

Learning and Support Preferences of Adult Patients With Cancer at a Comprehensive Cancer Center

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Purpose/Objectives: To identify content items for an inclusive education curriculum for adult patients with cancer, as well as describe their learning and support preferences, determine the level of information provided to them, and assess the patients' interest in potential new services.

Design: Exploratory, descriptive survey research.

Setting: A National Cancer Institute-designated Comprehensive Cancer Center.

Sample: All consenting adult patients with cancer who had appointments in the outpatient care setting during a two-week period (N = 1,310).

Methods: A 3-phase study identified core components of an inclusive educational curriculum, conducted structured interviews of patients with cancer, and validated findings in a selected sample.

Findings: The surveys were completed and returned by 48% (n = 625) of the patients. The most favored method for learning about all cancer topics was discussions with physicians (66%). Other preferred methods included brochures or booklets provided by physicians or nurses (33%), discussions with nurses (34%), self-selecting print media from information displays (20%), and talking with other patients with cancer (14%). Statistically significant differences in learning preferences were found among subgroups defined by age, gender, and education.

Conclusions: Patients preferred interactive, interpersonal communication with physicians or nurses. In addition, the prevailing method of education delivery for patients with cancer was providing print materials that support and enhance knowledge shared in the patient-healthcare team communication.

Implications for Nursing: This study confirms the importance of the learning and support preferences of patients with cancer. To implement a successful education program for their patients, nurses must be aware of patients' preferences for learning new information. Time must be set aside for one-on-one communication with patients, and print materials must be easily accessible to healthcare providers to support the patient-education process.

Key Points . . .

- ▶ Patients with cancer prefer to learn about their illness through interactive, interpersonal communication with their physicians.
- ▶ Providing reinforced messages in print materials can enhance communication between patients and healthcare teams.
- ▶ Successful education takes place when providers are aware of and adapt to patients' needs and preferences.

Assessment, planning, implementation, and evaluation are vital components of the patient education process. Assessment, the first and most crucial part of the process, leads to a description of learning needs and characteristics and is the foundation for education planning and implementation (Almquist & Bookbinder, 1990; Giloth, 1993; Lorig, 1996; Rankin & Stallings, 1990; Redman, 1993; Volker, 1991). When an assessment of learning needs is not conducted, trial and error become the basis for patient teaching.

Realizing the importance of assessment, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (1999a, 1999b), the Oncology Nursing Society (ONS) (1995),

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and the National Cancer Institute-Cancer Patient Education Network (NCI-CPEN) recommended assessing learning needs prior to patient teaching or program development. Learning needs may be assessed formally or informally and with individuals or groups. Structured interviews, focus groups, and survey research are common approaches (Lorig, 1996; Schulmeister, 1991).

Surprisingly, only a few published reports of learning-needs assessments appear in the literature. Sumpmann (1989) described findings from an assessment of learning needs conducted before a patient education center was developed. Grahn and Johnson (1990) conducted a learning-needs assessment prior to planning a cancer education program. Tarby and Hogan (1997) reported on a learning-needs assessment that was used to guide the development of hospital patient information services. Fitch et al. (1997) conducted an assessment before creating a cancer detection program for older adults. Meade (1996) conducted an assessment of learning needs in a Hispanic audience before producing a smoking cessation video for pregnant women.

Although not described as learning-needs assessments, descriptive studies on information needs of patients with cancer are documented in the literature. Information needs and preferences vary across the course of illness and treatment (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998). Patients with cancer and their families give highest priority to obtaining information about their cancer diagnosis and treatment plan (Brandt, 1991; Carlsson & Strang, 1996, 1998; Fallowfield, 1995). Fieler, Wlasowicz, Mitchell, Jones, and Johnson (1996) reported that patients undergoing radiation therapy desired information about the side effects of therapy, when to expect them, and their duration.

In a seminal research study, Cassileth, Zupkis, Sutton-Smith, and March (1980) found that younger, more educated, Caucasian patients were more likely to seek detailed information about their illness than others. In a 1996 study of rural patients with advanced cancer, White, Given, and Devoss reported that most (78%) had gaps in knowledge about the disease process and the effects of chemotherapy.

The information needs and preferences of patients with cancer also vary among ethnic groups. Younger, more educated, Caucasian patients were more likely to seek detailed information than patients who were African American, but both groups identified their physicians as the most helpful source of information (Guidry, Aday, Zhang, & Winn, 1998). In another study consisting mostly of African American patients, Foltz and Sullivan (1996) found that patients desired all information possible about their cancer, yet preferred personal, interactive learning with healthcare professionals.

Several reports on the information needs of women with breast cancer have appeared in recent literature (Bilodeau & Degner, 1996; Galloway et al., 1997; Harrison-Woermke & Graydon, 1993; Luker, Beaver, Leinster, & Owens, 1996; Ravdin, Siminoff, & Harvey, 1998; Silliman, Dukes, Sullivan, & Kaplan, 1998). Patients with breast cancer preferred personal communication with healthcare professionals over written resources (Harrison-Woermke & Graydon; Luker et al.). Among the highest-ranked information needs at the time of diagnosis were the extent of the disease, prognosis, type of treatment available, and nature of further diagnostic testing (Bilodeau & Degner). Older women, however, were more likely to rely solely on their physicians for information (Silliman et al.).

With the exception of breast cancer, few studies have been conducted in specific tumor groups. Davison, Degner, and Morgan (1995) concluded that men with prostate cancer had information needs similar to other patients with cancer. Galloway and Graydon (1996) found that patients recovering from surgery for colon cancer identified information about their diagnosis, treatment, and self-care as most important. Corney, Everett, Howells, and Crowther (1992) found that women with gynecologic cancer, in retrospect, wanted more information about the effects of their surgery and treatment and desired that their husbands be present during this discussion.

Although the information needs of patients with cancer have been reported, an assessment of preferred learning methods has been neglected. A formal assessment of these patients' learning needs and preferred methods had never been conducted at the study sites. The authors of the current study, as a formal cancer education program, analyzed the learning needs and preferences of the center's patients, believing that the information would benefit patient education delivery and program development.

The specific aims of this study were to

- Identify content items for a general education curriculum for patients with cancer.
- Describe learning and support preferences of patients receiving treatment at a National Cancer Institute (NCI)-designated Comprehensive Cancer Center in the upper Midwest.
- Determine the level of information provided by the health-care team.
- Assess patients' interest in potential new patient education services.
- Explore differences in learning and support preferences among demographic variables in patients with cancer, such as gender, education level, tumor type, and income level.

Methods

The study was conducted in three phases. In phase I, a multidisciplinary cancer-care team identified the core components of an inclusive patient education curriculum. The cancer-care team used nominal processing (e.g., identifying the core components of the curriculum), then reached agreement through consensus. The components identified were cancer diagnosis, cancer treatment, coping, clinical trials, nutrition, side-effects management, alternative treatments, complementary treatments, sexuality, financial and legal issues, and pain control.

To validate the components of the curriculum, learn about patients' cancer education experience, and determine their interest in new educational services, 100 structured interviews were conducted in phase II. Interviews were conducted with patients with breast, prostate, lung, or colorectal cancer, or with lymphoma. Each group consisted of 20 patients. These cancer-treatment groups were selected because they were representative of both the number and types of cancer diagnoses seen at the NCI-designated Comprehensive Cancer Center. Researchers conducted the 20-minute, one-on-one structured interviews in a private location as patients waited to visit with the cancer-care team and after they signed an informed consent form.

In phase III, findings from the structured interviews were translated into a questionnaire. The questionnaire was evaluated for readability by an RN with expertise in literacy. It was tested for clarity and readability with patients with cancer until the point of saturation—the point at which no new informa-

tion was revealed. The final version of the questionnaire contained 37 items.^a

The questionnaire was mailed to 1,310 patients selected from a patient-appointment database over a two-week period in three outpatient areas—radiation oncology, medical oncology, and the chemotherapy-treatment unit. The two-week period of patient selection occurred three months before the date of the mailing. This time frame ensured the investigators that patients at all stages of diagnosis and treatment were included in the sample.

Patients were 18 or older and lived in Minnesota, Wisconsin, Iowa, North Dakota, or South Dakota. They were excluded if they previously had denied authorization for research or if they were residents of a nearby federal prison. A cover letter describing the purpose of the study accompanied the initial mailing. Completion and return of the survey implied informed consent. After two weeks, researchers mailed a postcard to the entire sample to remind them to return the completed questionnaire in the stamped return envelope and to thank them for their participation if they already had mailed it in.

Statistical Methods

The data analyses primarily were descriptive and exploratory. The two main areas summarized were information received by patients for a specific content item and their preference for the information's format. Responses were summarized for each of the 11 content items. A known limitation with this analysis was patients' ability to accurately recall the information they received.

Researchers used the Wilcoxon rank-sum test to evaluate the relationship between the number of items endorsed and each demographic variable univariately. Multivariate logistic regression was used to explore the relationship between endorsement of items and the demographic variables of gender, age, education, tumor type, and time since diagnosis.

Findings

The surveys were completed and returned by 48% (n = 625) of the patients. The age of respondents ranged from 22–87 years, with a median age of 64. The time since diagnosis ranged from 2 weeks to 32 years, with a median of 1.9 years. Ten percent were at least 10 years beyond the date of initial diagnosis. More than half (54%) were female. The sample was highly educated, with 54% having completed some postsecondary education to advanced degrees. Only 10% had less than a high school education. These demographics reflect the patient population at the study site and are summarized in Table 1.

Results were similar for each of the 11 content items; therefore, results are presented with the median endorsement rate over all 11 content items. The most favored method for learning about all cancer topics was discussions with physicians (66%). Responders also favored personal communication with nurses for all cancer-related topics (34%) (see Figure 1).

Only 41% of patients recalled receiving information about clinical trials. A small percentage of patients recalled receiving information on topics concerning sexuality (28%), complementary therapy (23%), and alternative therapies (17%). A summary of information received by topic is found in Figure 2.

^aThe complete questionnaire can be obtained from Amy M.B. Deshler, MSW, at deshler.amy@mayo.edu.

Table 1. Demographic Characteristics

Characteristic	n	%
Gender		
Male	267	43
Female	336	54
Unknown	22	4
Education		
Postsecondary	335	54
High school or less	269	43
Unknown	21	3
Age (years)		
21–34	20	3
35–59	205	33
60+	350	56
Unknown	50	8
Time since diagnosis (years)		
< 1	189	30
1–2	91	15
2–5	123	20
5+	132	21
Unknown	90	14
Currently receiving treatment		
Yes	192	31
No	393	63
Unknown	40	6
Tumor type^a		
Breast	161	26
Prostate	86	14
Hematologic	73	12
Lung	58	9
Colorectal	55	9
Ovary	36	6
Melanoma	18	3
Bladder	14	2
Uterus	14	2
Oral cavity	11	2
Stomach	11	2
Cervix	10	2
Pancreas	10	2
Other	186	30
Unknown	8	1

N = 625

^aTumor types are not mutually exclusive.

Note. Because of rounding, not all percentages total 100.

Statistically significant differences in learning preferences were found among subgroups defined by age, education, and gender. Mature adults (older than 60) were less likely to endorse a variety of preferences for learning (median number of endorsed items across all cancer topics 16.5 versus 22;

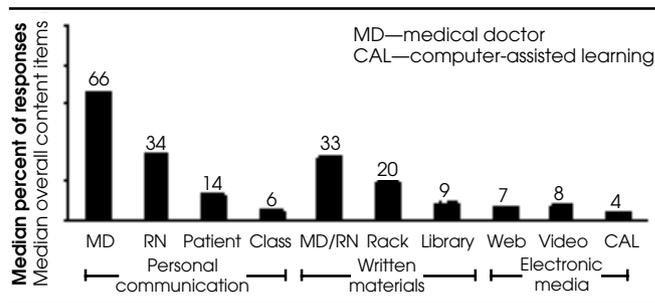


Figure 1. Overall Endorsed Methods for Learning

indicated they were interested in and would use a toll-free number for access to information (68%) and support (54%).

Discussion

Patients with cancer desire clear, accurate information about their diagnosis. This is crucial if patients are to become active partners in their care. However, given time pressures resulting from healthcare economics, providing patients with information and learning methods they prefer is increasingly challenging.

One-on-one personal communication that includes the distribution of supportive written materials is the most widely used method for teaching patients with cancer. Patients in this study endorsed this approach. As a result, healthcare providers must have these supportive written materials available during encounters between patients and cancer-care teams. One solution is printing patient education materials directly from the Internet or the institution's intranet. Little is known about the efficiency of downloading materials for patient education or about patient acceptance and satisfaction with this method.

In general, the differences in learning preferences among demographic subgroups reflect the authors' experiences regarding cancer education practice. Of particular interest, however, is the desire of male patients to discuss sexuality directly with their physicians. (The largest subgroup of males was patients with prostate cancer.) A follow-up study to determine whether these needs are being met is under consideration at the study site.

The results of this study show that participants in the study had little interest in classes or support groups. Clearly, if the cancer-care team believes that group learning and support activities improve quality of life of people with cancer, they must recommend that patients attend them and offer them as one part of a comprehensive patient education program.

Surprisingly, patients in this study were not interested in computer-assisted learning (CAL). This may be because the patient population is, on average, older and not as proficient with computers. This will change with time, as patients become more comfortable with this method of learning and the edges of the "digital divide" come together. Clearly, educators must not rush to substitute it for other methods, because many patients do not have access to or desire the use of CAL.

Nurses and educators are vital members of the cancer-care team and serve as advocates for patients in the cancer-care environment. As patient educators, nurses are creative in responding to the challenges of the learning environment. Barriers to educating patients with cancer arise from a variety of

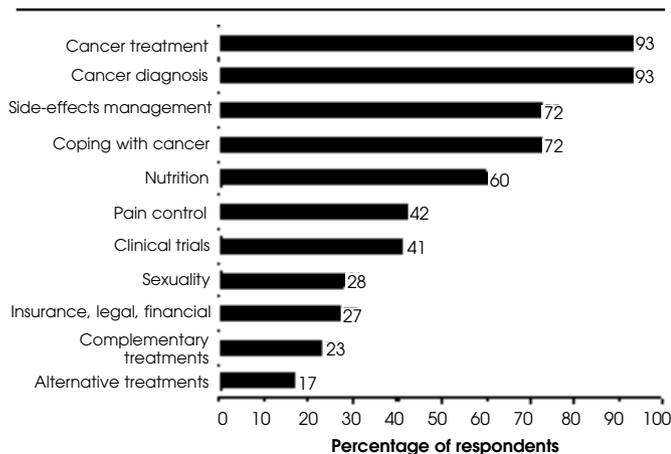


Figure 2. Percentage Who Received Information by Topic

$p < 0.0001$). Respondents with postsecondary education were more likely to endorse a variety of learning methods (median 21 versus 16; $p < 0.0001$).

Women were more likely than men to endorse a variety of methods for learning (median 20 versus 17; $p = 0.003$) and were more likely to endorse talking with a nurse about all content areas (69% versus 52%; $p = 0.001$). This finding is independent of age, education, and time since diagnosis (see Figure 3). On average, women endorsed talking with a nurse for 3 of 11 content items, with men only 1 of 11 ($p < 0.0001$). Men were more likely than women to endorse talking with a physician as a preference for learning about sexuality (odds ratio 2.4; $p = 0.001$). This finding is independent of age, education, and time since diagnosis (see Figure 4).

Most respondents did not attend support groups, with only 4% ($n = 22$) attending support groups offered at the study site. Fifty-seven percent indicated that they did not attend support groups because they received adequate support from family and friends. Other reasons cited for not attending support groups were lack of interest (13%), concerns about privacy (8%), and the belief that support groups were depressing (5%).

Interest in use of the computer to assist in learning was low. Although 23% had used a computer to obtain cancer information, only 7% preferred the Internet and 4% preferred the CancerHelp™ interactive computer for learning. Respondents

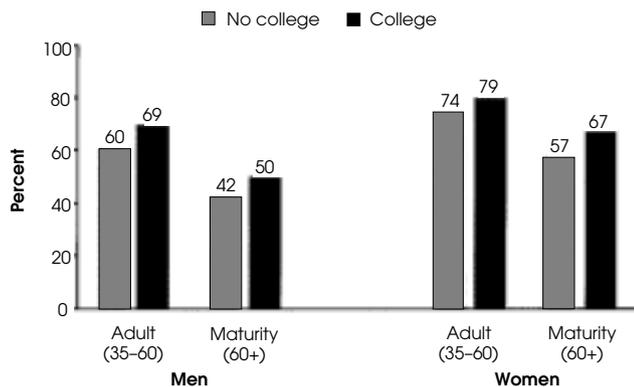


Figure 3. Learning: Percent Endorsing Personal Communication With Nurse for Any Cancer Topic

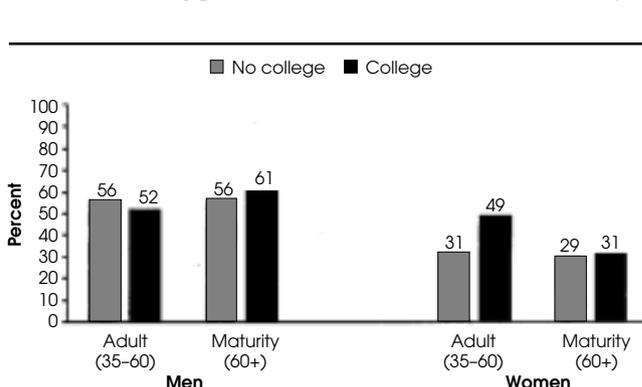


Figure 4. Learning About Sexuality: Percent Endorsing Personal Communication With Physician

sources. Nurse educators remain sensitive to psychosocial concerns that accompany the cancer experience. Educating patients about their disease, its implications, side-effects management, and quality-of-life techniques, can reduce patient anxiety, enhance coping mechanisms, reduce decisional conflicts, promote patient autonomy, and improve the experience for patients and their families. The ongoing assessment of learning needs, preferred learning methods, and learning outcomes contributes to more efficient teaching and learning.

Educators need to consider the benefit of studying the patient education process in well-designed and well-controlled studies. Findings could determine which learning methods are preferred and most effective for specific patient populations. This would serve to strengthen partnerships between patients and cancer-care teams.

Education of patients with cancer is an ongoing process that uses a variety of methods for delivery. No one best method or a "one size fits all" approach exist. Nurses and health educators are key players on cancer-care teams and often play lead roles in the education process. This includes assessing the need for developing comprehensive patient education programs. Cancer centers benefit patients and cancer-care teams when comprehensive programs are developed, delivered, and evaluated. Perhaps this study will support nurses' efforts to obtain funding for education centers for patients with cancer.

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