

The Role of Community-based and Philanthropic Organizations in Meeting Cancer Patient and Caregiver Needs

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ABSTRACT We examined information from community-based and philanthropic organizations to document the cancer-related services that are currently available, establish which services are still needed, and determine who utilizes these formal support networks. In Phase I, 32 of 41 eligible organizations participated in a survey conducted from December 1999 to March 2000. The most common mission focus among participating organizations was information/referral-centered. The most common services provided were referrals to information resources and provision of cancer-related information. Only two of the organizations in Phase I provided client demographic information and both indicated that client populations were predominantly white, female, and over age 40. Phase II of the study involved analyzing patient data from Cancer Care, Inc., a national service organization for cancer patients. Between 1983 and 1997, there were 2,714 prostate cancer patients and 9,451 breast cancer patients included in the Cancer Care database. Their most commonly reported problems were related to personal adjustment to illness, financial, home care, and transportation needs. There were significant differences in problems reported depending upon age and disease status.

In addition, the results of this study support the idea that those at highest risk for developing and dying of cancer are the least likely to utilize formal support networks. Further, a gap in service provision for assistance with practical needs (e.g., transportation, home care, child care, psychosocial support) was identified. Due to the increasing use of outpatient care for cancer patients, a greater demand for practical assistance can be expected in the future. The availability of practical services will need to be increased in order to effectively meet cancer patient needs. (*CA Cancer J Clin* 2002;52:229-246.)

INTRODUCTION

Due to rapid changes in the traditional medical care model for cancer patients, current patient needs are increasing as new needs arise. The increased use of outpatient services for cancer treatment, shortened hospital stays, longer survival, and the rise in the number of patients receiving home hospice care have created a greater need for assistance with regard to transportation, home medical care,

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This research was funded by a contract from Cancer Care, Inc. and by the National Cancer Institute (K07-CA72645) to Kathryn L. Taylor, PhD.

This article is also available at www.cancer.org.

activities of daily living, and out-of-pocket expenses.¹⁻⁴ Further, the focus on shared medical decision-making and the greater demands placed on caregivers providing home care has increased the need for treatment-related cancer information.⁵

As the needs of cancer patients and their families increase, informal support networks (e.g., family, friends) may become strained and unable to meet the greater demand for assistance.⁶ When patient needs become too much for the informal support network to manage, formal support networks (e.g., community organizations) are needed.

Community-based and philanthropic organizations have historically provided cancer patients and their families with essential services that have been unavailable from traditional medical sources. In the past several years, reliance on these organizations has become even greater. In an effort to better understand who utilizes these formal support networks, which services are currently available, and what services are needed, we undertook a two-phase study. In Phase I, we accessed the National Cancer Institute's Cancer Net,⁷ the Y-Me Web site links,⁸ Cancer Resources,⁹ and telephone directories, and we identified 71 national, regional, and local nonprofit organizations that provide information, referral, financial assistance, counseling, and other services for patients with cancer and their families. Forty-one of these organizations met our inclusion requirements, and information was received from 32 of the 41 eligible organizations. The goal of Phase I was to compile information about the services these organizations provide and obtain demographic information about their client population.

In Phase II, our objective was to closely examine a single organization in terms of its services, client demographics, medical characteristics, and client needs. Cancer Care, Inc. (CCI), which offers free emotional

support, education, information, referral, and financial assistance to cancer patients and their families, was included in Phase II.¹⁰ By examining data from Phase I and Phase II together, our goal was to identify cancer patient and caregiver needs that are not met by existing services as well as those needs that are already satisfied by existing services.

REVIEW OF LITERATURE ON CANCER PATIENT NEEDS

Needs most often reported by cancer patients and caregivers include those related to: personal adjustment to illness (38 to 70 percent); psychosocial support (30 to 60 percent); transportation issues (31 to 58 percent); financial assistance (50 to 52 percent); home care (10 to 42 percent); and medical information (3 to 29 percent).^{2,3,11-13} Studies examining the needs of cancer patients and caregivers have found that 60 to 90 percent of patients report a need for assistance in at least one area, with 18 to 30 percent reporting that at least one need for assistance remains unmet.^{2,6,14,15} Those most likely to report unmet needs include younger patients, low-income patients, those without children nearby who can assist them, those with a caregiver who is not their spouse, and those with smaller and less resilient support systems.^{2,12,15} Since unmet needs for assistance can interfere with patient-treatment compliance, compromise patient health status, and reduce quality of life,¹⁶ it is important to identify patient needs and those patients most at risk for having unmet needs.

Financial Needs

The financial impact of cancer is far reaching and includes costs beyond what medical insurance plans cover. In one study, the most intense burden reported by cancer caregivers was financial.¹⁷ As new cancer

treatments allow patients with complex medical problems to live longer, these concerns can become increasingly important.¹⁸ As a patient's functional capacity diminishes, out-of-pocket expenses rise due to an increase in needs for such necessities as: transportation, child care, home care services, extra or specific foods, clothing, and lost income and wages.^{19,20} Since medical insurance plans do not cover expenses for needs in these areas, patients may be unable to afford these services. If such needs remain unmet, a patient can face setbacks in treatment adherence, overall functioning capacity, and quality of life.

The out-of-pocket expenses related to cancer do not differ by income level, indicating that both low- and high-income patients absorb the same or similar costs.¹⁹ Additional out-of-pocket expenses due to cancer coupled with gaps in medical insurance coverage may cause long-term financial difficulty and jeopardize patients' ability to obtain or keep health insurance coverage.¹⁸ In a study examining the financial impact of cancer, Mor et al. found that 41 percent of households studied reported a 50% increase in expenses and 16 percent of households studied were unable to meet their monthly bills by at least \$1,000.²¹ Further, in a study conducted by CCI in 1999, monthly expenses exceeded available monthly income by an average of \$1,900.²²

Additional financial problems occur among low-income families. For example, patients with a low-socioeconomic status often have difficulty obtaining medical care or home care assistance, as the eligibility criteria for Medicare and Medicaid have become increasingly stringent, with only 40 percent of the poor qualifying for Medicare and/or Medicaid in 1985 compared with the approximately 70 percent who met the criteria during the 1970s.^{18,23} For many of the working poor who do not qualify for public assistance and cannot afford health coverage, prolonged

illness may cause them to lose employment altogether.¹

Transportation Needs

Access to transportation or lack of it directly impacts patient ability to adhere to treatment regimens and receive medical care. Among elderly cancer patients, Goodwin et al. found that those with less access to transportation were four times less likely to receive radiation therapy following surgical treatment.²⁴ In a study examining the needs of low-income cancer patients, almost half reported difficulty finding transportation, which impinged upon their ability to obtain treatment and care.²⁵ Providing information materials regarding transportation options did not help them. This could suggest that even when aware of alternative services, patients need assistance completing paperwork and understanding eligibility requirements. Those most likely to experience transportation difficulties are older, African American or Hispanic, reside further away from their treatment center, and live on a low income.^{24,26}

Personal Adjustment to Illness and Psychosocial Support Needs

Bunston and Mings¹¹ assert that the psychosocial needs of cancer patients are clinically relevant because such needs can impact treatment adherence, quality of life, subsequent affective illness, and medical care outcomes. Because a diagnosis of cancer may be accompanied by feelings of anger, helplessness, fear, and depression, one's personal adjustment to illness comprises a significant proportion of psychosocial support needs among cancer patients.^{27,28} While post-diagnosis distress may decrease within a period of six-to-twelve months time, many cancer patients continue to experience elevated levels of distress as long as five years after diagnosis.²⁹

Studies examining the needs of cancer patients and caregivers have found that 40 to 50 percent of patients reported psychosocial support needs and over half reported at least one unmet need in this area.³⁰⁻³³ Patients who were younger, female, unmarried, and living at a low-income level with advanced disease were most likely to report unmet psychosocial needs.³² Mor et al. assert that an increase in unmet psychosocial needs may occur as cancer advances due to a decline in the patient's functional capacity and ability to make use of opportunities for social interaction.³⁴ And though patients are reporting high levels of psychosocial support needs, their health care providers are not actively promoting formal support networks. Guidry et al. found that a majority of their study sample had never been asked to join a support group³⁵ and Chan and Woodruff found that less than half of their study sample, which was comprised of advanced-stage cancer patients, were given referrals to social services.³⁶ This suggests that the psychosocial needs of cancer patients may be underestimated and/or that they do not receive adequate attention from health care providers.

Home Care for Daily Activity Needs

Needs for assistance with personal care (e.g., bathing) and daily activities (e.g., housekeeping, shopping) increase as cancer progresses. As patient needs increase, the likelihood of having an unmet need also increases.³⁴ In a study by Heinrich and colleagues, the majority of patients reported a severe impact on day-to-day functioning with over 90 percent reporting problems with physical appearance and ability, 85 percent reporting problems with physical activities, and over 50 percent reporting difficulties sleeping, eating, and carrying out domestic tasks.³⁰ Of patients with unmet needs, over half reported needing help in all areas of daily activities,²¹ and

both patients and caregivers cited personal care as one of the most intensely unmet needs they experienced.³⁷ Since needs, such as assistance with daily living activities, represent additional out-of-pocket expenses, they may remain unmet.

Communication with Health Care Professionals and Medical Information Needs

Unmet needs for both cancer-related information and assistance with understanding medical communications can lead to lapses in treatment adherence, increases in patient anxiety, reduced quality of life, and diminished understanding of symptoms or treatment side effects. Heinrich et al. reported that among a study sample of cancer patients, a majority indicated problems communicating with medical staff and understanding what medical staff said.³⁰ Among hospitalized cancer patients, Tamburini et al. report that over 50 percent of patients in the study sample indicated they had unmet needs regarding information about their diagnosis, future condition, exams, and treatment.³⁸ When patients do not understand medical communications or if they desire more information, they may be reluctant to seek assistance due to time constraints in the clinical setting or the desire to obtain information anonymously. For these patients, information and support provided by a telephone hotline has been a feasible option.³⁹

For patients who have difficulty understanding written information or understanding English, additional barriers to obtaining information exist. In the United States, approximately 20 percent of the population is functionally illiterate. This percentage is higher among older persons, ethnic minorities, and low-income groups. Since most cancer literature is written at a tenth-grade reading level, it remains inaccessible to many patients and caregivers.⁴⁰ In effect, patients who have difficulty

understanding English need assistance with information given to them by medical professionals.

In a comparison between the needs of English and non-English speaking palliative care patients, Chan and Woodruff found that non-English speaking patients were less likely to have a complete understanding of their diagnosis, less likely to have adequate pain control, and less likely to die at home.⁴¹ Assistance in understanding information regarding diagnosis, treatment options, and prognosis could dramatically improve care among non-English speaking patients.

Factors Impacting Patient Needs

Due to the effect of unmet needs on patient treatment compliance, health status, and quality of life, it is important to identify demographic and medical characteristics that influence patient needs. Although the needs reviewed in the previous section are almost universal among cancer patients, there are several factors that, if combined, can result in a patient having an even greater level of need. Characteristics that have been shown to impinge upon patient and caregiver needs include age, disease stage, and treatment status.^{42,43} Identifying factors that impact a patient's needs can help health care service providers better understand patient concerns and take steps to resolve needs.

Patients' quality of life is influenced by treatment status and disease progression with those at diagnosis having the highest quality of life, followed by those in treatment, and diminishing further for terminal patients.³⁴ Studies examining the needs of cancer patients report that those in the first year of diagnosis and those with early-stage disease (i.e., Stage I and II disease) report fewer needs, are less likely to have unmet needs, and are less likely to develop new needs compared with metastatic patients.^{6,16,17,44} As cancer progresses, patient functioning deteriorates making it even more

difficult to fulfill all patient needs. In a study examining the unmet needs of cancer patients, Houts et al. found that terminal patients were three times more likely to report unmet needs related to daily activities compared with those in their first year of diagnosis.⁴⁴

In addition to increasing needs, patient needs change over time and as a function of treatment status. At diagnosis, patients often focus on obtaining cancer-related information and support to help them adjust to their illness. Once patients begin treatment, important needs and concerns include: management of treatment side effects, transportation, work time-off issues, and coping with functional decline. Among patients studied in a cancer center setting, the reported concerns include a desire for adequate preparation for discharge from the hospital; finding a caregiver; work time-off issues; and the need for treatment information, active decision-making, and support.⁴⁵

Terminal patients may experience the highest levels of need due to disease progression, increased symptoms, and functional decline. The goal of treatment shifts from achieving remission to controlling disease symptoms (e.g., pain, fatigue) and maintaining patient quality of life.^{36,46} Gates et al. found that among hospice patients, the most important needs reported included support from family and friends, frequent and honest communication, and coping with illness and death.⁴⁵

Utilization of Formal Support Services

While findings show that groups at high risk for developing and dying of cancer underutilize support services,⁴⁷⁻⁴⁹ little is known about the reasons patients and their families do not seek such assistance. Hypothesized reasons patients and caregivers may not utilize community support resources include lack of awareness about available

services, lack of knowledge about how to access services, financial constraints, fear of the stigma of accepting help, family resistance, patient refusal of care, and transportation problems.^{5,50} Lack of knowledge appears to be one of the biggest barriers to receiving needed assistance. Siegel et al. report that the majority of cancer patients who were enrolled in a needs-assessment program demonstrated poor knowledge about available services.¹⁴ Mor et al. found that in rural areas, those patients who were male, older, and had less education showed low levels of knowledge regarding hospice care and its availability.⁵¹ The lack of knowledge regarding available services may be greater among those who cannot afford medical care because most people either learn about or are referred to community services through the medical care system.¹⁸

The purpose of the current study is to examine formal support networks in order to document which cancer-related services are currently available, what services are needed, and who utilizes formal support networks. As medical care for cancer patients becomes increasingly outpatient-based and patients become more involved in making medical decisions, non-medical resources for cancer patient care and cancer-related information are in greater demand. A large body of knowledge exists regarding cancer patient and caregiver needs, but little is known about the community-based and philanthropic organizations designed to meet these needs. By examining a subset of these organizations and their clients, our goal was to provide valuable information to medical professionals, cancer patients and their families, and the organizations working to provide such services.

PHASE I: SURVEY OF ORGANIZATIONS PROVIDING SERVICES AND INFORMATION TO CANCER PATIENTS AND THEIR FAMILIES

Method

Organizations

Phase I of this project involved collecting information regarding the characteristics, services, and client information of the nonprofit organizations providing services to cancer patients and their families. Nonprofit organizations were found through the National Cancer Institute's Cancer Net,⁷ the Y-Me Web site links,⁸ Cancer Resources,⁹ and telephone directories. Seventy-one organizations were identified and contacted by telephone to determine eligibility and interest in participation. Eligible organizations were those that focused on providing services to cancer patients, provided services to a geographic area at least as large as one US state, and were currently in operation. Thirty organizations were excluded from the study based on one or more of the above criteria.

Of the remaining 41 organizations, 32 (78 percent) completed the questionnaire, which included four organizations that provided a demographic profile of their clients. Nine organizations (22 percent) did not return the questionnaire due to: 1) a lack of staff time (N = 3); 2) a decision to decline to participate (N = 4); and 3) a failure to complete the questionnaire prior to the study deadline (N = 2).

Procedure

A mailing, consisting of an introductory letter and questionnaire, was sent to each organization, addressed to a contact established there in advance. Reminder calls were conducted at three- and six-week intervals following the mailing. Organizations that did not return the questionnaire by the 10-week cut-off date were classified as having declined to participate.

Measures

ORGANIZATION INFORMATION

Participants indicated: 1) the organization's primary mission; 2) the types of cancer for which services are provided; 3) the geographic areas receiving service; and 4) the primary methods of referral.

SERVICE PROVISION

Participants indicated whether their organization provided services via the Internet, by mail, in person, or by telephone. Participants also indicated which services were provided through each mode of contact.

HOTLINE CHARACTERISTICS

Those organizations providing a hotline indicated whether their telephone numbers are toll free; whether calls are answered by a telephone operator or through a messaging system; whether bilingual/Spanish services are provided; the service's hours of operation; and the background or training of their telephone operators. Organizations were also asked whether client quality of life was assessed and the method of assessment used.

CLIENT INFORMATION

Organizations that collected client data provided: client demographic information; clients' reasons for contacting the organization; caller identification (e.g., patient, family member); the patient's age; length of time since diagnosis; ethnicity; marital status; gender; tumor site; disease stage; medical insurance coverage status; and treatment status.

Results

Organization Characteristics

Among the 32 organizations participating in this study, the most frequently cited services included: information/referral-based assistance (87.5 percent); educational assistance (87.5 percent); advocacy assistance (75 percent); and counseling/support (56 percent) (Table 1).

While 38 percent of organizations provided services for all tumor sites, most organizations providing services for a single cancer site (43 percent) served breast cancer only. Ninety-one percent of organizations provided services to the entire United States with 39.4 percent also providing services outside the United States.

Service Provision

When asked which modes of contact were used to provide services, 97 percent indicated the telephone, 97 percent indicated the mail, 84 percent indicated the Internet, and 69 percent indicated person-to-person contact. As seen in Table 2, the four most common services provided included referrals to information resources (100 percent), provision of cancer-related information (84.4 percent), distribution of a newsletter (84.4 percent), and referrals to counseling/support services (78.1 percent).

Hotline Characteristics

Among those organizations providing services by telephone (N = 31), 77 percent (N = 23) provided a telephone hotline (Table 3). Most of the hotlines were toll free (87 percent) and over half provided bilingual/Spanish hotline services (52.2 percent). The majority (87 percent) of hotline operators consisted of employees or volunteers trained by the organization. Among the 13 hotlines collecting quality-of-life information, 15 percent assessed all callers, while 85 percent only assessed callers seeking counseling or psychosocial support. Only two hotlines used a standardized quality-of-life measure with the majority (84 percent) using open-ended questions.

Client Information

Approximately one-half of organizations reported that they tracked client information

TABLE 1

Phase I Organization Information				
Organization	Mission*	Cancer Site	Geographic Area	Contact Information
Adelphi NY Statewide Breast Cancer Hotline and Support Program	1,2,3,4,8	Breast	New York	800-877-8077 www.adelphi.edu/ nysbreastcancer/
AMC Cancer Research Center	1,2,4,5,8	All Sites	Entire US	800-525-3777 www.amc.org
American Cancer Society	1,2,3,4,5,8	All Sites	Entire US	800-ACS-2345 www.cancer.org
American Foundation for Urologic Disease	1,2,3,4,5,8	Prostate, Bladder, and Kidney	Entire US Outside US	800-242-2383 www.afud.org
American Institute for Cancer Research	2,5,8	All Sites	Entire US	800-843-8114 www.aicr.org
American Society of Clinical Oncology	1,2,3,5	All Sites	Entire US Outside US	703-299-0150 www.asco.org
Brain Tumor Foundation for Children, Inc.	1,2,3,4,5,8	Brain	Southeast US	770-458-5554 www.btfcginc.org
Cancer Care, Inc.	1,2,3,4,5,8	All Sites	Entire US Outside US	800-813-HOPE www.cancercare.org
Cancer Research Foundation of America	1,2,3,5,8	Lung, Breast, Prostate, Colorectal, Testicular, Ovarian, Skin, and Cervix	Entire US	800-227-2732 www.preventcancer.org
Candlelighters Childhood Cancer Foundation	1,2,3,4	All Sites	Entire US Outside US	800-366-CCCF www.candlelighters.org
Children's Hospice International	1,2,3,5,8	Pediatric Cancers	Entire US Outside US	800-2-4-CHILD www.chionline.org
Cure for Lymphoma Foundation†	1,2,3,4,5,6,8	Lymphoma	Entire US	800-500-9976 www.lymphoma.org
Hospice Education Institute	1,2,3,4,8	All Sites	Entire US Outside US	800-331-1620 www.hospiceworld.org
International Myeloma Foundation	1,2,3,4,5,8	Myeloma	Entire US Outside US	800-452-CURE www.myeloma.org
Kidney Cancer Association	1,2,3,5	Renal Cell	Entire US Outside US	800-850-9132 www.kidneycancer association.org
Leukemia Society of America	1,2,3,4,5,6	Leukemia, Lymphoma, and All Hematological Malignancies	Entire US	800-955-4LSA www.leukemia.org
Lymphoma Foundation of America	1,2,3,4,5,8	Lymphoma	Entire US	202-223-6181 www.lymphomahelp.org
Lymphoma Research Foundation of America†	1,2,3,4,5,6,8	Leukemia, Lymphoma	Entire US	800-500-9976 www.lymphoma.org
Multiple Myeloma Research Foundation	1,2,3,5	Multiple Myeloma	Entire US Outside US	203-972-1250 www.multiple myeloma.org
National Alliance of Breast Cancer Organizations	1,2,3,8	Breast	Entire US	888-80-NABCO www.nabco.org
National Brain Tumor Foundation	1,2,5,8	Brain	Entire US	800-934-CURE www.brainumor.org

TABLE 1—Continued

Organization	Mission*	Cancer Site	Geographic Area	Contact Information
National Coalition for Cancer Survivorship	1,2,3,8	All Sites	Entire US	877-622-7937 www.canceradvocacy.org
National Hospice and Palliative Care Organization	1,2,3,5,8	All Sites	Entire US	800-658-8898 www.nhpco.org
National Lymphedema Network	1,2,3,4,5	Breast	Entire US Outside US	800-541-3259 www.lymphnet.org
National Ovarian Cancer Coalition	1,2,3	Ovarian	Entire US Outside US	888-OVARIAN www.ovarian.org
Share	1,2,3,4,8	Breast, Ovarian	Northeast US	Breast: 212-382-2111 (English); Ovarian: 212- 719-1204 (English); 212-719-4454 (Spanish) www.sharecancer support.org
Sunshine Kids	4,7	All Pediatric Sites	Entire US	800-594-5756 www.sunshinekids.org
Susan G. Komen Breast Cancer Foundation	1,2,3,4,5,8	Breast	Entire US Outside US	800-462-9273 www.komen.org
The Wellness Community	1,2,3,4,5	All Sites	Entire US	888-793-WELL www.wellness-communi- ty.org
Vital Options and The Group Room Cancer Radio Talk Show	1,2,3,4,8	All Sites	Entire US	818-788-5225 (vital options); 800-GRP- ROOM (radio talk show) www.vitaloptions.org
Y-Me National Breast Cancer Organization, Inc.	1,2,3,4,8	Breast	Entire US Outside US	800-221-2141 (English) 800-986-9505 (Spanish) www.y-me.org

*Mission: 1. Information/Referral. 2. Education. 3. Advocacy. 4. Counseling/Support. 5. Research Funding. 6. Financial Assistance. 7. Recreational Activities. 8. Hotline/Helpline.

† In November 2001, the Cure For Lymphoma Foundation and the Lymphoma Research Foundation of America merged to become the Lymphoma Research Foundation. Contact information for the Lymphoma Research Foundation is provided above.

(53 percent, N = 17). However, only two organizations provided client demographic information, four organizations provided reasons for contact based on collected data, and four organizations provided reasons for contact based on estimated data. The remaining organizations were unable to provide data because data were not readily available or contained confidential information. Cancer Care, Inc. and the AMC Cancer Research Center (AMC) provided data for client

demographic information from 1998 to 1999. For both organizations, the majority of callers was female, white, and over age 40. Breast cancer was the tumor site that was most often identified as the reason for the call.

In terms of client reason for contact, AMC and CCI reported their clients' primary reason for calling (one reason per client) instead of reporting all client concerns (Table 4). In general, the reasons for contact reflected the mission of the organization. The most

TABLE 2

Phase I Services Provided					
Services	Telephone 97% (N = 31)	Mail 97% (N = 31)	Internet 84% (N = 27)	In Person 69% (N = 22)	All 100% (N = 32)
Information Resource Referral	90.3%	67.7%	88.9%	59.1%	100.0%
Cancer Information	71.0%	83.9%	85.2%	—	84.4%
Newsletter	—	80.6%	81.5%	—	84.4%
Support/Counseling Referral	71.0%	51.6%	63.0%	63.6%	78.1%
Telephone Hotline or Helpline	74.2%	—	—	—	72.7%
Educational Seminars	35.5%	—	—	86.4%	68.8%
Support/Counseling for Patients	58.1%	—	55.6%	50.0%	68.8%
Support/Counseling for Family	54.8%	—	44.4%	40.9%	59.4%
Advocacy	—	—	59.3%	54.5%	56.3%
Financial Assistance Referral	48.4%	35.5%	40.7%	27.3%	56.3%
Support by Cancer Survivors	35.5%	—	37.0%	50.0%	53.1%
Educational Materials	—	58.1%	—	—	54.5%
Cancer Services Referral	41.9%	38.7%	33.3%	40.9%	46.9%
Medical Referral	45.2%	19.4%	33.3%	27.3%	46.9%
Bereavement Support/Counseling	29.0%	—	14.8%	22.7%	37.5%
Pen/Phone Pal Network	22.6%	9.7%	14.8%	—	31.3%
Financial Assistance	12.9%	12.9%	14.8%	9.1%	15.6%
Recreational Events	—	—	—	13.6%	9.1%
Transportation	—	—	—	9.1%	6.1%

common reason clients contacted AMC was to obtain medical information (46 percent) while only 13 percent of CCI clients called for this reason. Half of all CCI clients called seeking psychological or psychosocial support compared with only 10 percent of AMC callers. The second most common reason for contacting both AMC and CCI was to obtain information, referrals, or education.

The Lymphoma Research Foundation of America (LRFA, which merged in November 2001 with the Cure For Lymphoma

Foundation to become the Lymphoma Research Foundation) and the Leukemia Society of America (LSA) also reported their clients' reasons for contact based on data. Both of these organizations reported all client reasons for calling (more than one reason per caller) so the percentage of callers for each reason totals more than 100 percent. All LRFA and LSA clients were seeking information, referrals, or education with 10 percent of LSA clients contacting the organization due to financial or medical insurance coverage concerns.

TABLE 3

Phase I Hotline Characteristics		
Variable	N*	Percent Endorsed
Hotline Toll Free		
Yes	20	87.0%
No	3	13.0%
Phone Services in Spanish (bilingual)		
Yes	12	52.2%
No	11	47.8%
Operator Background/Training†		
Trained Employee/Volunteer	20	87.0%
Cancer Survivor	7	30.4%
Counselor/Therapist/Social Worker	6	26.1%
Medical Professional	5	21.7%
Hours of Operation		
Business hours, Monday-Friday	16	69.6%
Business hours, 7 days per week	3	13.0%
24 hours, 7 days per week	2	8.7%
Other	1	4.3%
Missing	1	4.3%
Assess Quality of Life		
Yes	13	56.5%
No	10	43.5%

*Twenty-three of the 32 organizations (77 percent) provide a hotline.

†Percentages do not add to 100 because organizations endorsed all items that applied.

TABLE 4

Reason	Organizations Providing Collected Data				Organizations Providing Estimates			
	CCI (N = 27,324)	AMC (N = 1,612)	LRFA** (N = 11,888)	LSA* (N = 23,000)	Komen Foundation* (N = 65,000)	CLF** (N = 5,000)	NBTF* (N = 15,000)	AFUD (N = 40,000)
Information/Referral/Education	19%	24%	100%	100%	40%	100%	95%	70%
Medical/Medical Communication	13%	46%	—	—	40%	2%	10%	5%
Psychological/Psychosocial†	50%	10%	1%	—	75%	70%	20%	20%
Financial/Insurance	18%	5%	1%	10%	15%	30%	30%	—
Transportation	—	3%	—	—	—	2%	10%	5%
Other	—	12%	10%	21%	—	—	—	—

CCI = Cancer Care, Inc.

AMC = American Medical Center Cancer Research Center.

LRFA = Lymphoma Research Foundation of America.

LSA = Leukemia Society of America.

Komen Foundation = Susan G. Komen Breast Cancer Foundation.

CLF = Cure for Lymphoma Foundation.

NBTF = National Brain Tumor Foundation.

AFUD = American Foundation for Urologic Disease.

*These organizations recorded more than one reason per client, thus percentages sum to greater than 100. N refers to the number of callers.

†For CCI, this category collapses adjustment to personal illness (29 percent) and adjustment to family illness (21 percent).

‡In November 2001, the Cure For Lymphoma Foundation (CFL) and the Lymphoma Research Foundation of America (LRFA) merged to become the Lymphoma Research Foundation (LRF).

TABLE 5

Phase II Cancer Care, Inc. (CCI) Prostate and Breast Cancer Patient Characteristics Stratified by Age

Sample Characteristics for CCI Prostate Cancer Patients			
Variable	69 Years or Younger (N = 1,164)	70 Years or Older (N = 1,304)	Significance
Ethnicity			
White	66.7% (N = 556)	69.7% (N = 620)	0.10
African American	23.9% (N = 199)	20.8% (N = 185)	
Hispanic	7.9% (N = 66)	6.7% (N = 60)	
Other	1.6% (N = 13)	2.8% (N = 25)	
Marital Status			
Married	72.7% (N = 644)	66.6% (N = 710)	< 0.001
Single	12.2% (N = 108)	8.9% (N = 95)	
Divorced	9.1% (N = 81)	4.4% (N = 47)	
Widowed	6.0% (N = 53)	20.1% (N = 214)	
Time Since Diagnosis			
5.6 Months or Less	59.4% (N = 260)	39.8% (N = 179)	< 0.001
5.7 Months or More	40.6% (N = 178)	60.2% (N = 271)	
Metastatic Disease			
No	78.7% (N = 916)	63.7% (N = 830)	< 0.001
Yes	21.3% (N = 248)	36.3% (N = 474)	
Sample Characteristics for CCI Breast Cancer Patients			
Variable	53 Years or Younger (N = 4,339)	54 Years or Older (N = 4,393)	Significance
Ethnicity			
White	63.9% (N = 1,922)	75.5% (N = 2,246)	< 0.001
African American	19.9% (N = 600)	14.0% (N = 417)	
Hispanic	12.4% (N = 374)	8.1% (N = 240)	
Other	3.8% (N = 114)	2.4% (N = 72)	
Marital Status			
Married	52.2% (N = 1,774)	40.1% (N = 1,363)	< 0.001
Single	27.1% (N = 920)	14.5% (N = 492)	
Divorced	17.4% (N = 592)	11.7% (N = 398)	
Widowed	3.2% (N = 110)	33.8% (N = 1,148)	
Time Since Diagnosis			
4.6 Months or Less	51.6% (N = 1,008)	46.7% (N = 798)	0.003
4.7 Months or More	48.4% (N = 946)	53.3% (N = 912)	
Metastatic Disease			
No	72.6% (N = 3,150)	68.2% (N = 2,998)	< 0.001
Yes	27.4% (N = 1,189)	31.8% (N = 1,395)	

Four organizations provided client reasons for contact based on estimated data. The Susan G. Komen Breast Cancer Foundation, the Cure for Lymphoma Foundation (CLF; CLF and LRFA merged in November 2001 to become the Lymphoma Research Foundation), and the National Brain Tumor Foundation (NBTF) reported more than one reason per caller while the American Foundation for Urologic Disease (AFUD) reported only one reason per caller. As seen in Table 4, NBTF and AFUD primarily provide information, referrals, and education whereas the Komen Foundation and CLF provide psychological or psychosocial support to a large number of their clients. Three of the organizations indicated that between 15 and 30 percent of clients contacted their organizations due to financial or medical insurance coverage concerns.

PHASE II: CHARACTERISTICS OF PROSTATE AND BREAST CANCER PATIENTS CONTACTING CCI

Method

Participants

Phase II of this study involved analyzing a portion of CCI's data from 2,714 prostate cancer patients collected from 1986 to 1997 and 9,541 breast cancer patients collected from 1983 to 1997. CCI's database included all clients who contacted the organization either by telephone, via the Internet, by mail, or in person.

Procedure

Social workers collected data on patient demographics and medical information. The reason for contacting the organization was explained by the client, and additional problems were identified by the social worker.

Measures

Variables assessed included patient age, ethnicity, religious affiliation, marital status, period of time since diagnosis, presence of metastatic disease, and identified problem(s). Although each of these variables was unavailable for a portion of the respondents, these variables represent the best available information across both the prostate and breast cancer data sets. However, as certain variables (e.g., age, period of time since diagnosis, marital status, and ethnicity) had large amounts of missing data (> 10 percent), the results need to be interpreted with caution.

Results

Sample Characteristics

The average age of prostate cancer patients was 70 years (SD = 10.4; N = 2,468) and the average age of breast cancer patients was 55 years (SD = 14.4; N = 8,732). Table 5 presents the demographic and medical data stratified by age. Older prostate and breast cancer patients were more likely to be widowed, have allowed a longer time to elapse since diagnosis, and have metastatic disease (χ^2 , $p < 0.001$) (Table 5). Approximately 28 percent of both the prostate and breast cancer patient samples had metastatic disease. Among prostate cancer patients, 70 percent were married, while only 47 percent of breast cancer patients were married. The median time period between diagnosis and contacting CCI was 5.6 months for prostate cancer patients and 4.6 months for breast cancer patients.

Identified Problems

Among prostate cancer patients, the five most frequently identified problems included: personal adjustment to illness (37.5 percent), home care (22.2 percent), financial assistance

TABLE 6

Phase II Cancer Care, Inc. (CCI) Identified Problems Stratified by Age and Metastatic Disease					
Identified Problem for Prostate Cancer Patients					
Variable	Personal Adjustment	Financial	Home Care	Transportation	Health Care Communication
Age [§] (N = 1,737)					
≤ 69 (N = 799)	40.6% [†]	14.5% [*]	8.8% [†]	7.6% [†]	6.9% [*]
≥ 70 (N = 938)	19.0%	17.9%	28.3%	13.3%	4.9%
Metastatic Disease (N = 1,905)					
No (N = 1,379)	37.0% [†]	13.6% [†]	9.4% [†]	11.1%	7.8% [†]
Yes (N = 526)	13.5%	20.5%	40.7%	9.3%	3.4%
Identified Problem for Breast Cancer Patients					
Variable	Personal Adjustment	Financial	Home Care	Transportation	Health Care Communication
Age (N = 5,892)					
≤ 53 (N = 2,868)	43.3% [†]	17.5%	6.9% [†]	7.3% [†]	4.3%
≥ 54 (N = 3,024)	27.2%	15.9%	16.3%	15.8%	3.9%
Metastatic Disease (N = 6,403)					
No (N = 4,603)	37.8% [†]	15.6% [†]	6.1% [†]	11.0%	5.4% [†]
Yes (N = 1,800)	29.1%	18.1%	23.6%	11.4%	2.7%

*p < 0.10.

†p < 0.05.

‡p < 0.001.

§Significance values represent a significant difference between older patients versus younger patients and patients with no metastatic disease versus patients with metastatic disease.

(19.1 percent), transportation (13.0 percent), and communication with health care professionals (8.1 percent). Similarly, the five most frequently identified problems among breast cancer patients were: personal adjustment to illness (45.1 percent), financial assistance (20.8 percent), transportation (14.2 percent), home care (14.1 percent), and communication with health care professionals (5.9 percent). The remaining problems (e.g., family adjustment, child care, employment, pain, and loss/bereavement) constituted only 20 percent of calls for both prostate and breast cancer patients. The overall majority of prostate and breast cancer patients (70.2 percent; N = 1,905 and 67.1 percent; N = 6,403,

respectively) listed a single reason for contacting CCI; when respondents listed a number of reasons for contacting CCI, the reasons did not differ significantly by any particular demographic characteristics.

The association between age, metastatic disease status, and identified problem(s) was examined among prostate and breast cancer patients. The results must be interpreted with caution due to the association between age and metastatic disease (χ^2 , p < 0.001). Analyses controlling for the relationship between age and metastatic disease were not conducted as the amount of missing data would have limited the ability to interpret the analyses for both age and identified problem(s).

As seen in Table 6, compared with younger patients, older prostate and breast cancer patients were less likely to report problems regarding personal adjustment to illness, but more likely to report problems with regard to home care and transportation. Prostate and breast cancer patients with metastatic disease were less likely to report problems regarding personal adjustment to illness and communication with health care professionals, but were more likely to report problems with home care and financial issues than prostate and breast cancer patients without metastatic disease.

In addition to differences in identified problems among patients with different demographic and medical characteristics, patient needs may differ as a function of time. To address this issue, we examined Phase II/CCI-identified problems by the year during which calls were received. Based on a median split in the number of clients, years were divided into calls made prior to 1995 versus calls made between 1995 and 1997. Prostate cancer clients calling from 1995 to 1997 were more likely to call due to a problem with personal adjustment to illness (43.5 percent) and communication with health care professionals (9.7 percent) compared with those calling prior to 1995 (27.6 percent and 5.7 percent, respectively) (χ^2 , $p < 0.001$). Breast cancer patients calling from 1995 to 1997 were also more likely to call due to a problem with personal adjustment to illness (51 percent) and communication with health care professionals (7.2 percent) compared with those calling prior to 1995 (35.9 percent and 3.8 percent, respectively) (χ^2 , $p < 0.001$). Among both prostate and breast cancer patients, financial problems, home care, and transportation issues did not differ by the year calls were received.

Differences in CCI Phase I and Phase II Data

For this study, we received two separate sets of caller data from CCI. In Phase I, we received caller data from 1998 and 1999 for all tumor

sites. In Phase II, we received caller data from 1983 and 1997 for breast cancer patients, and from 1986 to 1997 for prostate cancer patients. While it is difficult to interpret any comparisons between the Phase I and Phase II/CCI data due to sample differences such as tumor site (Phase I included all tumor sites), there were several differences in identified problems that merit mentioning and may warrant further investigation.

In the data collected most recently (Phase I: 1998 to 1999), the five most frequently identified problems included: adjustment to personal illness (29 percent); adjustment to family illness (21 percent); professional consult/information (19 percent); financial (18 percent); and health care communication (13 percent) (Table 5). However, in the data collected earlier (Phase II: 1983 to 1997) for both breast and prostate cancer patients, adjustment to family illness was less often reported and ultimately accounted for approximately eight percent of reported problems (Table 6). This difference may reflect the increasing burden of care for family members due to the decrease of inpatient services for cancer patients.

Secondly, professional consult/information and health care communication needs were much less prevalent among the earlier data (Phase II: 1983 to 1997) for breast and prostate cancer patients (four percent and eight percent, respectively) compared with the most recent data (Phase I: 1998 to 1999) for patients (19 percent and 13 percent, respectively). The greater need in these areas expressed by the most recent patients may be a product of the increased focus on shared medical decision-making and home care. The remaining three categories did not change over time.

DISCUSSION

In this two-phase study of national, regional, and local community-based and philanthropic

organizations providing services to cancer patients and their families, we examined which cancer-related services are currently available, which services are requested, and who utilizes these formal support networks. The current study makes a contribution to what is known about cancer-patient needs by identifying gaps in service provision based on data from both cancer patients and service providers.

In Phase I, organizations indicated which services they provide. The most frequently endorsed services included: referral to information resources, cancer information, a newsletter, and support/counseling for cancer patients and their families. While these services are extremely valuable and needed, few organizations provided services for practical needs such as transportation, financial assistance, and home care. However, when examining the problems identified by patients in Phase I, we found that up to 30 percent of patients reported financial needs and up to 10 percent reported transportation needs. Similarly, in Phase II, we found that three of the five most frequently identified problems reported were home care, financial assistance, and transportation needs with 10 to 29 percent reporting needs in these areas. These data suggest that a large gap exists between needs and service provision for practical assistance needs within this group.

The results of this study also support the finding that those at highest risk for developing and dying of cancer are the least likely to utilize formal support networks.^{47,49} The demographic and medical characteristics of the Phase I/CCI and AMC clients and Phase II/CCI clients were similar to the characteristics of cancer patients utilizing formal support networks in previous studies.^{47-49,52,53} Since most of the Phase I/CCI and AMC clients and Phase II/CCI were female, white, middle-aged, and had a high school diploma, these data suggest that cancer patients who are male, non-white, older, and less educated are

underrepresented among individuals utilizing formal support networks.

CONCLUSION

Increasing utilization of services among high-risk groups such as the elderly and minorities may have an impact on patient treatment compliance, quality of life, and prognosis. Studies conducted by NCI's Cancer Information Service Research Consortium have shown that promotional campaigns targeting specific high-risk groups can increase at least short-term utilization.^{48,49,52,54} Future studies are needed to examine the factors that contribute to underutilization and to shape efforts to ameliorate this problem.

The Phase II/CCI data showed that patient needs differed by age and by the presence of metastatic disease. This finding is consistent with previous studies showing that patient needs increase and change as a function of disease progression.^{6,16,17,34,44,45} While it is difficult to interpret the impact of the relationship between age and the presence of metastatic disease on identified problems, it is clear that older and metastatic-disease patients present with greater needs for financial, transportation, and home care services and fewer needs for assistance with psychological adjustment to their illness compared with younger and non-metastatic-disease patients.

In addition to an increase in needs for practical assistance, further information is needed on metastatic-disease patients in terms of their understanding of a host of end-of-life issues, such as palliative care resources, the appropriate use of do-not-resuscitate orders and a living will, pain management, and Phase I clinical trials. It is also important to consider the needs of older patients due to the large burden of cancer among older people and the aging of the US population.²⁴ Many cancer patients will have needs or concerns related to

aging regardless of their disease status.

The findings of this study highlight the need for additional research regarding the changing needs of cancer patients, the impact of demographic and medical characteristics on needs, utilization of formal support networks, and gaps in service provision. While many organizations lack the staff and financial resources to collect client information, several organizations, including the Y-Me National Breast Cancer Organization, the Susan G. Komen Breast Cancer Foundation, the Hospice Education Institute, and the American Society of Clinical Oncology, are currently beginning data collection or working to make previously collected data available. Client information collected by these organizations will provide a wealth of information regarding cancer patient needs and the utilization of formal support networks. Further, the Behavioral Research Center at the American Cancer Society (ACS) is currently conducting a nationwide population-based questionnaire survey of cancer survivors called the Study of Cancer Survivors. The purpose of this study is to identify unmet needs of cancer patients and their families, monitor changes in quality of life, evaluate ACS programs and services, and learn more about the long-term effects of cancer and its treatment.⁵⁵

While the findings of the current study are

limited by the lack of complete participation on the part of eligible organizations in Phase I and by the missing data in Phase II, this study makes a contribution to what is currently known about non-medically based services for cancer patients. The results of this study support the idea that those at highest risk for developing and dying of cancer are the least likely to utilize formal support networks. Further, a gap in service provision for assistance with practical needs (e.g., transportation, financial assistance, home care) was identified. Few organizations provide practical assistance, despite the substantial proportion of patients reporting needs in these areas. Clearly, the increasing use of outpatient care and home care for cancer patients can be expected to create a greater demand for practical assistance in the future. It is apparent that the availability of practical services will need to be increased in order to effectively meet cancer patient needs.

Finally, this study is a starting point for future research designed to meet cancer patient needs via formal support services. Since the most ill and those with the fewest resources are least likely to utilize available community services, increasing outreach efforts that assist these patients is the next step in this line of research.

CA

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