

Cancer Information Needs in Rural Areas

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Although cancer presents obstacles for all who experience it, persons in rural communities must negotiate additional challenges. This study determined the cancer information (CI) needs and the CI-seeking behavior and preferences among rural-dwelling persons. Patients ($N=801$) ≥ 50 years of age seen in 36 rural Kansas primary care practices completed a Cancer Care Information Needs Survey (CCINS); physicians completed a cancer resource knowledge and preference survey. Of the 801 patients, 184 (23%) reported a CI need. Of these 184 patients, 45% reported either not discussing cancer or having insufficient discussion time with their physicians; 44% needed more information after consulting their physician. Patients more likely to report a CI need were young, female, Internet users, persons with a prior cancer diagnosis, and persons seeing male physicians or physicians in group/multispecialty practices. Patients and physicians were unfamiliar with services provided by national cancer organizations. Physicians are a primary CI source; however, patients who need CI report insufficient cancer discussion time with their physician and need more CI after consulting their physician. Promoting access to national CI sources could bridge the CI needs gap that exists in rural areas currently.

Background

Despite improvements in cancer treatment and increased cancer survival rates, a cancer diagnosis can invoke emotional distress (Deimling, Kahana, Bowman, & Schaefer, 2002; Northouse & Northouse, 1987). Although cancer presents unique obstacles for all who experience it, persons living in rural communities must negotiate additional challenges endemic to rural life. Specific barriers include lack of public transportation, fewer health care providers, longer distances to access health care, and limited local information resources and community support services. Compared with their urban counterparts, rural residents are more likely to be elderly, poor, less educated,

This study was supported by a Masonic Foundation Award to the Kansas Cancer Institute and by the National Cancer Institute under the Cancer Information Service Contract No. NO2-CO-01110.

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uninsured, or suffer from a chronic disease (Friedell et al., 2001). As such, rural Americans commonly access health care at a lower rate (Calle, Flanders, Thun, & Martin, 1993; Coughlin, Thompson, Hall, Logan, & Uhler, 2002). Not surprisingly, given the lower level of health care access and screening participation in rural areas, rural residents are diagnosed at more advanced stages of disease than are urban populations (Freeman, 1989; Liff, Chow, & Greenberg, 1991).

Cancer patients as well as close family members and friends have a significant need for information on the many issues surrounding cancer (Luker et al., 1995). Providing the right type and amount of CI to patients are key factors in helping individuals cope with cancer, as a choice of cancer treatments may exist (van der Molen, 1999). Further, Tropman and colleagues (1999) found that rural breast cancer patients receive less adjuvant breast cancer therapy than national standards indicate. In addition, various cancer screening modalities are available and confusion over screening guidelines may contribute to reduced cancer screening delivery in rural areas (Santora et al., 2003). Given the complexities of cancer patients' needs for information, disparities in cancer treatment in rural communities, and the availability of various cancer screening options, relying solely on the physician for CI may not be the optimal course of action for a given patient, particularly for those in rural settings. Therefore, determining the best methods for disseminating state-of-the-art treatment and screening information to rural patients and physicians is a key component of improving cancer-related outcomes for rural residents.

Despite the widespread availability of CI from national organizations such as the National Cancer Institute (NCI) and the American Cancer Society (ACS), little evidence exists to substantiate its access and use by rural populations. In Kansas, for example, a state whose population is 50% rural based on 2000 Census Bureau statistics, only 28% of calls from Kansas to the NCI's Cancer Information Service (CIS; 1-800-4-CANCER) during 2001 came from rural areas (CIS, 2001).

The purpose of this study was to assess the CI needs and awareness of cancer resources of persons residing in rural Kansas communities and their physicians. Specifically, we intended to do the following: (1) assess perceptions of need for information related to cancer screening and treatment among rural primary care patients and (2) assess knowledge of, and preferences for, cancer resources.

Methods

Cancer Care Information Needs Survey

A 39-item CCINS was derived from earlier work on the supportive care needs of cancer patients (Bonevski et al., 2000; Sanson-Fisher et al., 2000). The CCINS originally was developed and pilot tested with 155 patients seen in four primary care practices across Kansas. Following this pilot test, we revised the survey questions that appeared unclear and distributed the revised survey to an additional pool of 30 primary care patients prior to using it in the current study. The 30 patients reported no problems in understanding the items, and all successfully completed the survey.

In addition to demographic information, the CCINS included questions to assess two main categories: (1) the need for CI and (2) knowledge of CI resources. The CI needs questions inquired about where the respondent obtains CI, how much

time the patient has had to discuss cancer detection with his or her physician, and whether the patient has needed to access CI. The CI resource questions asked about the respondent's familiarity with cancer-related national organizations and services such as the NCI and the ACS and how likely the respondent would be to use various CI resources if they were available (e.g., reading materials, videos, toll-free telephone number answered by a CI specialist, or the Internet). Demographic questions included the respondent's race/ethnicity, education level, Internet access at home, age, gender, marital status, and home zip code. An open-ended question asked patients about their primary sources of CI.

Physician Survey

We developed a separate survey to assess physician familiarity with national CI resources such as the NCI and the ACS. Additional questions asked about the respondent's likelihood of contacting these services as well as the physician's perception of how important it is for his or her patients to access these resources. Demographic questions included physician gender, type of practice (solo, group, or multispecialty), years in practice, and average number of patients seen each week.

Data Collection and Participants

The surveys were distributed within 36 primary care physician (PCP) offices by University of Kansas medical students. The medical students were between their first and second year of medical school and completed the project as part of a summer rural primary care practice clerkship. During this clerkship, the medical students spent 5 weeks conducting supervised clinical practice in separate rural Kansas PCP offices. During the first week of the clerkship, students received 40 hours of training in human subjects protection, study design, study recruitment, survey administration, and data management. The study investigators and experienced staff from the NCI's Heartland Cancer Information Service at the University of Kansas Medical Center conducted all research training sessions with medical students.

Medical students identified patients who were at least 50 years of age that they saw at their assigned primary care practice site. The students excluded patients if the office visit was for a critical acute complaint, if the patient appeared to be in immediate emotional distress, if the patient suffered from dementia, if there were language difficulties that would preclude the patient from completing the survey, or if the student previously saw the patient at the practice. The students recruited patients by asking them if they would like to participate in a rural CI and supportive care needs assessment. Students were instructed to identify the first eligible patient in each morning and afternoon clinic session. Subsequent patients were asked to participate until one survey was completed in each half-day clinic session. The goal for each student was to distribute the survey to 25 patients; students discontinued recruitment after 25 successfully completed surveys or at the conclusion of the 5-week clerkship. The students obtained verbal consent from each patient, administered the survey verbally, and recorded survey answers on a printed survey instrument. The project protocol was approved by the University of Kansas Medical Center Human Subjects Committee prior to implementation.

Analysis

All data were entered into a Microsoft Access database and analyzed using SAS version 8.1 for PC (SAS Institute, Inc., Cary, NC). Twenty percent of all surveys were cross-checked for data entry accuracy. Quantitative data from both the patient and physician surveys were analyzed using descriptive statistics. Continuous variables were collapsed into ordinal categories. Qualitative data from open-ended questions were collated and coded manually.

Our primary outcome variable of interest was a respondent's need for cancer information. We also identified patient familiarity with cancer resources, patient use of cancer resources, and patient likelihood of using cancer resources in the future as secondary outcomes of interest.

We examined bivariate relationships between patient need for CI and physician and patient characteristics. To control for potential correlated responses within practices, generalized estimating equations were used to test for significant associations of the patient level characteristics with the outcomes.

Approximate adjusted odds ratios were computed by modeling each of the outcome variables as a function of a subset of patient and physician/practice characteristics. To control for potential correlations within physician offices, we developed these multivariate models using generalized estimating equations with backward elimination.

Results

Patient Characteristics and their Need for Cancer Information

A total of 1,098 patients were approached to participate in the survey. Thirty-one patients refused to participate and 266 did not meet at least one aspect of the patient inclusion criteria. Thus, we obtained completed surveys from 801 Kansans aged 50 and older (mean age = 69 years, range 50–97) in 36 rural primary care practices in Kansas during the summer of 2002. Most of the patients surveyed were female (61%), Caucasian (93%), married (65%), and had a high school education or less (57%). In response to the open-ended question on the primary source of CI, 42% of patients indicated their physician, whereas 37% used popular media, including television, newspapers, and magazines.

Of all 801 patients, 23% ($N = 184$) reported that they had needed to obtain CI in the past for a person diagnosed with cancer, 84% of whom reported that this need was for someone other than him or herself. Persons with greater needs for CI were significantly more likely to use the Internet, have a prior cancer diagnosis, and be young, female, or highly educated (Table 1). Patients' primary source of CI (physician, popular media, or other) and their marital status was not associated with their need for information. Forty-five percent of those patients in need of CI reported either not discussing the cancer or having insufficient time for discussion with their physician. Forty-four percent reported needing more information even after talking with their physician.

Physician Characteristics and Patient Need for Cancer Information

The 36 physicians surveyed were predominately male (75%), saw an average of 102 patients per week in their practice (range = 33–200 patients), and had an average of

Table 1. Characteristics of patients and their need for cancer information

Demographic characteristic	Patients <i>N</i>	Patients in need of information for a person diagnosed with cancer %
All patients	801	23.3
Age		
50–59	196	33.2***
60–69	200	24.5
70+	391	17.7
Gender		
Male	315	15.9***
Female	486	28.0
Race/ethnicity		
White	748	22.7
Other	53	31.4
Education		
Less than high school	139	17.3*
High school	317	21.3
Some college/college graduate	344	27.0
Marital status		
Married	522	22.6
Not married	279	24.6
Cancer diagnosis		
Yes	162	30.9**
No	639	21.3
Cancer information source		
Physician	337	26.2
Popular media	295	18.4
Other	167	26.4
Internet use		
Yes	258	34.4***
No	540	18.1

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

15 years in practice (range 1–44 years; see Table 2). Most of the physicians identified their practices as a group or multispecialty practice (72%). Solo practitioners had fewer patients reporting a need for CI than did practitioners from “other” practices (e.g., community health clinics).

Predictors of Patient Need for Cancer Information

After adjusting for physician and patient variables included in the model, results of the multivariate regression model predicting patients’ need for CI indicate that being younger (odds ratio [OR] = 4.9; confidence interval [CI], 1.1–21.0), having a diagnosis of cancer (OR = 4.8; CI, 2.1–11.1), using the Internet (OR = 3.9; CI, 1.7–8.9), and female (OR = 6.3; CI, 2.8–13.9) were predictive of a need for CI (Table 3). While the CI for age is large, it is statistically significant and therefore was included in the

Table 2. Physician/practice characteristics of 36 rural primary care physicians and patient cancer information needs

Physician/practice characteristic	Physicians <i>N</i>	Patients in need of information for a person diagnosed with cancer %
All physicians	36	23.3
Gender		
Male	27	24.6
Female	9	19.6
Years in practice		
0–14	19	21.1
15+	17	26.0
Mean # of patients per week		
<100	15	24.0
≥100	21	22.8
Type of practice		
Group/multispecialty	26	22.5**
Solo	5	15.9
Other	5	34.6

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

model. Female physicians (OR = 0.4; CI, 0.2–0.9) and those who practice in group or multispecialty practices versus other types of practices (OR = 0.12; CI, 0.02–0.60) were likely to have fewer patients who reported needing CI.

Patient and Physician Awareness of National Cancer Resources

Most patients (87%) were familiar with the ACS, although only 37% were familiar with the NCI and 7% knew about the NCI website www.cancer.gov (Table 4). Only 12% of patients were familiar with the NCI 1-800-4-CANCER telephone service, while even fewer were aware of the NCI's CIS Internet-based LiveHelp instant messaging service (2%). Patients who were younger, non-Caucasian, more

Table 3. Odds ratios and 95% confidence intervals of need for cancer information in 801 Kansas rural primary care patients

Characteristic	Odds ratio	95% confidence interval
Patient characteristics		
Age 55–59 vs. 70–79	4.89	1.14–20.95
Female	6.32	2.87–13.91
Previous diagnosis of cancer	4.78	2.06–11.07
Use internet	3.87	1.68–8.90
Physician/practice characteristics		
Female MD	0.40	0.15–0.93
Group/multispecialty practice vs. other	0.12	0.02–0.60

Table 4. Patient and physician familiarity with National Cancer Information organizations and services

Characteristic	Patients familiar with organization/ service		Physician familiar with organization/ service	
	<i>N</i>	(%)	<i>N</i>	(%)
American Cancer Society	698	(87)	36	(100)
National Cancer Institute	300	(37)	33	(92)
Cancer Information Service 1-800-4-CANCER	95	(12)	13	(36)
National Cancer Institute website (cancer.gov)	58	(7)	18	(50)
National Cancer Institute LiveHelp on-line instant messaging service	18	(2)	7	(19)

educated, used the Internet, and those reporting a prior need for CI reported increased familiarity with and use of CI resources.

All 36 physicians reported familiarity with the ACS, while 92% reported familiarity with the NCI. Approximately one-third of physicians (36%) were familiar with the NCI's 1-800-4-CANCER telephone service and 50% reported knowledge of the NCI website (www.cancer.gov). Only 19% of the physicians reported familiarity with the NCI's LiveHelp Internet instant messaging service.

Many of the physicians (64%) indicated being moderately or very likely to contact the NCI's CIS for information on cancer treatment options or screening information. A majority reported that it is moderately or very important for patients to obtain CI from national organizations (94%) and also indicated that they would be moderately comfortable referring their patients to the NCI CIS (94%).

Discussion

Cancer diagnoses influence not only the individual, but also can dramatically affect family members and close friends of the person diagnosed with cancer. Cancer patients and persons in their close social network have significant needs for CI (Luker et al., 1995), which often are not met fully (Wilson, Andersen, & Meischke, 2000). Because prior research has shown that persons residing in rural communities often experience more barriers to accessing health care (Friedell et al., 2001), this study assessed the CI needs of persons in rural communities. Results indicate that approximately one-fourth of rural primary care patients 50 years of age and older have had a need for CI, with a majority (84%) reporting that this need was for someone other than themselves.

Patient characteristics most strongly associated with needing CI included being young, female, having a current or past personal cancer diagnosis, and being an Internet user. These results are not surprising, given that research has shown that women tend to use health care more frequently than men (Dunlop, Manheim, Song,

& Chang, 2002; Field & Briggs, 2001) and serve more frequently as caregivers than men. It is interesting to note that many persons from this study with CI needs used the Internet. We hypothesize that individuals in this study with CI needs also may have an overall greater interest in obtaining information, whether their information interest is health related or otherwise. In their quest for information, information seekers may migrate to the Internet naturally because of the high volume and quality of information that is available through reputable web sites. Knowledge of reputable Internet sites such as cancer.gov and LiveHelp is important to rural residents since there are fewer community-level resources and less access to health care. Also, due to the plethora of misinformation on the Internet, it is important for rural patients to be aware of reputable sites. Nonetheless, as younger, Internet-savvy individuals advance in age, we would expect the numbers of persons using the Internet for information to grow. This also will be the case in rural communities as more and more rural-dwelling persons gain access to and become more familiar with the Internet (McDuffee, 2000; Licciardone, Smith-Barbaro, & Coleridge, 2001). Given these inevitable increases in the rate of Internet use, providing high-quality CI on the Internet and increasing the awareness of the availability of such information should remain a priority.

Patients seeing female physicians and those presenting at other types of practices (not including solo practitioners) as opposed to group/multispecialty practices had more CI needs. Other types of practices in our study included community health clinics. We suspect that larger group/multispecialty practices are located in more densely populated rural areas and thus have more resources available to them to meet the CI needs of their patients (such as ancillary health information providers including nurses, physician assistants, health educators).

Of the patients needing CI, nearly half reported either no discussion of cancer or having insufficient time for discussion with their physician; half also reported a need for more information even after talking with their physician. The majority of patients who needed CI, however, needed it for someone other than themselves, and we must acknowledge the potential inappropriateness for a physician to answer questions about a person's cancer if that person is not his or her patient. Despite this study limitation, many patients still considered their physician as their primary source for CI and physicians either are not able to, or cannot, meet the CI needs of their patients fully. As such, patients in need of CI have chosen to access alternative information sources such as newspapers, magazines, books, or the Internet, with most indicating a preference for cancer education in the form of reading materials if such materials were made available to them. Awareness of alternative CI resources outside of PCPs was limited. Although patients and physicians were aware of respected national organizations such as the NCI and the ACS, they had less knowledge about the services that these organizations provide. In particular, respondents had very little knowledge of NCI's CIS 1-800-4-CANCER telephone service or NCI's CIS Internet-based LiveHelp instant messaging service. Lack of awareness of the CIS may be due in part to the CIS approach of disseminating CI by working with partner organizations and coalitions that are established and trusted in their communities. It can be hypothesized that there are fewer existing community organizations for CIS to work with in rural areas and that these organizations reach fewer individuals than their counterparts located in more populated areas. In addition, CIS does not have funding to purchase media coverage to promote the service, and hence must rely on less effective free promotional opportunities.

Nonetheless, there is a great need for widespread dissemination of CI resources in rural areas. Beyond general community outreach and advertising efforts, one unique method of disseminating such information, as demonstrated by this project, may be through the development of partnerships between national cancer organizations and health care providers. Such partnerships would not only provide a reliable and efficient platform for transferring information on the services provided by national cancer organizations to health professionals and their patients, but also strengthen the relationship between national organizations and the health care community. Future research is needed to improve the dissemination of CI to rural audiences. Potential strategies to be explored may be the following: (1) technology-based delivery methods such as telemedicine, telehealth, and interactive computer networks; (2) interventions involving nonhealth-related partners who are established in the community and who the community already relies upon for services (i.e., U.S. Department of Agriculture [USDA] cooperative extension offices); and (3) forming academic-service organization-community partnerships to educate future health professionals about the existing CI needs of rural populations and available resources to address those needs.

Our study had several limitations. First, it was a cross-sectional study that relied upon retrospective self-report. Many patients may not have remembered correctly whether they had sought CI in the past. Additionally, patients may have been reluctant to admit they needed more information than their physician was able to provide to them. Methodologically, we used a systematic patient recruitment procedure, but not a random sampling technique. Finally, the use of 36 medical students to administer the survey at individual primary care practice sites may have introduced variation in the way in which surveys were administered. Careful training of the students prior to survey distribution was conducted, however, to reduce survey administration variation.

Rural primary care physicians are besieged with caring for patients with multiple presenting problems as well as with trying to keep up with current medical literature and findings. As such, keeping abreast of the latest cancer-related information for their patients may become secondary priorities. Results from this study suggest that physicians are open to their patients accessing respected national CI sources. Physicians and their patients, however, lack awareness of the services provided by national CI sources, indicating a clear need for NCI and ACS to promote their information sources aggressively in rural communities. By educating both physicians and the public about the various reputable national organizations, we may be able to bridge the CI needs gap, especially in rural communities, where local CI resources may be limited (Hawkins & Curtiss, 1997).

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