as much or more distress and lower QOL than the patients themselves (Clipp & George, 1992; Hardwick & Lawson, 1995; Kurtz, Given, Kurtz, & Given, 1994; Robinson et al., 1998; Stetz, 1987). Thus, trials of novel interventions are needed in these areas. Obtaining adequate sample sizes in a reasonable period of time and in a single setting is difficult in studies of educational interventions. Collaborating with CIS to conduct such studies may be an opportunity to overcome these difficulties.

Given the success of prior intervention studies using CIS recruitment, the resource of potential study participants available through CIS, and the need to address pain and QOL issues in people with cancer and their significant others, the present study was conducted to determine the feasibility of testing brief telephone interventions regarding pain or QOL delivered to CIS callers. These feasibility data could be useful to investigators seeking funding support for such studies. The specific research questions addressed were: (a) What percentage of eligible callers will be invited to participate by CIS staff? (b) How long would it take to reach the recruitment goal? (c) What percentage of callers who are invited to participate will agree to participate in this feasibility study? (d) What percentage of callers would be willing to join a future telephone-based intervention study? (e) What is the prevalence of concerns about pain and analgesic use among callers to the CIS? and (f) What is the prevalence of QOL concerns among CIS callers?

## Methods

### Overview

The study can be viewed as consisting of two substudies that ran consecutively: One studied pain, whereas the other studied QOL. The development and implementation of all phases of both substudies were a collaborative effort between University of Wisconsin investigators and North Central CIS staff members. CIS information specialists (N = 8) who respond to telephone inquiries were the data collectors. For each substudy, a pilot survey of 10 callers was conducted before beginning the formal study to determine the final survey format, instructions, and wording of items. This research study was approved by the Health Sciences Center Institutional Review Board at the University of Wisconsin.

### Participants and Procedure

For the pain substudy, the criteria for inclusion were callers to CIS who were patients diagnosed with cancer or significant others (e.g., spouses, relatives, friends of patients). For the QOL substudy, because the focus was family concerns affecting QOL, participants were significant others or family members of people with cancer. For both substudies, eligible

callers were asked by a CIS information specialist at the end of the usual service to participate in a research study that would take an additional five to seven minutes of telephone time. The purpose of the study was explained and verbal informed consent obtained. Data collection continued for each substudy until recruitment goals were achieved: 100 patients and 100 significant others for the pain substudy and 100 significant others for the QOL substudy.

### Instruments

For the pain substudy, a checklist of 15 items was developed based on the Barriers Questionnaire, a validated instrument that addresses common concerns that are barriers to reporting pain and using analgesics, such as exaggerated fear of addiction (Ward, Carlson-Dakes, Hughes, Kwekkeboom, & Donovan, 1998; Ward et al., 1993). Participants responded “yes” or “no” to each item.

For the QOL substudy, a 26-item checklist was developed based on the empirical literature identifying the major concerns and stressors of family members of patients with serious illnesses and cancer (Clipp & George, 1992; Hardwick & Lawson, 1995; Kurtz et al., 1994; Robinson et al., 1998). Major areas of concerns included mood and symptoms, impact on personal life, finding information about cancer and treatments, and providing or receiving emotional support. Participants responded “yes” or “no” to each item.

The pain and QOL substudies included an item regarding willingness to participate in future studies: “Our Cancer Information Service is considering doing a research project in the future that would involve teaching patients and family members about [managing pain/improving quality of life]. It would take about 10 minutes of someone’s time on the telephone and another 10 minutes to complete a mailed questionnaire. If you called our service in the future and such a study were offered, would you join it?” Response options were “no,” “yes,” and “not sure.” The surveys ended with a brief set of demographic questions.

## Results

Data relevant to research questions one through four can be found in Table 1 and are summarized here. In the pain substudy, 95% of eligible patients and 100% of eligible significant others were invited by CIS staff members to join the study; 91% of these patients and 85% of these significant others agreed to do so. Recruitment goals were attained in 14 days. In the QOL substudy, 99% of eligible callers were invited to join the study; 69% agreed to do so, and recruitment goals were attained in 22 days. In both substudies, most participants were female, and the average age was 50–58. The vast majority of participants (78% and 89% for pain, 86% for QOL) responded “yes” to the hypothetical question about willingness to join a future study.

To assess the prevalence of pain or QOL concerns, the number of “yes” responses on each list of concerns was tabulated, and the mean number of concerns was computed (see Table 1). For each substudy, the top 10 concerns—in terms of frequency of “yes” responses—were determined (see Table 2).

Of the 15 concerns in the pain substudy, on average participants responded “yes” to 4. Although the mean number was not high, the most frequently reported concerns reflected

**Table 1. Sample Characteristics**

Variable	Pain Participants		Quality-of-Life Participants
	Patients	Significant Others	Significant Others
Number of eligible callers	118	121	148
Number (%) invited	112 (95%)	121 (100%)	146 (99%)
Number (%) accepting	102 (91%)	103 (85%)	101 (69%)
Time to recruitment goal (days)	14	14	22
Age (years)			
$\bar{X}$	58	52	49.8
SD	12.2	14.1	13.9
Female participants	67%	85%	83%
Patients' diagnostic situation			
New diagnosis, no treatment	33%	20%	34%
New diagnosis, current treatment	27%	48%	37%
Post-treatment	19%	9%	8%
Recurrence	21%	22%	21%
Other	—	1%	—
Number (%) responding "yes" to hypothetical question about joining future study	80 (78%)	92 (89%)	86 (86%)
Number of potential concerns			
$\bar{X}$	15	15	26
SD	4.3	5.3	11.4
SD	2.43	2.67	5.26

**Table 2. Top 10 Concerns in Each Substudy**

Concern	Yes Responses	
	n	%
<b>Barriers to reporting pain and using analgesics (N = 205)</b>		
1. Pain medicine hides changes in one's body.	166	81
2. Pain with cancer is inevitable.	98	48
3. People get addicted to pain medicine easily.	98	48
4. Pain is a sign that the cancer has gotten worse.	98	48
5. The time for aggressive pain management is when the cancer no longer can be treated.	98	48
6. Pain medicine works best when given as a shot.	85	42
7. Pain medicine cannot really control cancer pain.	59	29
8. Pain medicine weakens the immune system.	59	29
9. Side effects from pain medicine are worse than the pain.	53	26
10. Complaints of pain could distract a doctor from focusing on treating the cancer.	40	20
<b>Concerns about quality of life (N = 100<sup>a</sup>)</b>		
1. Feeling anxious or afraid	81	81
2. Feeling depressed	71	71
3. Difficulty sleeping	68	68
4. Wondering how to provide emotional support to your loved one	63	63
5. Getting information on the course of disease and prognosis	62	62
6. Having physical symptoms (e.g. stomach upset, backache)	61	61
7. Worrying how loved one's cancer will affect future plans	58	58
8. Getting information about cancer	56	56
9. Feeling lonely	53	53
10. Feeling angry	52	52

<sup>a</sup> One subject was dropped because of incomplete data.

some of the major difficult barriers to the management of cancer pain (e.g., "pain with cancer is inevitable"; "people get addicted to pain medicine easily"). Of the 26 concerns in the QOL substudy, on average participants responded "yes" to 11. The most frequently reported concerns were in the areas of moods and symptoms, providing emotional support to the person with cancer, and plans for the future.

## Discussion

The results of this study will provide researchers with the data they need to demonstrate to funding sources that it would be feasible to conduct a study of a telephone-delivered intervention using CIS. The high percentage of callers who reported that they would be interested in such a study attests to the feasibility of conducting such studies. CIS staff participation in data collection and the rapid pace with which data were collected provide additional support for the feasibility of conducting research with CIS.

These results also suggest that pain intervention studies, which potentially could be delivered by telephone, are needed, as evidenced by the percentage of "yes" responses to some of the items about barriers and the very high percentage of respondents who were willing to join such a study if one was offered. Similarly, QOL interventions for families may be needed, as evidenced by the high percentage of callers who had QOL concerns and agreed to join a telephone intervention study if one was offered. Thus, the data in this study support the feasibility of conducting trials of telephone-delivered interventions that address difficult topics such as pain and family QOL among patients with cancer and their family members who call CIS.

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### For more information . . .

- Cancer Information Service  
[www.cis.nci.nih.gov](http://www.cis.nci.nih.gov)
- National Cancer Institute  
[www.cancer.gov](http://www.cancer.gov)
- Breast Cancer Information Service  
[www.bcis.org](http://www.bcis.org)

*Links can be found using ONS Online at [www.ons.org](http://www.ons.org).*