Professional and Patient Perspectives on Nutritional Needs of Patients With Cancer

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Purpose/Objectives: To identify and compare perceptions of RNs, registered dietitians (RDs), and patients regarding the best format and key nutrition information components that should be provided to patients during cancer treatment.

Design: Cross-sectional study using an opinion-based questionnaire.

Setting: Outpatient cancer centers.

Sample: 506 RNs and 367 RDs, as well as 653 patients undergoing cancer treatment.

Methods: Two similar self-administered questionnaires were developed, one for patients and one for healthcare professionals. Face and content validity were assessed by a panel of experts. Data were analyzed using descriptive statistics, chi-square statistic, and a Spearman Correlation Coefficient to compare responses.

Main Research Variables: Patient nutrition concerns as well as format and content of printed educational materials.

Findings: Significant differences existed among groups regarding the most common nutrition concerns, the perception of importance of information frequently provided to patients with cancer, and rank order of importance for eight items typically provided to patients. The dietary information format preferred by all groups was an all-inclusive booklet; RNs (75%) were more likely than RDs (43%) or patients (50%) to prefer this format. Data also revealed that almost half of the patients (47%) received no dietary counseling, including 18% who experienced significant weight loss.

Conclusions: RNs and RDs who provide nutrition education to patients with cancer should consider the need to develop and use a variety of printed materials to meet individual needs. Because major concerns of patients and healthcare professionals were related to patients' ability to consume adequate amounts of food, this should be the primary focus of any nutrition education materials.

Implications for Nursing: These findings provide information that can be applied to the development of informational materials and counseling practices.

Key Points . . .

- An all-inclusive booklet containing recipes was the format preferred by RNs, registered dietitians (RDs), and patients for nutrition education during cancer treatment, although RDs were more inclined to believe that patients would prefer a simple, one-page diet sheet.
- The three major nutrition concerns for patients with cancer are appetite loss, nausea and vomiting, and the ability to get enough nutrients. These should be the main focus of patient education materials.
- Only 50% of the patients received professional dietary counseling.

Adequate nutrition is especially important for patients with cancer, and food is viewed as significant not only for its nutritional value but also as a quality-of-life issue (McGrath, 2002). Intensive chemotherapy can cause difficulty with eating, which may be stressful for patients and caregivers. This can lead to problems such as anorexia, which may be life-threatening if significant weight loss occurs (Bloch, 2000). Therefore, recommendations and suggestions regarding consuming a healthy diet during and following treatment are key to helping patients maintain strength and overcome their disease.

Many patients with cancer are unable to eat, and prevalence of weight loss and malnutrition in patients has been reported to range from 9% in patients with breast cancer to 80% in patients with esophageal cancer. Capra, Ferguson, and Reid (2001) estimated that 20% of patients with cancer die from the effects of malnutrition rather than malignancy. Cachexia, characterized by weight loss, lipolysis, muscle wasting, anorexia, chronic nausea, and asthenia, can result in changes in body image and psychological distress (Bruera & Sweeney, 2000). These adverse responses may result in complications that require unplanned hospitalization and increased costs of care (Nitenberg & Raynard, 2000; Ottery, 1996). Benefits associated with nutritional support for cachexia include increases in weight, anthropometric measurements, and serum albumin as well as improvements in nitrogen balance and immune function (Bloch, 2000).

Assessment at diagnosis or at the start of treatment can determine a patient's nutrition status. When a compromised nutrition status exists, further assessment and nutrition education are recommended before beginning treatment. For patients who are not at nutritional risk at the time of assessment, nutrition education should be provided to enable them to cope with likely side effects of treatment. The primary goal of this study was to identify the dietary needs of patients with cancer from patients' perspectives as well as the two groups of healthcare professionals who provide the majority of nutrition counseling during treatment: RNs and registered dietitians (RDs). RNs provide more than half of patients' nutrition counseling during cancer treatment, and RDs counsel approximately one-quarter of these patients (Polisena & Wade, 1993). The purpose of this study was to provide basic data for use in designing successful strategies for educating patients with cancer about their dietary needs. The assumption was that

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increased knowledge would provide a basis for a framework for patients to make reasonable, informed choices (Brown et al., 2001).

Literature Review

Since the 1990s, studies have shown that patients who undergo cancer treatment want information about their disease, although the amount, timing, and type of information desired varies with no apparent relationship to patients' demographics or treatment modality (Blacklay, Eiser, & Ellis, 1998; Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Chelf et al., 2001; Foltz & Sullivan, 1996; Galloway et al., 1997; Thomas, Thornton, & Mackay, 1999). Various methods have been used to provide this information, including verbal, written, and audio- or videotape. Printed information typically is used to supplement discussions with healthcare professionals; however, the accuracy of the information and patients' ability to understand it determine whether patients are satisfied with written materials (Blacklay et al.; Buck, 1998; Butow et al.; Chelf et al.; Foltz & Sullivan; Mossman, Boudioni, & Slevin, 1999; Wilson, 2000). Printed materials frequently are written at a reading level that is too high for many patients with cancer; this difference may be more pronounced in older patients (Foltz & Sullivan; Wilson). Patients with low literacy levels often have difficulty reading and organizing information and may seek information from friends and family members rather than from healthcare professionals (Lee, 1999; Macario, Emmons, Sorensen, Hunt, & Rudd, 1998; Parikh, Parker, Nurss, Baker, & Williams, 1996). Computer-assisted learning, telephone interventions, and audio- and videotapes also have been documented as effective educational tools for patients, and no single approach for educating patients about treatment seems better than another (Chelf et al.). Although many patients have increased their access to cancer information via the Internet, its use as a source of information for patients has not been studied in depth. Because controlling what patients find on the Internet is not possible, they may adopt ways to cope with cancer treatment that may be incorrect or dangerous (Chelf et al.; Mossman et al.).

Many problems related to eating and physical activity occur during cancer treatment, and nutrition advice and information regarding symptom management and appropriate food choices from qualified healthcare providers are recommended (Brown et al., 2001; Wilson, 2000). Because the risk of malnutrition is great in many patients with cancer, identification and management of related symptoms are essential. Nurses have the opportunity to intervene early and foster collaboration among the healthcare professional team (Beach, Siebeneck, Buderer, & Ferner, 2001; Borbasi et al., 2002; Eckert, 2001; Rose, 1999; Whitman, 2000; Yen, 1999). When patients with cancer present with a greater than 10% weight loss, a referral to an RD for individual dietary counseling is recommended, although problems relating to the availability of an RD, medical insurance restrictions, and lack of time may prevent referral follow through (Whitman).

Some studies have noted problems experienced by nurses with the information they provide to patients with cancer related to nutrition, nausea, and taste changes. The majority of patient-focused literature has been written from the perspective that eating-related problems are minimal (Lennie, Christman, & Jadack, 2001; Rustoen, Schjolberg, & Wahl, 2003; Rutledge & Engelking, 1998; Wickham et al., 1999). Likewise, RDs may experience problems in settings where funds no longer are available for medical nutrition therapy. Instead, RDs are asked to train others to perform nutrition screening and education, making them facilitators of services rather than providers who monitor outcomes (Laramee, 1996).

A review article about patient information materials in oncology by Thomas et al. (1999) noted the importance of tools to reinforce information provided in clinics. These materials allow the learning process to continue at home and encourage patient involvement in treatment decisions. Brown and Hartmuller (1998) provided a list of reputable nutrition resources for patients with cancer and noted that many tools are available, although additional materials are needed for the visually impaired, non-English speakers, and people with specific ethnic or religious dietary needs. Considerable investments of planning, time, and money are required to develop educational tools in accordance with patients' needs and preferences, and scientific evaluation is necessary before such materials are given to patients (Coulter, Entwistle, & Gilbert, 1999; Sainio & Lauri, 2003).

Methods

Sample Recruitment

Healthcare professionals: During the first part of the study, a convenience sample of eligible respondents consisting of RNs and RDs (N = 1,041) was surveyed to determine their perceptions about patients' nutritional needs during cancer treatment. At the 1996 Oncology Nursing Society Annual Congress, 666 questionnaires were completed by RNs who visited the National Cancer Institute (NCI) exhibit. Two sampling methods were used to obtain a representative group of RDs who worked with patients with cancer. RDs completed 375 questionnaires; 180 were distributed at the NCI exhibit at the 1996 American Dietetic Association (ADA) Annual Meeting, and 195 additional questionnaires were returned by mail following inclusion in a national newsletter mailed to members of the Oncology Nutrition Dietetic Practice Group. Duplication of RD respondents did not occur. Eligibility criteria for healthcare professional respondents included a bachelor's degree and appropriate healthcare professional licensure, current experience in direct care of patients with cancer during treatment, and having followed directions and completed all items on the questionnaire.

Patient recruitment: The second part of the study was conducted in 1998 and 1999 with a convenience sample of 653 patients with cancer seen in outpatient treatment facilities. Patients were identified through contact with patient educators who were members of the Cancer Patient Education Network (CPEN), which represented 47 NCI-designated comprehensive, clinical, and consortium cancer centers in the United States. CPEN members were contacted via a letter that requested assistance in identifying appropriate staff willing to ask patients at their institutions to participate in the study. Twelve institutions (see Table 1) agreed to participate and to collect data from patients seen in a one-month period at their chemotherapy or radiation outpatient cancer treatment clinics. The goal was to obtain a sample of male and female patients who were undergoing different types of treatment and who had a variety of cancer types. Following institutional review board approval at each institution, data collection was conducted within a 30-day period. On arrival at the clinic, patients were asked by the clinic coordinator, RN, or RD to complete the questionnaire. Patients

who agreed to be part of the study and signed the consent form received a questionnaire that contained a six-digit preassigned institution code. Participants' names were not included to ensure patient anonymity. A cover letter was provided that explained the purpose of the survey and directions for answering each question. All participating patients were required to complete the questionnaire during their clinic visit. Completed questionnaires were returned to the principal investigator for data analysis within two weeks following the 30-day collection period. Patients were considered eligible if they underwent treatment in the participating CPEN clinic at the time they completed the questionnaire, followed the directions on the questionnaire, and answered all items.

Instruments

Healthcare professional instrument development: A 16-item questionnaire was developed by the researchers based on a needs assessment conducted during the revision process for the NCI publication, *Eating Hints for Cancer Patients* (NCI, 1995), using telephone interviews with 17 RNs and 20 RDs (Hartmuller, 1996). The questionnaire was designed to measure specific constructs that demonstrated differences of opinion between RNs and RDs and was reviewed by a panel of four experts, including one RD, one RN, and two health educators from the NCI Office of Cancer Communications. These experts assessed the content validity of the instrument. Because this was an opinion-based instrument and was not designed to measure psychological concepts, construct validity was not assessed.

The first four items on the questionnaire focused on demographic and education-related characteristics, such as credentials, affiliation and type of institution, setting and type of cancer treatment for which patients were counseled, and cancer-related nutrition education materials currently used.

Four items elicited responses about the perception of the respondent about the needs of patients with cancer for specific dietary information during treatment. One question asked respondents to choose the most preferred format for dietary information from the following five choices.

- An all-inclusive booklet with recipes (about 100 pages)
- An all-inclusive booklet without recipes (about 50 pages)
- A small booklet (fewer than 10 pages) about an individual nutrition-related problem
- One-page handouts
- Another format specified by the respondent

Another question sought to obtain the most common nutrition concerns of patients from a choice of 12 items: ability to obtain adequate nutrients, alternative dietary therapies, appetite loss, diarrhea, difficulty with swallowing or chewing, excessive weight gain, excessive weight loss, following previously recommended diets, nausea and vomiting, psychological issues related to eating, constipation, and vitamin supplementation (beyond recommended daily amounts).

Next, respondents were asked to characterize as very important, somewhat important, or not especially important the need to receive different types of nutrition information, namely,

- General cancer prevention nutrition information
- A list of all eating problems that may occur during cancer treatment
- Tailored information about eating problems pertaining to an individual treatment plan
- Information about all special diets and products that may be used for patients with cancer
- Information about a specific dietary need prescribed for an individual patient
- Additional informational resources in the community
- A glossary of terms
- A set of specific recipes for use before, during, and after cancer treatment
- Tips and suggestions for family members.

The last item in the questionnaire asked respondents to select key items to be included in printed nutrition publications for patients with cancer from a list that included ways to cope with side effects resulting from treatment, tips for eating a balanced diet during cancer treatment, a glossary of terms, hints to increase calories and protein, resources in the community, special dietary guidelines, suggested recipes, and use of nutritional supplements.

Patient instrument development: A comparable 28-item patient questionnaire was developed. As with the healthcare professional questionnaire, an expert panel at NCI reviewed the questionnaire for comprehension and literacy level as well as for content and face validity. Two pilot tests were conducted for this questionnaire, including a cognitive interview technique with 27 patients at a hospital cancer treatment facility and test-retest reliability with 25 patients treated at the National Institutes of Health's Warren Grant Magnuson Clinical Center. Based on responses from the cognitive interview process, the patient questionnaire was revised. Test-retest reliability then was conducted comparing matched responses of patients. Reliability was assessed by calculating a percent agreement on appropriate questions between time one (test 1) and time two (retest). Agreement exceeded 75%, with the exception of the respondents' experience with dietary counseling (68%), two

Table 1. Acknowledgment of Coordinators and Investigators From Participating Cancer Centers

Institution	Coordinator(s)
Case Western Reserve Comprehensive Cancer Center	Amy Landfield, MS, RD; Bonnie Rigutto, Med, RD
Fred Hutchinson Cancer Research Center	Kim Robien, PhD, RD, FADA, CNSD
Kimmel Cancer Center at Johns Hopkins	Ginger Muscalli, RD; Peter Kwiterovich, MD
Mayo Clinic Comprehensive Cancer Center	Jane H. Chelf, RN, MDiv
Robert H. Lurie Cancer Center of Northwestern University	Sara Coveny, RN, MS
Roswell Park Cancer Institute	Suzanne Carroll, RN, MS, OCN®, AOCN®
San Antonio Cancer Institute	Sue Cunningham, MS, RD
University of Colorado Cancer Center	Colleen Gill, MS, RD; Linda Krebs, PhD, RN
University of North Carolina Lineberger Cancer Center	Wendy L. Johnson-Taylor, PhD, MPH
University of Pittsburgh Cancer Institute	Catherine Vandermer, RD; Joyce Yasko, PhD, FAAN
University of Texas M.D. Anderson Cancer Center	Cynthia Stewart, RN; Kathleen Bradford, RD; Sally Scroggs, MS, RD, LD
Warren Grant Magnuson Clinical Center (Bethesda, MD)	Sharon Quint-Kasner, RN, MSN

concerns related to loss of appetite (68%), and concern about taking extra vitamins (68%).

The first six items on the patient questionnaire asked for demographic data, including gender, date of birth, type of cancer, whether surgery related to cancer had occurred during the past four months, type of cancer treatment and present treatment status, weight changes noted during the past four months, indication of dietary counseling or nutrition guidance, and cancer-related dietary education materials that were found to be helpful.

The next four questions were designed to elicit the same information as was collected from the healthcare professional questionnaire, including patients' preferred format for receiving nutrition information, most common nutrition concerns, perceptions of the importance of receiving different types of nutrition information, and identification of key items to include in printed nutrition publications for use during treatment.

Two questions were added to the patient questionnaire that were not included in the healthcare professional questionnaire. One item asked patients if methods other than print materials were preferable for receiving dietary information and what was preferred. Another question asked respondents to provide additional comments regarding diet and cancer treatment.

Data Analysis

Data analyses were performed to compare responses from the professional and patient questionnaires to answer research questions using the statistical software SPSS® for Windows® Based Systems, version 7.5 (SPSS Inc., Chicago, IL). A chi-square statistic was calculated to determine whether differences existed among the three groups in their opinion on the most preferred print format for dietary information provided to patients during treatment. A Spearman Correlation Coefficient was calculated to determine group differences for the three top nutrition concerns, and a chi-square statistic was applied to determine differences for the perceived importance of nine categories of information that patients should receive in any form. In addition, a mean was calculated for responses for each group to identify the five top items to include in printed nutrition publications.

Results

Sample Characteristics

Table 2 presents the demographic composition of the eligible RNs (N = 506) and RDs (N = 367). As expected, the healthcare professionals were predominately female from a variety of work and counseling settings. Demographic characteristics of eligible patients (N = 653) are provided in Table 3. Male and female patients were included; they represented a variety of ages, with the majority ranging from 50–64 years. Twelve major cancer sites were represented, most involved cancers of the breast or digestive and respiratory tracts, and most patients were undergoing chemotherapy treatment. Ethnicity and socioeconomic status were not ascertained for any of the groups to protect the confidentiality of the patients at the clinic visit.

Patients' Preferred Format for Receiving Nutrition Information

A chi-square analysis was calculated for the most preferred format for patients to receive dietary information. Results were significant ($p > 0.001$), indicating differences of opinion among groups (see Figure 1). RNs (75%) were more likely than were RDs (43%) or patients (50%) to prefer an all-inclusive booklet with recipes. Overall, this format was preferred most by all three groups. RDs, however, were more likely than were RNs to think that patients would prefer a one-page information sheet specific to their individual eating problems.

Table 2. Demographic Characteristics of RNs and Registered Dietitians (RDs)

	RNs (N = 506)		RDs (N = 367)	
Characteristic	**n**	**%**	**n**	**%**
Gender				
Male	11	2	–	–
Female	467	94	367	100
Education				
Bachelor's degree	363	72	207	56
Master's degree	103	20	137	37
PhD	4	1	6	2
No response	36	7	17	5
Work setting				
Academic center	134	27	141	38
Community hospital	219	43	133	36
Home health	33	7	16	4
Other	120	24	77	21
Patient counseling setting[a]				
Inpatient	279	55	259	71
Outpatient	297	59	258	70
Home of patient	58	12	54	15
Other	31	6	27	7
Patient cancer treatment type[a]				
Surgery	342	68	322	88
Radiation	393	78	344	94
Chemotherapy	460	91	346	94
Hormone treatment	17	3	10	3
Biologic treatment	19	4	17	5
Other	67	13	53	14

[a] Respondents could choose more than one response.

Note. Missing data exist for some variables. Because of rounding, percentages may not total 100.

Most Common Nutrition Concerns for Patients During Treatment

Table 4 shows the rank order and Spearman Correlation Coefficient calculation for the three top nutrition concerns of patients from the 12 options provided. A high correlation existed between the RNs and RDs (Spearman Rho = 0.88) on their perception of the patients' primary concerns, especially appetite loss and nausea and vomiting. Although patients also included appetite loss and nausea and vomiting among their most common nutrition concerns, the correlation between patient and RN responses (Spearman Rho = 0.51) and patient and RD responses (Spearman Rho = 0.54) was moderate. Patients, unlike either professional group, believed that vitamin supplementation was one of the three top nutrition concerns. Psychological concerns, excessive weight gain, and the ability to follow a prescribed diet were not major concerns of any group.

Perception of Importance of Types of Information Frequently Provided to Patients With Cancer

When comparing all three groups with regard to the importance rating for information provided in any format, group

Table 3. Patient Demographic Characteristics

Characteristic	n	%
Age (years)		
< 35	41	6
35–49	150	23
50–64	251	38
65–75	147	23
> 75	50	8
No response	14	2
Gender		
Male	293	45
Female	359	55
No response	1	0
Type of cancer		
Brain	18	3
Breast	139	21
Digestive	109	17
Endocrine	8	1
Leukemia	21	3
Lymphoma	48	7
Multiple myeloma	12	2
Oral	17	3
Prostate	39	6
Reproductive	38	6
Respiratory	104	16
Skin	11	2
Urinary	13	2
Other	76	12
Type of cancer treatment[a]		
Radiation therapy	251	38
Chemotherapy	429	66
Hormone therapy	22	3
Biologic therapy	12	2
Other	48	7

N = 653

[a] Respondents could choose more than one response.

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

means were calculated. A higher mean indicated a higher importance rating. Differences were noted between RNs and RDs for information that was considered very important. As shown in Figure 2, the percentage of RNs who believed that general cancer prevention information, information about special diets, and a glossary were very important was significantly higher ($p > 0.001$) than the percentage of RDs who were of that opinion. Significant differences ($p \leq 0.0001$) also were noted between the percentages of patients and members of both professional groups who indicated that a previously prescribed diet, community resources, and tips for family members were very important.

Importance of Types of Information to Include in Print Materials

A lower rank order number for the eight types of information that respondents felt should be included in print materials indicated greater importance (see Table 5). No differences existed between RNs and RDs in this ranking, although differences did exist in the patient group. The five top types of information that the healthcare professional groups thought were important for patients to receive in nutrition print materials were coping with side effects, hints for increasing calories and protein, eating a balanced diet, providing special dietary guidelines, and using nutritional supplements.

Patients agreed with this ranking for the first four items but chose a slightly different order than did the professional groups. Patients ranked suggested recipes in the five top items, whereas the professionals ranked use of nutritional supplements higher.

Patients' Preferences and Counseling Experiences

Almost half of the patients (n = 304) surveyed did not receive dietary counseling from any healthcare professional. Also, 38% of patients surveyed (n = 247) experienced weight loss within a four-month period prior to completing the questionnaire. Although more than half of the patients who experienced weight loss received some form of dietary counseling from a healthcare professional, 47% (n = 115) received no professional counseling related to their diet. Another 12% (n = 75) of patient respondents noted weight gain during treatment, but only 28% (n = 21) of this group had received professional dietary counseling.

The patient questionnaire also indicated that 72% (n = 504) preferred to receive nutrition education materials in print during treatment. Patient respondents also indicated that they wanted to receive dietary information in other ways, including individual contact (9%), videotapes (8%), and the Internet (5%).

Discussion

Because all three groups agreed on the best format for printed dietary materials for patients with cancer during treatment, the implication is that an all-inclusive booklet that contains recipes should be made available. Examples include an NCI publication, *Eating Hints for Cancer Patients: Before, During and After Treatment* (NCI, 1998), and an American Cancer Society (ACS) publication, *Nutrition for the Person With Cancer: A Guide for Patients and Families* (ACS, 2000). At the time of the survey, the NCI publication was available; it has since been updated. The ACS publication was distributed to the public only recently. Single copies of each booklet are available free of charge through the respective organizations. They should be considered as tools to have available in treatment facilities as resources for patients with cancer and for use in nutrition counseling.

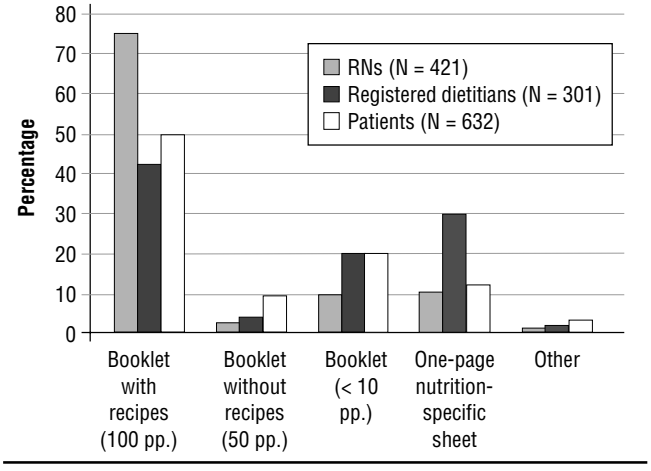


Figure 1. Preferred Format for Providing Dietary Information to Patients With Cancer During Treatment

Table 4. Ranking of Patient Nutrition Concerns as Perceived by RNs, Registered Dietitians (RDs), and Patients (PTs)

	RNs (N = 280)		RDs (N = 253)		PTs (N = 427)	
Nutrition Concern	**Rank**	**%**	**Rank**	**%**	**Rank**	**%**
Appetite loss	1	84	1	85	1	48
Nausea and vomiting	2	53	3	47	3	34
Ability to obtain adequate nutrients	3	43	5	28	4	30
Excessive weight loss	4	29	2	55	10	18
Difficulty with swallowing or chewing	5	28	4	39	7	20
Diarrhea	6	22	7	12	8	20
Constipation	7	15	9.5[a]	6	5	27
Alternative diet therapies	8	11	6	14	6	21
Psychological issues related to eating	9	8	9.5[a]	6	9	19
Excessive weight gain	10	6	11.5[a]	4	12	11
Vitamin supplementation (> recommended daily allowance)	11	4	8	8	2	36
Following previous diet	12	3	11.5[a]	4	11	16

Spearman Rho between PT and RN = 0.5105; PT and RD = 0.5385; RN and RD = 0.8846

[a] Indicates tie score

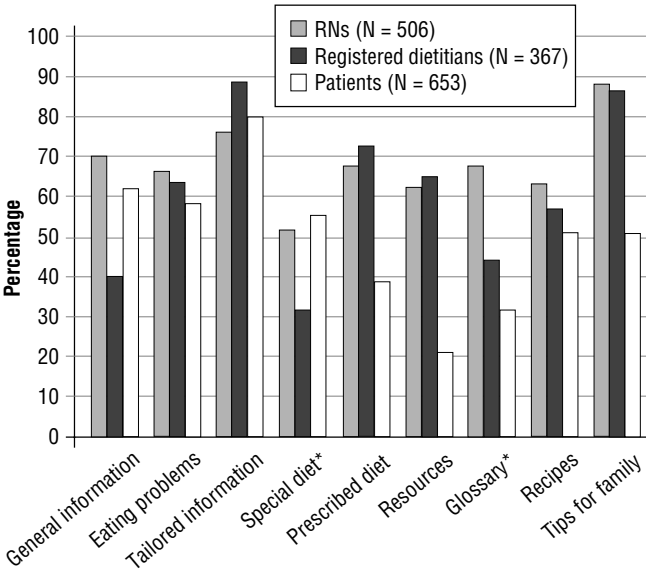
Because RDs believed that patients with cancer would prefer one-page dietary sheets, RDs may be likely to provide simple handout materials, perhaps by creating customized materials or by choosing appropriate existing patient education materials. The opinions of RNs and patients differed from those of RDs, which may be explained by the fact that many RDs provide individual dietary counseling to patients and may prefer to focus on primary eating problems experienced by patients. In contrast, RNs may not have time to address individual dietary concerns because they often must focus on other symptom-related issues (Patrick et al., 2003).

Survey results showed that the three top nutrition concerns agreed on by all three groups were appetite loss, nausea and vomiting, and ability to get enough nutrients. Because these all relate to the ability of patients with cancer to consume adequate amounts of food that can be metabolized properly during treatment, these areas should be the primary focus of nutrition education materials for these patients. Vitamin supplementation, a primary concern for patients, was not cited as a concern by either healthcare professional group. Healthcare professionals should be encouraged to discuss vitamin supplementation with patients and to document the types and amounts of vitamin supplements that patients may use during treatment (Cunningham & Herbert, 2000; Hamilton, 2001; Prasad, Kumar, Kochupillai, & Cole, 1999).

Comparisons among each group's rating of the importance of nine types of nutrition information were not significant. Differences should be noted between professionals and patients, however, concerning tips for family members, information on following previously prescribed diets, and community resources. Patients did not consider access to information about these three items as important as the professional groups did. Perhaps such resources are valued more by family members than by patients themselves, and healthcare professionals may realize this.

The groups' rankings of the types of information to be included in print materials about eating during cancer treatment were in general agreement, and consensus existed on items that should be key topics for healthcare professionals to address with patients with cancer. These include coping with side effects, increasing intake of calories and protein, eating a balanced diet, and providing special dietary guidelines. A major difference was that patients assigned their top importance ranking to recipe suggestions, whereas RDs and RNs ranked use of nutritional supplements highest. Nutritional supplements may not have been included in patients' treatment plans, or perhaps patients tried the supplements and did not like the taste or considered them to be too expensive. The higher rank order assigned by patients to recipes differs from results from the question that compared the importance rating for nutrition information. Why this difference was expressed by patients surveyed was unclear. However, because a large number of patients with cancer assigned high importance to recipes, they should be made available during dietary counseling.

Weight loss was an important nutrition concern for patients by both healthcare professional groups but not by the patient respondents. Male patients were more concerned about weight loss than were female patients, which may be explained by the fact that 8% of women versus 4% of men aged 25–34 years experience a major weight gain of greater than 10 kg (Lovejoy, 1998). Because women may be concerned about their appearance, they may not view weight loss as negative. In addition, many patients with breast cancer gain rather than lose weight during treatment (Lankester, Phillips, & Lawton, 2002), which may cause them more concern. Healthcare professionals therefore should be aware that a single set of recommendations concerning the need to gain weight or maintain weight loss during treatment may not be appropriate in print materials provided to patients. Patients with breast cancer may need two phases of nutrition counseling during treatment: the first providing ways to minimize side effects related to treatment and the second



* p > 0.001 between RNs and registered dietitians

Figure 2. Types of Nutrition Information for Patients With Cancer During Treatment Rated as Very Important

Table 5. Rank Order of Importance of Type of Nutrition Information in Print Materials

Nutrition Information	RNs	Registered Dietitians	Patients
Coping with side effects	1	1	1
Hints to increase calories or protein	2	2	3
Eating a balanced diet	3	3	2
Special dietary guidelines	4	4	4
Use of nutritional supplements	5	5	6
Suggested recipes	6	6	5
Community resources	7	7	8
Glossary	8	8	7

focused on professional dietary counseling to calculate a diet aimed at achieving or maintaining a healthy weight. As noted by McMahon, Decker, and Ottery (1998), significant weight loss and poor nutritional status were documented in more than 50% of patients at the time of diagnosis. Therefore, the fact that almost half of patient respondents who experienced weight loss did not receive professional dietary counseling is disconcerting. The implication is that a need exists to routinely assess the nutritional status of all patients during treatment so that appropriate counseling and interventions can be initiated as soon as they are warranted. About 20% of breast cancer survivors gain more than 20 pounds, and those who gain more than a median of 13 pounds have a 1.5-fold greater chance of recurrence (Chlebowski, Aiello, & McTiernan, 2002; Demark-Wahnefried, Rimer, & Winer, 1997; Segal-Isaacson & Wylie-Rosett, 1998). Therefore, the fact that patients (primarily those with breast cancer) who experienced weight gain did not receive professional nutrition counseling also is a concern.

Study Limitations

This study employed a convenience sample, which limits its generalizability to the patient population as a whole. Comparisons were made between healthcare professionals with appropriate credentials (RNs and RDs) who worked directly with patients with cancer and were willing to complete the questionnaire. For patients with cancer who were undergoing treatment, the cooperation and willingness of staff at 12 selected institutions were needed to contact patients and ask them to complete the questionnaire. Also, although most patients were undergoing chemotherapy treatment (n = 429), 98 patients also received a second concurrent treatment that was not addressed in these analyses. A second limitation was the survey instrument. Although reliability testing was performed on the patient questionnaire, reliability testing was not performed on the healthcare professional questionnaire prior to its administration. The fact that the questionnaire was administered to healthcare professionals in 1996 and to patients in 1998 could suggest that during the two-year time span, patients in treatment may have developed different concerns. Another limitation was that information regarding ethnic and cultural diversity in the sample was not sought.

Clinical Implications

The findings from this study provide information applicable to the development of materials for patients with cancer and to the counseling practices of healthcare professionals. Significant differences in opinion were found between healthcare professional groups and patients regarding the content of nutrition education materials. RNs and RDs should ascertain what their patients want and whether an individual dietary counseling session should be scheduled. Alternatively, patients may find that providing appropriate materials and then following up with a telephone call to answer questions are acceptable. This is especially important when valuable resources (e.g., time, money) are limited. Although these results do not apply directly to all patients with cancer, healthcare professionals must consider expanding the information they provide about items that patients rated as more important or of greater concern, such as supplying recipes, adding information about vitamin supplementation, and clarifying recommendations about weight gain and loss.

Since this survey was administered, several resources have been developed or revised by NCI (*Eating Hints for Cancer Patients* is available at www.cancer.gov/cancerinfo/eating hints) and ACS (a variety of information is available from www.cancer.org/docroot/MBC/MBC_6.asp?sitearea=ETO). Resources for healthcare professionals also are available for purchase from ADA (materials are available from www.eatright.org/Public/ProductCatalog/104_ProfReferncePage.cfm) for those involved in dietary counseling for patients with cancer. One is a packet of patient education materials designed to help with nutrition-related symptom management titled *Oncology Nutrition: Patient Education Materials* (Walker & Masino, 1998). In addition, the *Clinical Guide to Oncology Nutrition* (McCallum & Polisena, 2000) includes information about diet and cancer prevention, nutrition assessment, treatment, and alternative therapies. Another resource is a recipe booklet titled *Pass the Calories, Please* (Farmer, 1994). A new reference titled *Management of Nutrition Impact Symptoms in Cancer and Educational Handouts* (Eldridge & Hamilton, 2004) also is available to help nutrition professionals work with coping with eating symptoms associated with cancer. Use of these new resources should be evaluated, and materials developed in the future should be tested before distribution by RNs and RDs who are involved in counseling patients with cancer.

Additional evaluation studies are needed to help understand how patients receive dietary information. The most striking result from this study was that almost half of the patients received no dietary counseling. Because recent changes in the healthcare delivery system may limit the amount of time patients spend with allied healthcare professionals, a major concern is whether patients who are likely to experience weight loss receive appropriate information. One method recommended to prevent the development of cachexia is to ensure that all patients receive some form of standardized dietary information before they begin treatment. Likewise, studies are recommended to determine how dietary information is provided to patients with breast cancer who may be likely to gain weight. Also, printed materials used frequently by professionals may not be preferred by patients, as shown by patient responses to a question that asked them to indicate, from a list of four dietary publications, which were helpful. Forty-seven percent of respondents circled "none." Healthcare professionals should follow up with patients with cancer to determine whether the dietary materials that were provided met their needs. Further, newly developed materials should be tested with patients prior to general distribution.

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